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## Acquired Brain Injury Ireland

A transformation of the health services in Ireland is critical in order to sustain ourselves as a healthy society and an economy. Health services need a radical re-orientation in order to be responsive to the needs of our population. Increasing number of people are surviving and living with complex conditions due to advances in medicine. However, the health services have not responded accordingly to this demographic. Those living with an acquired disability (s.a. an acquired brain injury) are not currently being prioritised in the health services, particularly in terms of their need for rehabilitation. They 'exist' rather than live full and meaningful lives.

### List of recommendations

It is essential that **neuro-rehabilitation is recognised as playing a critical role in healthcare policy in Ireland** and an **integral part** of our health services. With survival rates as they are, the healthcare services must embed rehabilitation as an essential part of the response for both patients and families.

The Irish health services must be **re-orientated in terms of priorities** in order to **develop neuro-rehabilitation services** and a **seamless pathway** for patients from hospital to home.

The **role of the NGO sector** in terms of services development and delivery must be recognised and a fully resourced NGO sector is a vital element of a fully integrated health system. NGOs are essential to elevate **the voice of the patient/family** in the milieu of stakeholder voices in healthcare discourse.

There is a need for a **systemic approach to collecting comprehensive** data. It must be a **resourced function** across the health services.

**Case management** for complex cases that require **interdisciplinary, cross-agency** working must become an embedded feature of our health service.

Prevention of disease and injury and taking a **comprehensive and meaningful public health approach** is essential for the long term sustainability of the health service in Ireland.

### Introduction

Acquired Brain Injury Ireland (ABI Ireland) welcomes the opportunity to make a submission to the Oireachtas Committee on the Future of Healthcare. Our submission focuses on the key strategic issues that our healthcare system from the perspective of people with an acquired brain injury (ABI).

### People with brain injury in the health system

When a person experiences a brain injury, as a result of a fall, assault, accident, stroke or tumour, they will need to re-learn the skills of life again. Many required specialist services with skilled multi-disciplinary teams support them on their rehabilitation pathway. Depending on what part of the brain is injured and the extent of the injury, the person will have to live with different consequences, many hidden, others not and may range from physical, sensory, cognitive, psychological and emotional.

### Key roadblocks

There is limited recognition of people with ABI as a group with who require specialised rehabilitation within current health policy. Rehabilitation services are **under-developed** and **under-resourced**. Their experience of the health system can be summed up as:

**Lack of availability** of timely neuro-rehab services and therefore forced to remain in hospital or go to live in a nursing home

There are massive **inequities** in terms of the *access to the neuro-rehabilitation* services that do exist and getting a service is largely based on luck and a post-code lottery.

**Waiting long periods** of time to access both in-patient and community neuro-rehabilitation services that are there

Lack of a **meaningful pathway** from hospital to home

Lack of **co-ordination** and **integration** of services and providers

Major challenge with '**navigating the system**'

Lack of **support** and **training** for **family members** who are propelled into role of carer

Lack of **availability of skilled (neuro) rehabilitation healthcare professionals** across the service providers

A vacuum in terms of **leadership** and **vision** in the Department of Health and the HSE to drive the necessary change in relation to growth and development of neuro-rehabilitation services within the Irish health service.

### **Key issues**

#### **Demographic challenge – people surviving and living with conditions**

We often hear of the ageing demographic challenge but another significant demographic challenge for our health service is the ever increasing numbers of people who are surviving and living with a complex injury or condition due to advances in medicine, technology and science. How the health service responds to these continually increased demands on a finite resource is a massive challenge.

Our health services, (emergency services, emergency medicine, intensive care, neuro-surgery) have improved enormously in Ireland in terms of saving people who experience an injury whether traumatic or vascular but once the person is kept alive what next? If we continue to 'save' people then we must develop a response to that goes beyond leave people to 'exist'. To date, the health services have not responded and are failing these people due to the lack of a pathway for rehabilitation and enabling the person to maximise their recovery and lead a meaningful life again.

#### **The data challenge – evidence based policy making and planning**

The paucity of data to inform evidence based policy making is a massive challenge in the Irish healthcare system. Collecting robust and reliable health service data is an essential cornerstone of policy making and service planning. This must be a priority to ensure a sustainable future for our health service. Again, there are pockets of good practice in our healthcare services, such as the Irish Cancer Registry <http://www.ncri.ie/> but there is a need for a systemic approach to collecting comprehensive data. It must be resourced function across the health services

#### **Re-orientation and re-prioritisation of the health services**

There is a need to have a radical shift in healthcare priorities in order to develop services to ensure that there is a meaningful rehabilitation pathway for those who experience brain injury. This requires systemic change in terms of the way our health services are provided and funded. Addressing the currently 'silos' in terms of funding for our health services must be a priority in any reform of healthcare in Ireland.

It is essential that neuro-rehabilitation is recognised as playing a critical role in healthcare policy in Ireland and an integral part of our health services. With survival rates as they are,

the healthcare services must embed rehabilitation as an essential part of the response for both patients and families.

For rehabilitation to be successful in terms of outcomes, it should be timely and part of a seamless pathway that extends from the acute hospital phase right through to the community. Success of one element in the pathway (for e.g. acute rehab) is predicated on the successful implementation of the other (e.g. the availability of community based neuro-rehab services). Timely intervention is a key determinant of the optimal outcomes for the person with a brain injury. In addition, rehabilitation must begin at the earliest possible time for the patient.

### **ABI Pathway – addressing deficits in services and fragmentation**

The current ABI pathway is extremely fragmented and there are massive limitations due to the lack of availability of services across the span of the pathway from hospital to home. Addressing the gaps in services and the lack of a meaningful and seamless pathway for the person with brain injury is essential to any reforms in the health within the health service. Investment must be driven by the principles espoused in the Neuro-rehabilitation Strategy<sup>1</sup> (2011). Diagrams 1 and 2 illustrate the contrast in the current and ideal ABI pathways.

Best practice guidelines published in the UK in 2005<sup>2</sup> recommends that people with ABI have access to specialist neuro-rehabilitation services provided by co-ordinated interdisciplinary teams. In addition there is a need for a clear rehabilitation pathway, where services are co-ordinated and integrated. People with ABI may require different services at different times and may need multiple services. Specialist support for the family is an essential component of rehabilitation and people with

ABI should have access to lifelong support if needed.

In particular for those with a brain injury, the lack of timely and appropriate rehabilitation services means that valuable recovery time is lost and the outcomes for the individual are not optimal. The lack of a pathway, means that people who despite surviving the major trauma, end up living in highly inappropriate settings including nursing homes, community hospitals or at home where families are unable to cope.

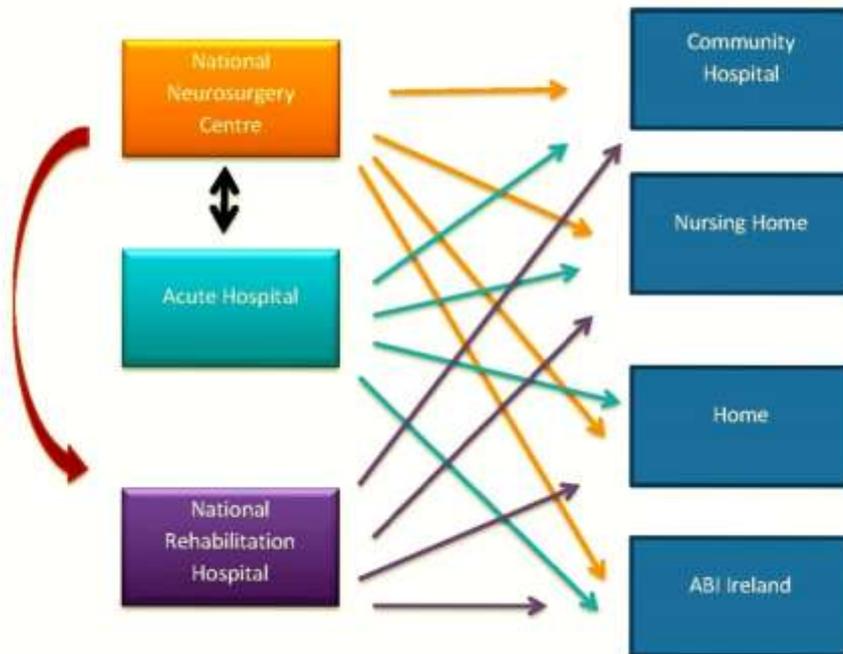
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<sup>1</sup> Department of Health and HSE (2011) National Policy and Strategy for the Provision of Neuro-rehabilitation Services in Ireland 2011-2015

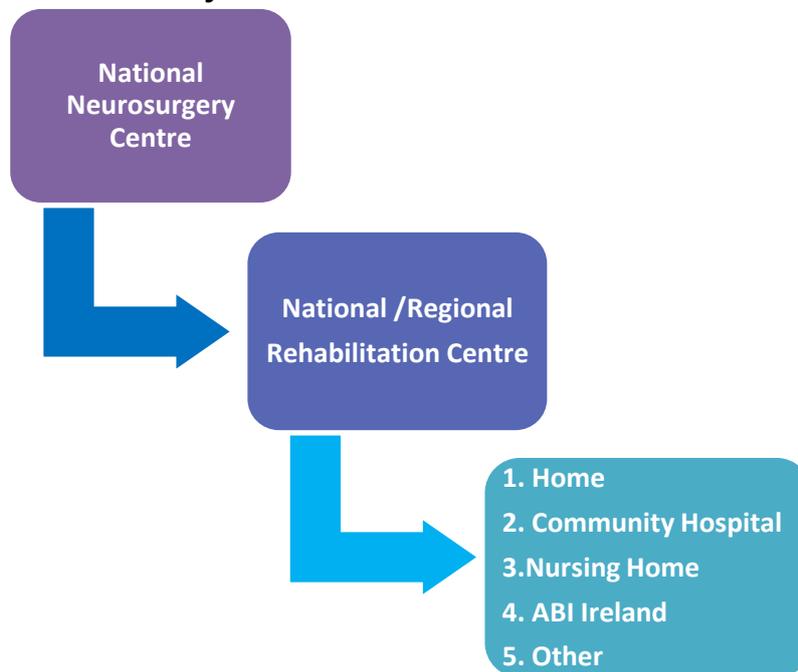
<sup>2</sup> British Society of Rehabilitation Medicine (2005) NSF for Long Term Conditions, UK

**Diagram 1: Actual ABI Pathway**

**Actual Rehabilitation Pathway**



**Diagram 2: Ideal ABI Pathway**



In addition, the role of the NGO sector in terms of services development and delivery must be recognised and a fully resourced NGO sector is a vital element of a fully integrated health system. NGOs also elevate the voice of the patient/family in the milieu of stakeholder voices in healthcare discourse.

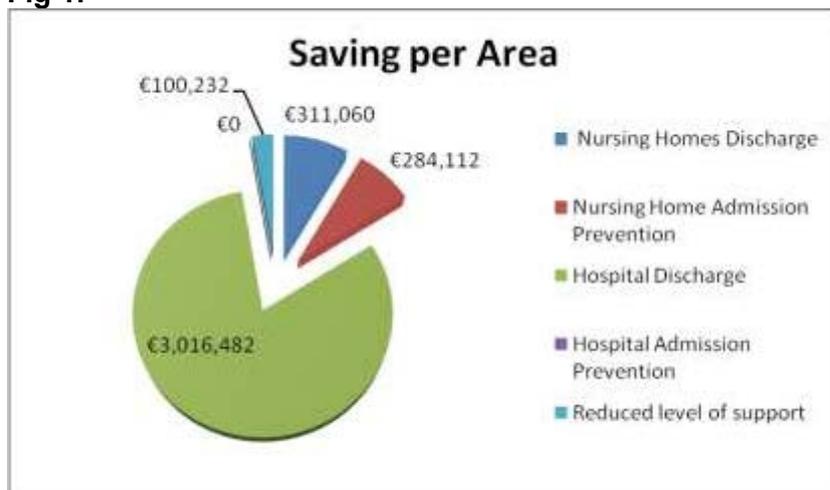
### Case Management – addressing integration and a seamless path

There is compelling evidence that case management is a key way to enable service integration across the range of specialists and service providers. Research from the UK indicates that case management for complex cases that require interdisciplinary working is both person centred

and serves to maximise the person’s independence and quality of life. It also leads to significant benefits to society including the reduction in the burden of care with avoidable, expensive and long or frequent hospital admissions being significantly reduced.<sup>3</sup>

A geographically based ABI-specific case manager acts as a single point of contact and provides a clear pathway to support the person’s transition from acute settings through post-acute and into community rehabilitation services. The case manager is the link person and helps to reduce the number of people with an ABI who fall through the net and provides ongoing support to ensure that the person receives the necessary services. Research carried out in 2009 in the North East HSE region on ABI-specific case management services proved that they were cost effective. The study showed that case management facilitated discharge from nursing homes and hospitals, prevented admission to nursing homes and hospitals and lead to a reduced level of support (post case management intervention). In the year in question, the research showed that a net savings of €3.5m occurred. The following graph (Fig 1) represents the savings in monetary terms across the whole of the North East HSE area<sup>4</sup>. Therefore, a comprehensive ABI case management service with national coverage and linkages to the CRTs is needed.

Fig 1:



### Final Comments

The Irish healthcare system is facing major challenges in the future. Our changing demographics are a massive factor that influences decision making with regard to resource allocation.

Finite resources require evidence based decision making. Research and good evidence for policy decision making and service planning must become an integral feature of our health policy discourse. Limited resources and their allocation also require strong policy and clinical leadership.

Prevention of disease and injury and adopting a comprehensive public health approach is essential to the long term sustainability of the health service in Ireland.

<sup>3</sup> Department of Health (UK) (2005) Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration, London, Department of Health

<sup>4</sup> Whelan, D. (2010) An evaluation of the cost effectiveness of acquired brain Injury Ireland case management in the North East Area (Meath, Cavan/Monaghan and Louth). Unpublished MA thesis, Institute for Public Administration

## Supporting Information

### About ABI Ireland

ABI Ireland is a dedicated provider of community-based neuro-rehabilitation services for people with an acquired brain injury (ABI) and their families. As a brain injury can affect a person's ability to manage their own life, ABI Ireland works in communities across Ireland to support and empower people to rebuild their lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

### ABI Ireland Services

ABI Ireland provides a diverse range of accredited neuro-rehabilitation services. The core services include:

- Clinical neuro-rehabilitation team
- Residential rehabilitation
- Transitional living
- Day resource/clubhouse
- Home and community rehabilitation
- Case management

Additional support services are also provided and include ABI information, family support and carer training.

### Key Facts on ABI

There are many ways in which a person can acquire a brain injury. These include, among others, a fall, assault, accident, infection, stroke or tumour.

Depending on what part of the brain is injured, and the extent of the injury, the person will have to live with different consequences.

Many of the consequences of brain injury may be hidden, others not. They range from physical and sensory to cognitive and psychological affecting how a person feels, thinks, acts and relates to others.

Each year it is estimated that 13,000 people in Ireland acquire a brain injury. However, there are no official statistics on ABI in Ireland.

ABI is one of the leading causes of disability and can have life-long consequences

Neuro-rehabilitation is a clinical and social process to aid recovery after a brain injury. It is about relearning, compensating and regrowth so the person lives a life of their own choosing. It supports the person to live a meaningful everyday life.

### Contact Details

Grainne McGettrick, Policy and Research Manager T: 01 280 4164 E:

[gmcgettrick@abiireland.ie](mailto:gmcgettrick@abiireland.ie)

[www.abiireland.ie/](http://www.abiireland.ie/)

## Adelaide Health Foundation

The Adelaide Health Foundation (AHF) is a voluntary independent charitable organisation which seeks to advance healthcare that is centred upon the dignity of every human being and that provides equal access to quality healthcare based upon clinical need. For more information: <http://www.adelaide.ie>

The establishment of the Committee on the Future of Healthcare is of critical importance to the development of high quality care coupled with timely access and equality- the fundamental principles underpinning social solidarity- in Ireland.

Healthcare in Ireland is generally regarded as of high quality- for those who can access it. We are among the worst in Europe in terms of access. This has forced the highest rate of double payment in Europe for healthcare- those theoretically entitled to free healthcare take out private insurance, not for better care, but simply to gain access to it.

There are many reports and plans to reform the health services. 'Healthy Ireland'<sup>1</sup> may be regarded as an exemplar. Yet many earlier reports and recommendations resulted in little finite change- access remains grossly inequitable, A&E trolley counts defy action plans and waiting lists for basic services seem to lengthen. So, the Committee, in developing its work streams, may wish to consider why the implementation of healthcare reform appears to be so difficult and appear to have defeated successive Ministries of Health. Reasons for may include:

Insufficient resource - and yet there is no correlation between waiting times for healthcare and GDP within Europe<sup>2</sup>, suggesting that the problem must be one of organisation as much or more than one of resource.

A five-year political cycle, which makes long- term strategic planning and execution difficult.

A political system that is based on confrontation and opposition, not problem solving (hence, we hope, the present Committee being built on an 'All Party' basis may be a welcome solution to this).

Effective power of veto by local politicians for local, not national gain.

A very large and cumbersome bureaucracy, the Health Service Executive, with apparent separation of power from accountability and performance.

The Committee may wish to consider these issues in order to maximise its effectiveness.

Finally, the underlying, fundamental principles of this discussion document are-

The achievement of optimal health care, and Acceptance of the principle of social solidarity (equal access for all regardless of means, creed or culture) to prompt, equal, high quality healthcare.

*Dr Catherine Darker and Professor Ian Graham  
On behalf of the Adelaide Health Foundation*

### **Main Body and Recommendations Strategy**

The Committee should determine at the outset a set of core principles that will guide their work and ultimately the desired outcome. The Committee should also determine what the end goal of universal healthcare (UHC) should be.

### **Principles of reform:**

Reform of the health system needs to be guided by a set of principles<sup>3</sup>, such as,

The health system treats everyone equally.

The health system is focused on the needs of all social groups in society

People have an entitlement to healthcare, free at the point of access.

The different elements of the health system work together and are connected.

The health and social care system is a universal, publically funded system.

### **What is the end goal?**

The end deliverable goal of universal healthcare (UHC) should be agreed by the Committee, including a definition of universal healthcare. A country which has UHC is an organised healthcare system that provides healthcare benefits to all persons, meaning that all residents are covered for predetermined healthcare services.

Although an international consensus has developed about the merits of universal healthcare, the definition of universality can vary. The European Union (EU) has accepted 'the overarching values of universality, access to good quality care, equity and solidarity' as 'the common values and principles that underpin Europe's health systems'<sup>4</sup>; while the World Health Organization (WHO) has advocated universal healthcare as the best means of improving global health<sup>5</sup>. There is overlap but not complete agreement between the EU and WHO definitions of universality. The EU articulates that:

*"Universality means that no-one is barred access to health care; solidarity is closely linked to the financial arrangement of our national health systems and the need to ensure accessibility to all; equity relates to equal access according to need regardless of ethnicity, gender, age, social status or ability to pay"*<sup>4</sup>.

The WHO defines its goal of universal health coverage (UHC) as *"that all people receive the quality, essential health services they need, without being exposed to financial hardship"*<sup>5</sup>.

We have strong concern that the WHO definition which includes *"does not expose the user to financial hardship"* will be used to justify user charges and the two-tier system. Therefore, the AHF advocate for the Committee to consider the implications of a chosen definition of 'universality' as this will have implications for all decisions thereafter.

The concept of which should pertain to a common basket of essential health services, which are free to all at the point of delivery and paid for by all according to their means separately - the social insurance system embodies this absolutely key concept. The paying options are many if we had a single health insurance fund - not-profit single payer, including premiums, anti-obesity taxes, wealth taxes etc., to ensure that the fund is adequate and allows for a surplus for capacity building etc. Government would pay the premium for those below certain income levels from general taxation. Ultimately it will come down to political will and the job of the Committee will be to keep clarity about the core principles and about the evidence-base for equality of treatment for every citizen combined with a financing system that maximises effectiveness and efficiency.

## **Integrated Care and Primary Care**

### **Primary Care**

Primary care (PC) at its best helps a person to remain healthy and well and living at home in his/her community and is able to address most of the patient's health and wellbeing issues. Patients know their GP and the GP knows them personally and coordinates their care when required. Often the GP knows the patients family history. Each patient should have an on-going relationship with a registered, personal, indemnified GP, trained to provide prompt first contact, continuous and comprehensive care.

How this may be achieved? The services in PC need to be relevant, understandable, accessible, responsive and properly resourced by either the State (through taxation) or health insurers (single payer model). The GP leads trained staff in the practice, who collectively take responsibility for the on-going care of patients. Other members of the PC team are available when required and the GP will organise and co-ordinate their input.

Patient outcomes: PC minimises the effects of ill health and prevent the patient from having unplanned admission to hospital for issues such as acute infections, acute medical problems, chronic disease or multiple chronic diseases, flare up of a chronic disease, mental health issues and substance misuse issues. If the patient requires assistance outside normal working hours, they have a prompt and direct access to a GP led, out of hours co-operative.

### **Integrated care**

Agree a definition of integrated care (there are approximately 175 of them!). The WHO define it as: "The organization and management of health services so that people get the care that they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money<sup>6</sup>".

There are many drivers of integration which have different degrees of evidence to support them, such as, integrated care pathways; funding models (money follows the patient; commissioning of services); organization models (regionalization of hospital, community & primary care services for geographic coverage, polyclinics, strengthening primary care services); human capacity models (MDT, physician integration, clinical leadership); aligning system incentives; developing ICT<sup>7</sup>.

### **A specific focus on electronic patient medical records to improve integration of care**

Each patient has his/her own secure, electronic, up to date health record.

How this may be achieved? The GP has access to comprehensive electronic patient record and these with the consent of the patient are shared with and updated with other health professionals. This will require investment in electronic patient medical records in our hospital services. We know that 63% of hospital consultants in 2014 in Ireland do not routinely use electronic patient medical records<sup>8</sup>, which places the Irish healthcare system at a disadvantage in delivering effective chronic disease management, as good technology systems are internationally recognised as cornerstone of modern quality healthcare delivery. IT will not only improve care delivery within hospitals but will also enhance communication across care systems. This is contrasted with good use of technology in general practice in 2011 with 82% of practices having electronic patient medical records<sup>9</sup>

Patient outcomes: Care is coordinated and integrated across the complex healthcare system and in the patient's community. The patient's pathway through the healthcare is both efficient and effective and the patient is fully informed at all times during their journey.

### **A specific focus on clinical care pathways to improve integration of care**

Clinical care pathways (CCPs) provide added value beyond clinical outcomes in terms of more effective administrative and financial management (REF: A-M Yazbeck's PhD thesis). There are currently 33 National Clinical Care Programmes within Ireland and are being restructured into integrated care programmes. The five Integrated Care Programmes are focused on older persons, prevention and management of chronic disease, patient flow, children's health and maternity. Their goal is to ensure that the health service is able to provide person-centred, coordinated care to all its users. The international literature would largely support this approach<sup>10</sup>.

## **Chronic disease management**

There is a strong need to consider the management of chronic diseases within the narrative of primary care and integrated care. The Chronic Care Model (CCM) is a World Health Organization (WHO) endorsed evidence based model, which outlines the elements that are essential to high quality chronic illness care. The readiness of the Irish healthcare system to respond effectively to the management of non-communicable diseases, such as, diabetes, asthma and heart disease has been measure in a series of stakeholder reports from the perspectives of general practitioners<sup>9</sup>, hospital consultants<sup>8</sup>, primary care practice nurses<sup>11</sup> and patients<sup>12</sup> themselves. Arising from this work is ten evidence based recommendations to improve Irelands capacity to meet the current and future demands of the management of chronic disease<sup>13</sup>. We propose that the Committee suggests the adoption of the CCM in an Irish context to act as a framework for the transition from the provision of acute episodic care to the provision of chronic care.

## **Funding model**

There are four main ways to fund healthcare – taxation (currently at about 76%), out-of-pocket expenses (approximately 14%), and private health insurance (approximately 10%). The type of private health insurance is based upon the country's model of policy implementation (multi-payer verses single payer). The Committee should resist 'picking a country' and trying to implement their system within Ireland. The choice of funding model should be guided by independent evidence developed by organisations such as the Adelaide Health Foundation<sup>14-16</sup> and the current<sup>17,18</sup> and future work of the ESRI. The ultimate decision should be made based on three criteria<sup>19</sup>:

1. Technical merit and likely performance;
2. Feasibility for implementation in relation to the changes required; and
3. The likelihood of support from key stakeholders.

The determination of the funding model should also be guided by the definition and goals of universality.

## **Additional areas of importance for the Committee to consider:**

### **Accessible care**

Primary Care - Enhanced access to care is available through systems such as appointments, expanded hours, out of hour's co-operative responsive electronic communication between patients, their GP, practice staff, other primary care professionals and hospitals/other care providers involved in the patients care<sup>20</sup>.

Access to diagnostics – the GP arranges diagnostic tests for the patient in a timely manner. Diagnostic reports are issues promptly and where necessary, arrangements for urgent cases and immediate reporting are available.

Access to hospital consultants – if the problem arises that cannot be managed in the community the patient attends a secondary or territory hospital if the specialist is located there. The arrangement to attend hospital or specialist care is made by the GP on behalf of patients. The reason for the patients' referral and type and urgency of specialist input is clearly communicated at point of referral. Integrated referral and care protocols/standards are in place between the hospital and GPs to make the process efficient and effective for the patient.

How this may be achieved: where appropriate, GPs and hospital consultants work together for the benefit of patients at community level. Occasionally GPs and hospital specialists work together at hospital level.

Patient outcomes: When patients attend hospital they are seen by a consultant who will endeavour to improve their health as speedily as possible. They are discharged home at the earliest opportunity and their GP is informed about the services and care provided and appropriate continuing care. Where a discharge plan needs to be put in place requiring the input of a number of healthcare professionals this is organised and mobilised by the members of the patients PCT.

If the patient requires rehabilitation, recuperation or long term care, it is arranged for the patient in facilities as close as possible to the patient's home as soon as acute hospital care is no longer required. On-going care is provided by a GP and if this care is not provided in the patient's home arrangements to continue the patient's own GP's involvement, where practicable are made.

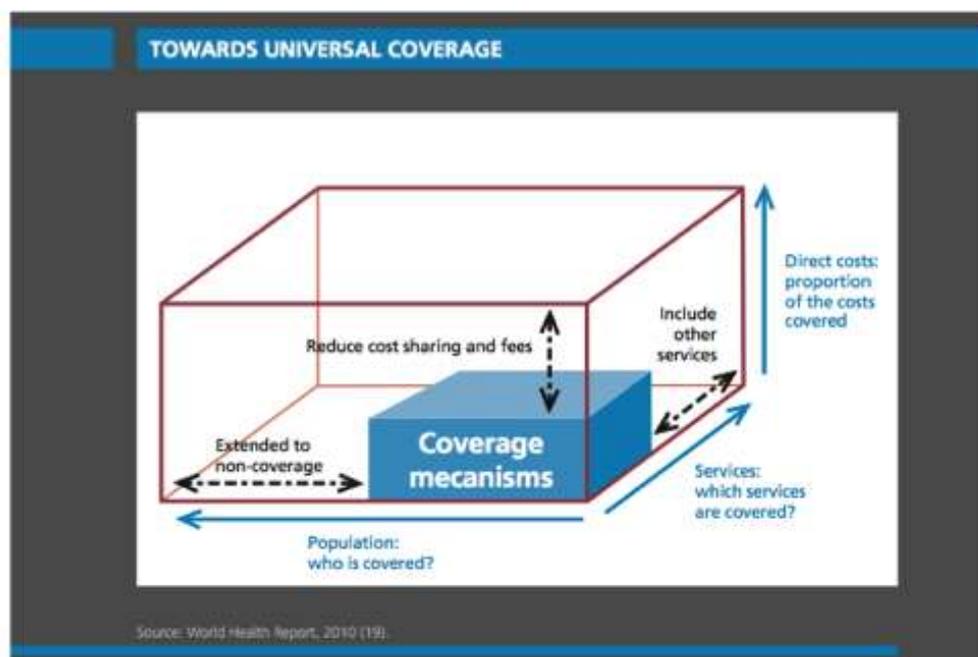
Where the patients are terminally ill they receive the highest standard of care and comfort in their own home. The hospice, GP and other healthcare professionals will liaise to achieve this outcome for the patients, his/her carer and his/her family.

### Quality and safety

GPs have an essential role in monitoring the health and wellbeing of their practice population and their local community. How may this be achieved? All GPs have an electronic register of patients, which is pro-actively used for alerts, recalls, and the monitoring of chronic illness. It is an important safety net in circumstance where the patients have difficulty looking after their health. Patient outcomes: Health is facilitated by informant technology, health information exchange and other means, such as, disease registers to ensure that patients get safe necessary care when and where they need it and in an appropriate manner.

### Monitoring implementation

In any system reform it is essential to monitor the implementation of same with a view to routine assessment of success or failures. If the end goal of the work of this Committee is UHC then we would advocate that the Committee considers using the World Health Organizations 'coverage mechanisms' framework. The Committee should measure, from baseline, the total numbers of the population who are covered under UHC, which services are covered, and the proportion of the costs covered. The routine collection of annual data would allow for the assessment of the effectiveness of the policy to move towards UHC in Ireland over a ten year time frame.



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## Age Action

Age Action, as Ireland's leading advocacy organisation for older people, welcomes the establishment of the Oireachtas Committee on the Future of Healthcare. The development of a 10 year plan is an important opportunity to end the two-tier health system and move Ireland towards a universal integrated health and social care system based on need and not on ability to pay. As a member of the Health Reform Alliance, Age Action supports the submission made by the Alliance to this consultation. Our own submission comments on issues of particular relevance to older people.

A comprehensive, universal health and social care system, which provides the right care, in the right place, at the right time, is essential for the health and well-being of all, but particularly older people as the main users of our healthcare system. In this submission we outline priorities for the 10 year plan including the development of comprehensive primary and community care services with integrated pathways to allow people to transition seamlessly between acute, primary and social care.

We also highlight the need to address the factors leading to the long delays in accessing services, and seek to improve the wellbeing of the population by advocating a Health in All Policies approach towards the development of health policy. To achieve this, we believe that it is important to change the operating assumptions on which our health services are based; reform the acute care system and how funding is allocated; and address gaps in the skill-mix required to meet future needs.

We suggest a number of actions in planning for the ageing population, including the introduction of a statutory entitlement to home care, to ensure the services required are funded to meet need. The steps required to move to an integrated care model are outlined and the barriers identified and we comment on the funding model best suited to Ireland.

### **Recommendations**

Move from current 'deficit model' on which health policy and services are based, to an asset based approach, which focuses on resources and services that promote the self-esteem and coping abilities of individuals and communities at a local level<sup>5</sup>. Within this model, early intervention and self management are prioritised and resourced, delivering care in the community and reducing pressure on hospitals.

Develop population-based (needs-based) funding to assist with planning and ensure equity. A number of formulae can be used and could include factors such as demographics like age and sex, socio-economic status, population distribution<sup>6</sup>.

Over the next five years, enable a move away from acute care services to primary and social care services through the provision of ring fenced funding for the development of comprehensive services in the community.

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<sup>5</sup> [http://www.gcph.co.uk/assets/0000/2627/GCPH\\_Briefing\\_Paper\\_CS9web.pdf](http://www.gcph.co.uk/assets/0000/2627/GCPH_Briefing_Paper_CS9web.pdf)

<sup>6</sup> <http://www.biomedcentral.com/content/pdf/1472-6963-13-470.pdf>

Provide a statutory basis for the allocation of home care. Entitlement will ensure public bodies develop, fund, plan and make available comprehensive services to support independent living.

Expand the chronic disease management programme to cover more conditions and make the programmes available in every Primary Care Centre.

Review the current skill-mix within the healthcare system. Raise the status of hands-on caring as a profession to ensure quality and the skills needed for the future.

To ensure patient flow through acute hospitals and tackle long waiting lists, implement the changes proposed in the various emergency task force reports<sup>7 8</sup>. Address delayed discharges by providing people with the care and support they need in the appropriate setting, creating an extra 100,000 bed days per year in the major Dublin acute hospitals<sup>9</sup>.

To maintain health and well-being, establish a process to actively engage with all government departments to address the wider determinants of health.

To progress a model of integrated healthcare:

Consult with all stakeholders and create a shared vision of an integrated health and social care system.

Set up integrated health and social care teams led by a coordinator in each CHO area.

Implement funding mechanisms that allow flexibility for pooling funding such as money follows the patient from hospital to the community.

## **Introduction**

Age Action was established in 1992 as the voice for older people and Ireland's leading advocacy organisation on ageing issues. Our mission is to empower all older people to live full lives as actively engaged citizens and to secure their rights to comprehensive high quality services according to their changing needs.

Older people's quality of life depends on a comprehensive, universal health and social care system, which provides the right care, in the right place, at the right time. We welcome the opportunity to respond to the committee's consultation on the Future of Healthcare.

## **Strategy**

### ***What are the key priorities for inclusion in a ten year plan for health services?***

The role of the committee is to plan for 'a universal single tier service'. We believe key priorities for advancing this strategy are

The development of a comprehensive, universal primary and community care system where people can access preventative, rehabilitative, medical and social care services in a timely manner based on need and not ability to pay.

Our health system is not working efficiently or effectively. Waiting times for potentially lifesaving tests and procedures are lengthy with public patients waiting up to 25 times

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<sup>7</sup> [health.gov.ie/wp.../Draft-ED-Task-Force-Report-020415-0914-FINAL-COPY.docx](http://health.gov.ie/wp.../Draft-ED-Task-Force-Report-020415-0914-FINAL-COPY.docx)

<sup>8</sup> <http://www.lenus.ie/hse/bitstream/10147/43524/1/3468.pdf>

<sup>9</sup> *ibid*

longer than those paying privately for tests for cancer<sup>10</sup>. A key priority must be to address the factors leading to the long delays for out-patient appointments, diagnostics and in-patient procedures. Delayed discharges contribute to high cancellation rates of scheduled procedures and adversely affect acute hospitals' abilities to provide their services efficiently<sup>11</sup>.

Develop integrated pathways between the primary, secondary and social care systems to ensure care is coordinated around the person and resources are used to meet the needs of the individual. This will entail putting into place of funding mechanisms that enable the transfer of funds between care sectors and/or ring-fenced funding for integrated pathways. Ensure the 10 year plan incorporates a Health in All Policies approach, where public policies across all sectors take into account the health implications of decisions. This will ensure critical decisions made by government departments will be subjected to health impact assessments, addressing the determinants of health, ensuring improved health outcomes.

### ***The key challenges to achieving a “universal single tier health service”***

#### **Changing the operating assumptions on which health services are based**

The current 'deficit' approach, based on problem oriented care, pays little attention to the individual's experience, preferences and knowledge. Instead the focus is on professional knowledge and interventions on behalf of the individual.

This approach is not effective as it 'rations' care to those most in need (e.g. those at risk and emergencies). Treating people further along in their illness, rather than taking preventative or early intervention, is more costly, with implications for the sustainability of this approach.

#### **Structural reform of the acute care system**

The current acute medical model presupposes that the main task is treatment and cure. However 66 per cent of emergency admissions are exacerbations of chronic disease<sup>12</sup>. Hospital medical specialities are designed around single organ diseases, yet 64.8 per cent of people aged 65 years and over live with multi-morbidity. Patients with multiple long-term conditions are now the norm and this will increase by over 50 per cent in the next 10 years<sup>13</sup>. The challenge is to move away from this high-cost, reactive, acute bed-based care to preventative, proactive and integrated care based close to people's communities, focusing on managing chronic illness and maintaining health and well-being.

#### **Funding is allocated based on service users' needs.**

Currently, allocation of funding is biased towards acute care, with less funding allocated to primary and social care. For example in 2016, out of a total budget of €12.89 billion, social care services for older people will receive €703 million, less than 6 per cent of the total healthcare budget<sup>14</sup>. Funding is not related to defined populations and their projected

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<sup>10</sup> [http://www.cancer.ie/sites/default/files/content-attachments/icgp\\_irish\\_cancer\\_society\\_report\\_-\\_access\\_to\\_diagnostics\\_to\\_detect\\_cancer.pdf](http://www.cancer.ie/sites/default/files/content-attachments/icgp_irish_cancer_society_report_-_access_to_diagnostics_to_detect_cancer.pdf).

<sup>11</sup> <http://arrow.dit.ie/cgi/viewcontent.cgi?article=1031&context=buschmanart>

<sup>12</sup> [http://tilda.tcd.ie/assets/pdf/glossy/Tilda\\_Master\\_First\\_Findings\\_Report.pdf](http://tilda.tcd.ie/assets/pdf/glossy/Tilda_Master_First_Findings_Report.pdf)

<sup>13</sup> Ibid

<sup>14</sup> <https://www.hse.ie/eng/services/publications/serviceplans/nsp16.pdf>

needs. Between 2009 and 2015, the healthcare budget fell by over 21 per cent even though the number of people aged 65 and over increased by 9 per cent<sup>15</sup>.

Since 2014, block grant funding of hospitals is being replaced gradually by Activity-Based Funding (ABF) (formerly Money Follows the Patient) with payment now based on episodes<sup>16</sup>. This is not conducive to addressing the complex care needs of older people.

The challenge therefore is to implement a pathway mechanism where 'Money Follows the Patient' from the acute hospital to the community to meet need and to facilitate the timely provision of home care packages. Acute hospital beds are among the most expensive resources in the entire healthcare system, costing up to €850 a night<sup>17</sup>.

The current HSE target for delayed discharges is 500 people per month. Hence, approximately €425,000 per day of the acute hospital budget is being spent on keeping people in acute care beds. In many instances people are waiting for community supports like Home Care Packages (HCPs). At the end of March 2016, 1,436 people were waiting for HCPs.

#### A workforce with the right skills to meet diverse needs.

The current professional workforce was trained and developed to work around single episodes of treatment in hospital. The greatest demand on services now and in the future is to meet the care and support needs of people with multi-morbidities requiring health and social care. The present skill-mix does not meet these needs. Older people in hospital cannot get assistance with eating; there is difficulty recruiting formal home care staff; home helps cannot shop or prepare a hot meal for a housebound person.

An NHS briefing paper<sup>18</sup> identified the need to realign training budgets and career pathways. Approximately 60 per cent of the NHS training budget is spent on the higher paid health professionals (doctors, nurses and allied health professionals), with no national funding for training less qualified workers such as healthcare assistants, despite the fact that biggest growth in need will be in hands-on, out-of-hospital, and social care<sup>19</sup>.

#### ***Actions needed to plan for, and take account of, future demographic pressures and their impact on the health system***

Over the next 30 years, the number of people aged over 65 is projected to double from 624,183 in 2016 to over 1.4 million in 2046. The very old population (those aged 85 and over) is projected to quadruple from 69,873 in 2016 to 266,900 in 2046<sup>20</sup>.

Whilst the vast majority of older people are fit and healthy, approximately 15 per cent have health problems which affect their ability to live full, active, lives in their communities. A further group, approximately 5 per cent, are very frail and dependent<sup>21</sup>. Chronic illnesses

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<sup>15</sup> <https://www.hse.ie/eng/services/publications/planningforhealth.pdf>

<sup>16</sup> [http://health.gov.ie/wp-content/uploads/2015/07/ABF\\_Implementation\\_Plan\\_20\\_05\\_2015.pdf](http://health.gov.ie/wp-content/uploads/2015/07/ABF_Implementation_Plan_20_05_2015.pdf).

<sup>17</sup> <http://arrow.dit.ie/cgi/viewcontent.cgi?article=1031&context=buschmanart>

<sup>18</sup> [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/perspectives-nhs-social-care-workforce-jul13.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/perspectives-nhs-social-care-workforce-jul13.pdf)

<sup>19</sup> *ibid*

<sup>20</sup> [http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016\\_2046.pdf](http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016_2046.pdf)

<sup>21</sup> <http://www.atlanticphilanthropies.org/app/uploads/2015/09/new-ageing-agenda-report.pdf>

like diabetes and cardiovascular diseases affect 8 out of 10 people aged over 65 in Europe. Ninety per cent of our total healthcare costs are spent on 30 per cent of our population with chronic disease<sup>22</sup>. Older age is associated with an increase in multiple long-term conditions and frailty. The percentage of the population aged 85 and over who have a disability is estimated to be 72.3 per cent<sup>23</sup>.

People aged 65 and over are major users of the acute hospital care. In 2014, 12.7 per cent of the population consisted of people aged 65 and over, yet 53.3 per cent of total hospital in-patient bed days and approximately 36 per cent of day case and same day bed-days were used by this cohort<sup>24</sup>.

The following actions are required to ensure that the health system meets the needs of an older population.

#### Provide a statutory right to home care

With increasing age, demand for long-term care and support will grow. Approximately 10-11 per cent of people aged 65 years and over in Ireland require some form of home care<sup>25</sup>. It is very difficult to access home care and support. Provision of these services is discretionary and there is a lack of transparency in the allocation of hours. Being able to access this vital support is dependent on the resources available at a given time and in a particular area<sup>26</sup>.

A statutory entitlement to home care is essential if the service is to attract ring-fenced funding and to meet the needs and preferences of older people. Without certainty in the allocation of home care, an increasing number of people with low to moderate level of dependency will have no choice but to go into long-term residential care, with a substantial cost to the State, estimated to be €1.234 billion in 2021<sup>27 28</sup>.

#### Provide care that is coordinated around the full range of the person's needs and prioritise prevention and support to maintain independence

A paper from the Kings Fund, 'Making Health and Care Systems fit for an Ageing Population' outlines the many components of care relevant to older people and how the quality, capacity and responsiveness of any one will affect others<sup>29</sup>.

The key components include support to live well for those with stable long-term conditions, but also for those with complex co-morbidity, dementia and frailty; rapid support close to home in crisis; good acute care; access to community rehabilitation and enablement after acute illness or injury to maintain independence.

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<sup>22</sup> <https://www.hse.ie/eng/services/publications/planningforhealth.pdf>

<sup>23</sup> <http://www.cso.ie/en/media/csoie/census/documents/census2011profile8/Profile,8,commentary.pdf>

<sup>24</sup> <https://www.hse.ie/eng/services/publications/planningforhealth.pdf>

<sup>25</sup> <https://www.hse.ie/eng/services/publications/planningforhealth.pdf>

<sup>26</sup> [https://www.ageaction.ie/sites/default/files/aa2c\\_asi2c\\_iasw\\_final\\_research\\_report-a4-report\\_lr\\_for\\_web\\_2.pdf](https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf)

<sup>27</sup> <https://www.hse.ie/eng/services/publications/serviceplans/nsp16.pdf>

<sup>28</sup> cost of 25 HCP hours for 3,414 people = 3,414 x €27,300 (€525 per week)= €93.2 million. Cost of NHSS for 3,414 people= 3,414 x €46,176 (NHSS bed per annum)= €157.6 million

<sup>29</sup> [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf)

To provide these types of support, multi-disciplinary teams including physical and mental health, social care, public health and the wider public, private and voluntary sectors are required to work together to deliver person-centred care within the community.

The remit of community intervention teams could be expanded to include the provision of Hospital at Home services to people who would otherwise be admitted to acute hospital. There is evidence to show this is effective and there is a high rate of patient satisfactions<sup>30</sup>.

Rapid access clinics or 'chair based' geriatric clinics in Primary Care Centres provide effective interventions for those experiencing an exacerbation of a chronic illness or deterioration in health or function<sup>31</sup>. Specialist care units such as stroke units have consistently been shown to save lives and improve outcomes<sup>32</sup>. Geriatric 'in-reach' assessments and consultations for frail older people under other medical and surgical specialties have also been shown to improve clinical effectiveness and efficiency<sup>33</sup>.

Managing frailty is a key issue for modern health and social care services. A holistic approach, seeing the whole person in terms of their medical and psychosocial needs, is critical. Early identification of individuals who are frail, providing them with comprehensive geriatric assessment, taking a case management approach in coordinating care, and preventing avoidable disability is essential in managing any deterioration<sup>34</sup>.

To prevent admissions to hospitals and nursing homes, and maximise independence following an acute admission or illness, investment in services such as re-ablement programmes is required<sup>35</sup>.

#### Mandatory inclusion of modules addressing ageism and competence in working with older people in all professional education and training.

The vast majority of professionals working in the health and social care field will engage with older people in the context of their work. It is therefore essential that they are competent to help people cope with physical and mental decline and treat their clients with dignity and respect.

#### **Integrated Primary and Community Care**

##### ***The steps needed to move towards a model based on integrated primary, secondary and community health care.***

Presently older people experience the health and care system as illustrated by Mrs Smith's experience here<sup>36</sup>.

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<sup>30</sup> <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007491/pdf>

<sup>31</sup> [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/the-care-of-frail-older-people-with-complex-needs-mar-2012.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/the-care-of-frail-older-people-with-complex-needs-mar-2012.pdf)

<sup>32</sup> Chan et al, 2013)

<sup>33</sup> [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/the-care-of-frail-older-people-with-complex-needs-mar-2012.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/the-care-of-frail-older-people-with-complex-needs-mar-2012.pdf)

<sup>34</sup> [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/the-care-of-frail-older-people-with-complex-needs-mar-2012.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/the-care-of-frail-older-people-with-complex-needs-mar-2012.pdf)

<sup>35</sup> <http://www.ifa-copenhagen-summit.com/wp-content/uploads/2016/04/Copenhagen-Summit-Final-Report.pdf>

<sup>36</sup> <http://www.kingsfund.org.uk/sites/files/kf/integrating-health-social-care-torbay-case-study-kings-fund-march-2011.pdf>

***Mrs Smith's experience of navigating through the health and social care system***



Integrated care will improve people's experience and outcomes of care, and deliver greater efficiencies<sup>37</sup>.

***Outcome for Mrs Smith of an integrated health and social care system***



To achieve this integrated model of care requires action at multiple levels and includes:  
Bring on board all stakeholders through participative consultation and create a shared vision for an integrated health system;

Set up integrated health and social care teams;  
Pool health and social budgets. Savings made through eliminating duplicate services such as assessments could facilitate a wider range of services;

<sup>37</sup> <http://www.kingsfund.org.uk/sites/files/kf/integrating-health-social-care-torbay-case-study-kings-fund-march-2011.pdf>

The appointment of a health and social care coordinator proved crucial to the success of an integrated health and social care model in Torbay<sup>38</sup>. The coordinator facilitated good communications, the building of relationships and trust and harnessed contributions from all of the team members;  
Establishing information sharing processes.

***What are the key barriers to achieving this, and how might they be addressed?***

The different value systems that underpin professional disciplines;  
Lack of a joint working approach between secondary services and primary care services;  
The operation of Primary Care teams:  
The public/private mix within Primary Care Teams. GP engagement with Primary Care Team has costs for the GP, so the level of participation depends on the individual GP. On the other hand, the public nurse and allied professionals are public servants.  
Inconsistency in the make up of the Primary Care Team e.g. social workers are not part of some teams.

Teams are not resourced properly so access to therapies such as physiotherapy and occupational therapy is inadequate, resulting in lengthy waiting times of 12 weeks or more for assessment and therapy<sup>39</sup>.  
The inconsistency in service provision, types of services available and eligibility criteria.  
Lack of comprehensive primary care services outside normal working hours.  
Absence of case management approach for people with complex needs.

To address these barriers

Implement collaborative working practices and shared decision-making ensuring stakeholders work together as a team, in the interest of the patient and the common good, and not in the interest of preserving professional roles and practices.  
Medical and psycho-social needs are accorded equal importance.  
Appointment of a coordinator for each Primary Care Team.  
Extend GP practice operating hours within Primary Care Centres to weekends and evenings through a rota system between practices within the centres. Ensuring access to patient history will be important.  
Introduce community case management for people with more complex needs.  
Extend the 'money follows the patient' approach from the hospital to the community.  
Resource Information and Communication Technology and establish information sharing pathways.

***In your experience, what are the key roadblocks you encounter in your particular area of the health service?***

Older people are the group most likely to suffer problems with co-ordination of care and transitions between services. An integrated healthcare model is crucial to enable them live independently in the community and to halt premature admission to nursing homes. Key road blocks for older people are:

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<sup>38</sup><http://www.kingsfund.org.uk/sites/files/kf/integrating-health-social-care-torbay-case-study-kings-fund-march-2011.pdf>

<sup>39</sup> HSE National Performance Assurance Report December 2014

Excessively long waits for procedures particularly salient to people aged 65 and over such as minor eye surgery and orthopedic surgery, which have consequences for older people's independence, resulting in premature admission to long-term care.

The discretionary nature in the allocation of home care, coupled with inconsistency in service delivery across the country acts as a road block to older people remaining in their own homes for longer<sup>40</sup>. Ten days in bed due to a delayed discharged can lead to a significant reduction in leg and hip muscle strength and in aerobic capacity even in healthy older adults<sup>41</sup>.

***How would you ensure buy-in from health care professionals to progress towards an integrated health care model?***

Through consultation and creating a shared understanding of what an integrated care model will look like and how it can improve service users' experiences. For example, the Torbay integrated health and social care model used a consultation process, starting with frontline staff. Through this consultation process, a vision of what an integrated model of care would look like was created. At the centre of this vision was the story of Mrs Smith, a fictitious user of health and social care services. Building a shared understanding of the changes need and the positive outcome for Mrs Smith ensured buy-in from all stakeholders including managers, clinicians, frontline and administration staff.

***Are there any examples of best practice that the Committee should consider?***

The Torbay Model<sup>42</sup> provides a good example of the process undertaken to integrate health and social care for older people. Much of the work of the King's Fund in the UK focuses on models of integrated care to meet the needs of the changing population using case studies<sup>43</sup>.

**Funding Model**

*Do you have any views on which health service funding model would be best suited to Ireland?*

Age Action believe that a general tax funded health system is the most effective and financially sustainable way to provide universal access to health and social care based on need and not ability to pay<sup>44</sup>.

***Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating.***

A tax funded system effectively pools health risk across a large contributing population as individuals contribute to the provision of health services through taxes on income, property, capital gains and activities such as alcohol consumption and gambling. Payment is mandatory, and risk is spread as contributions are not related to the individual's likelihood of needing or using health services.

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<sup>40</sup> [https://www.ageaction.ie/sites/default/files/aa2c\\_asi2c\\_iasw\\_final\\_research\\_report-a4-report\\_lr\\_for\\_web\\_2.pdf](https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf)

<sup>41</sup> <http://www.ncbi.nlm.nih.gov/pubmed/17456818>

<sup>42</sup> <http://www.kingsfund.org.uk/sites/files/kf/integrating-health-social-care-torbay-case-study-kings-fund-march-2011.pdf>

<sup>43</sup> <http://www.kingsfund.org.uk/topics/integrated-care/integrated-care-map>

<sup>44</sup> <https://www.esri.ie/pubs/BP201701.pdf>

However, financing of the health system is dependent on the efficiency of the taxation model and will depend on the effectiveness of the tax system to raise funds.

***What are the main entitlements that patients will be provided under your funding model?***

Universal healthcare should cover preventative, curative, rehabilitation, social and long-term nursing care services along with medical goods.

*Please provide examples of best practice, or estimated costs of such models if available.*

Comparative studies have examined models used in different countries for the financing healthcare<sup>45 46</sup>. Whilst these studies give some insight into the costs, universality in terms of coverage and cost varies.

Dr. Marita O'Brien

Health Policy Officer at Age Action Ireland

**Tel:** +353 (0)1 4756989

**Email:** [policyinclusion@ageaction.ie](mailto:policyinclusion@ageaction.ie)

**Website:** [www.ageaction.ie](http://www.ageaction.ie)

The work of the Age Action policy team is supported by the Scheme to Support National Organisations, funded via the Department of the Environment, Community and Local Government and administered by Pobal.

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<sup>45</sup> [http://www.who.int/health\\_financing/taxed\\_based\\_financing\\_dp\\_04\\_4.pdf](http://www.who.int/health_financing/taxed_based_financing_dp_04_4.pdf)

<sup>46</sup> [http://www.commonwealthfund.org/~media/files/publications/fund-report/2016/jan/1857\\_mossialos\\_intl\\_profiles\\_2015\\_v7.pdf](http://www.commonwealthfund.org/~media/files/publications/fund-report/2016/jan/1857_mossialos_intl_profiles_2015_v7.pdf)

## Alere

Founded in 2001, headquartered in Massachusetts, US, Alere is the number one global supplier of innovative point-of-care (POC) diagnostic tests, supplying 1.4 billion tests to patients in over 200 countries.

Globally we employ 9, 200 people. In Ireland, Alere has a significant presence in Galway employing 150 people. Our Galway centre oversees the processing and **delivery of Alere's next generation healthcare tests in Europe and the Middle East, Latin America and Africa.** Alere Galway also leads on the supply chain **management of the company's rapid, 'point-of-care' HIV tests.**

We provide healthcare professionals with the information they need to assist in making treatment decisions through reliable, high-performance diagnostic tests. Our focus is based around our core principle of *Knowing Now Matters*, encompassing delivering reliable and actionable information through rapid diagnostic tests, resulting in better clinical and economic healthcare outcomes.

### **Ten year health strategy**

As a company to the fore in the delivery of rapid diagnostic testing and educational resources to healthcare workers, we see first-hand the significant impact which bed-side/near patient testing can have; with test results delivered in minutes rather than more outdated methods which can take several days. Provision of diagnostic services in the primary care removes uncertainty around diagnosis, thereby reducing the number of referrals to acute hospitals. Treating patients in primary care leads to lower healthcare costs and improved patient outcomes.

### **Anti-microbial resistance (AMR)**

As a result of AMR, once treatable diseases are becoming much more serious, and even deadly. Data shows that currently up to 30,000 lives are lost annually due to antibiotic-resistant infections in Europe and this is increasing year on year. If significant action is not taken quickly AMR also jeopardises medical advancements such as routine surgeries, organ donation and chemotherapy which all rely on antibiotics to be successful and safe. If AMR rates continue to grow, these medical procedures will no longer be safe.

Up to 80% of antimicrobials are prescribed in the community setting in Ireland. It is estimated that up to 60% of these are unnecessary. The provision of rapid diagnostics in the community to quickly diagnose and guide treatment has been shown to significantly reduce antibiotic prescribing rates without negatively affecting patient outcomes in other European countries. These countries also have correspondingly lower AMR rates.

In Ireland a recent HIQA report pointed to the need for increased action in hospitals and particularly in community settings to urgently tackle the problem of AMR. Currently almost all resources to combat AMR are directed at acute hospitals, which bear the burden of the consequences of AMR.

However, the significant drivers of AMR are found in the community and resources to prevent the spread of AMR should be re-directed to address this.

Below we have outlined this issue in full and also included a number of key recommendations which we urge this Committee to examine in full and include in your final strategy. We look forward to working with all stakeholders to progress this critical objective.

Empowering a shift in prescribing behavior away from the over-use of antibiotics, which spawned the growing prevalence of serious healthcare-associated infections like MRSA and *C. difficile*;

- Enabling healthcare practitioners to distinguish between infections that require treatment and those that are self-limiting.

### **Antimicrobial Resistance – A role for rapid diagnostics**

Antimicrobial resistance (AMR) occurs when microbes become immune to the medications that previously used to kill them. The process happens naturally, but misuse of antibiotics in humans and animals is accelerating the problem. To keep pace, our behavior has to evolve faster than the microbes.

**After hundreds of years of steady medical breakthroughs, we're looking at the very real possibility of medical setbacks.**<sup>1</sup>

Due to antibiotic resistance, a growing number of bacterial infections — such as pneumonia, tuberculosis, and gonorrhea — are becoming harder to treat as microbes become more resilient to treatment.

**It's not inconceivable that one day, medical procedures such as organ transplantation, cancer chemotherapy, diabetes management, caesarean sections and hip replacements will be considered very high risk — and that the risk of dying from a common infection would outweigh the benefits of the medical procedure.**

Older people and immunocompromised people may have a higher risk of dying from a drug-resistant infection<sup>1</sup>, but antimicrobial resistance is a much bigger problem: Whenever anyone in a community abuses antibiotics, the drugs become less effective for everyone in the community.

Developing new **medicines isn't enough. The discovery of new antimicrobials is too slow to keep pace with how quickly microbes are evolving to resist old medicines.**<sup>2</sup> We need to preserve the effectiveness of the antimicrobials which we currently have. Just as important, **it's critical we move away from the broad over-prescription of antibiotics towards more targeted therapy.**

90% of Respiratory Tract Infections (RTIs) are caused by a virus.

Strep A is the cause of acute pharyngitis (sore throat) in only 15-30% of cases, however antibiotics are prescribed in up to 75% of cases.<sup>4</sup>

Globally, 480,000 people develop multi-drug resistant TB each year.

Annual deaths resulting from antimicrobial-resistant infections could rise to 10 million a year in 2050, from the current 700,000.

Imagine if your newborn was infected by a resistant strain of pneumonia and lapsed into a coma? Or your grandmother surviving a bypass operation — only to pass away from a minor infection that proved resistant to any medication?

### **Antimicrobial Resistance – A role for rapid diagnostics**

- Empowering a shift in prescribing behavior away from the over-use of antibiotics, which spawned the growing prevalence of serious healthcare-associated infections like MRSA and *C. difficile*;
- Enabling healthcare practitioners to distinguish between infections that require treatment and those that are self-limiting.
- Through our mission, we aim to deliver quality, accessible and effective healthcare for everyone.

### **Corporate Social Responsibility**

- Through our mission, we aim to deliver quality, accessible and effective healthcare for everyone.

### **HIV Continuum of Care**

- We are partnering with organisations such as [Population Services International](#) and the [Organisation of African First Ladies Against HIV/AIDS](#) (OAFLA) to donate and distribute HIV tests to sub-Saharan Africa and other rural areas where access to HIV testing and treatment is limited.

### **Malaria Eradication**

- Every minute a child somewhere dies from malaria. We work with global non profit Malaria No More to put an end to malaria deaths. Alere has donated 2 million tests to health clinics in Africa to screen children who may have been infected with malaria.  
See [http://www.unicef.org/health/index\\_malaria.html](http://www.unicef.org/health/index_malaria.html).

### **AMR in Ireland**

- Ireland has the ninth highest rate of antibiotic consumption in 30 countries;
- For every 1,000 members of the Irish population there are 22.5 daily defined doses of antibiotics per day in Ireland
- 80% antibiotics are prescribed in the community in Ireland
- Up to 60% of antibiotics are prescribed unnecessarily
- If you are resident in an Irish nursing home, you are more than twice as likely to be on an antibiotic than in any other European Country

## **2010 – HSE Healthcare Associated Infection (HCAI) and Antimicrobial Resistance (AMR) Clinical Programme**

Programme focuses on:

- Hand hygiene;
- Prudent use of antibiotics;
- Prevention of medical-device related infections, e.g. catheters.

### **Gaps in Existing Irish AMR Strategy**

- Programme does not have clear goals, deliverables or timelines;
- Broad, unfocused objectives;
- Strong focus on hospital, less so on primary care where largest proportion of antibiotics are prescribed;
- Need for set deliverables and timelines for same.

### **Immediate Priorities for Ireland**

- National Interdepartmental AMR Consultative Committee established in November, 2014;
- WHO Global Action Plan on AMR introduced in May, 2015 - national replication required;
- Irish Government commitment to have in place, by May 2017, a national action plan on antimicrobial resistance that is aligned with the global action plan.

### **Key Considerations for Irish Action Plan (1)**

- Need for clearer objectives/deliverables with timelines for implementation/achievement;
- Stronger focus on primary care and GPs, where greatest amount of antibiotics prescribed;
- Defined pathway for increased use of diagnostics to ensure patients' are quickly and accurately diagnosed; avoiding unnecessary use of antibiotics;
- Irish Action Plan must be backed up by Government policy and funds where needed.

### **Key Considerations for Irish Action Plan (2)**

- Research indicates that countries' antibiotic-prescribing rates are linked to resistance rates<sup>1,2</sup> and, consequently, that the reduction of unnecessary prescribing, particularly for acute respiratory tract infections (ARTIs), could directly contribute to lower resistance.

- Interventions such as CRP point-of-care testing have been shown to significantly reduce antibiotic prescribing for lower respiratory tract infections without compromising either patients' recovery or satisfaction with care.<sup>1,3,4</sup>
- A range of rapid diagnostics are available which enable healthcare practitioners to distinguish between respiratory tract infections that require treatment and those that are self-limiting as well as several other diagnostic tools that can help clinicians identify pathogens at the point of care and define whether antimicrobials are required.
- These include rapid diagnostics for Strep A, Influenza, *S. pneumoniae*, *E. coli* and *C. difficile*.

[www.alere.com/en/home.html](http://www.alere.com/en/home.html)

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4 Brookes-Howell, L, Hood, K, Cooper, L, Little, P, Theo Verheij T, Coenen, S., Maciek Godycki-Cwirko, M., Melbye, H. ,Borras-Santos, A., Worby, P., Jakobsen, K., Goossens, H., Butler, C. C.

## Alice Gormley, Occupational Therapist

Please note that my responses mainly relate to children with disability as this is my area of expertise.

What are the key priorities for inclusion in a ten year plan for the health service?

**Response:** There is no joined up thinking or integrated clinical and financial management systems operating between health and education services and other government departments who impact upon a child's lifestyle and ability to remain independent –e.g. the departments of education and transport. Engage and consult with the various Health and Social Care Professionals involved in paediatric health and social care in Ireland. **This should be a priority action to address this situation.**

**A list of recommendations I would like to be considered by the Committee.**

- There is no joined up thinking or integrated clinical and financial management systems operating between health and education services and other government departments who impact upon a child's lifestyle and ability to remain independent – e.g. the departments of education and transport. **This should be a priority action to address this situation.**

**See extract from National Disability Authority Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005.**

**“10.5 Health and education sectors.** The Health and Education cross-sectoral team, should commence a number of critical pieces of work to ensure that the interface with the education system does not negatively impact on the statutory assessment of need process.

**10.5.1 Education support should not require a prior diagnosis.** The resource allocation rules of supports for children with low incidence special education needs is driving a demand for diagnostic assessments, which assessors feel compelled to conduct.

The National Disability Authority also notes that in the absence of a full commencement of the Education for Persons with Special Educational Needs Act 2004, the assessment of need under the Disability Act 2005 is being used a means to unlock support in the education sector.

The Department of Health and the Department of Education and Skills should advance the implementation of the recommendation of the National Council for Special Education research report that, —a diagnosis should not be a prerequisite or determinant for the allocation of additional resources for a child or young person with SENII by developing a framework for SEN assessment using an interactionist/ecological model as recommended by the report authors 45.

The Department of Health and the Department of Education also need to bring clarity to:

what constitutes an education support

what constitutes a health support

what are the appropriate assessment processes for accessing either or both

The National Disability Authority acknowledges the work that the Health and Education cross-sectoral team have conducted to date. However, given the critical importance of the interface between health and education services for young children with disabilities and/or

special education need, the National Disability Authority advises that a Task Force to address these issues, reporting to both the Minister for Health and the Minister for Education and Skills, be established and requested to report within as short a timeframe as is appropriate.”

### **National Disability Authority Research 2011 into the Practice of Assessment of Need under Disability Act PAGE 78**

- Review of the 1970 Health Act - ? – fit for purpose in relation to children’s disability Services and integration of health and education services. **Conduct a review of 1970 Health Act in the context of contemporary health and demographic issues**
  - Conduct a review of G.M.S – the G.P only card blocks access to many services and facilities at primary care level .Non availability of a medical card blocks access to many services and facilities at primary care level. **Conduct a review of G.M.S as a matter of urgency**
  - Review Part 2 of the Disability Act in relation to Assessment of Need and consider the implementation of the EPSEN Act **Conduct a review of A.O.N as a matter of urgency**
  - Engage and consult with the various Health and Social Care Professionals involved in health and social care in Ireland.
  - Strengthen support structures for Health and Social Care Professionals – so much time of their time – up to 50% in some cases is taken up with administrative and clerical tasks
1. **The main body of your submission. This should be concise and highlight any relevant factual information, data or case studies from which the Committee could draw conclusions, or which could be put to other parties for their reactions.**

#### **Strategy**

What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?

**Response:** There is no joined up thinking or integrated clinical and financial management systems operating between health and education services and other government departments who impact upon a child’s lifestyle and ability to remain independent –e.g. the departments of education and transport. **This should be a priority action to address this situation.**

**Refer to National Disability Report attached.**

#### **Integrated Primary and Community Care**

- What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?

**Response:** The use of a social mode of care, case management and multi-disciplinary team co-ordination. **See extract from National Disability Authority Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005.**

### “3.1 Integrated structures

The Local Health Office areas, that informed this project, had a variety of configurations as to how children were assessed and services were delivered. Some were solely Health Service Executive, others a mix of statutory and non- statutory agencies and others worked in an interagency partnership. All struggled with similar issues like:

Delivering a statutory assessment of need within the statutory timeframes

The appropriateness of some of the language of the Disability Act 2005 in the context of delivering supports to children, particularly young children,

Trying to ensure that they operated in the best interests of the child

Attempting to ensure equity between a statutory assessment of need and other assessments and managing waiting lists and priorities

Dealing with impacts on service provision such as reduced resources

What was striking was that Local Health Office areas seem to be better able to cope with the requirements of operating Part 2 of the Disability Act 2005, where there were integrated structures with:

good cooperation among clinicians  
co-working  
coordinated early intervention teams”

### National Disability Authority Research 2011 into the Practice of Assessment of Need under Disability Act PAGE 28

- **In your experience**, what are the key roadblocks you encounter in your particular area of the health service?

**Response:** There is no joined up thinking or integrated clinical and financial management systems operating between health and education services and other government departments who impact upon a child’s lifestyle and ability to remain independent –e.g. the departments of education and transport.

**Response:** No clear strategy and implementation plan for services for children with disability. Services are very tokenistic and considered discretionary as opposed to essential. A study conducted by Dr Pillinger in 2002, on behalf of the National Disability Authority, “found broad international consensus on the trend towards provision of services within the framework of a social model of disability, but also difficulty in the speed of this transition due to a widespread historical and institutional reliance on a medical and welfare model of disability”. **Little has changed over the past decade in relation to children’s services .**

Recruitment of therapy staff is a very long convoluted, drawn out process. It can take up to 5 years to replace a vacant post or get approval for a new post. When a new post is created, the post often has no funds attached for clinical, office and administration support

- How would you ensure buy-in from health care professionals to progress towards an integrated health care model?

**Response:** Engage and consult with the various Health and Social Care Professionals. (H.S.C.Ps). The H.S.C.Ps have no voice at government /Dept of Health or H.S.E. level. At the moment, if you want to influence health services/strategy in Ireland, you need to move out of your H.S.C.P into a managerial /administrative role.

- Are there any examples of best practice that the Committee should consider? Please refer to any evidence you have to support this.
- Refer to work undertaken by the various health and social care professionals in relation to the acute medicine programmes.
- Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating.

**Response:** The use of long term planning, cost benefit analysis and economic evaluation, use of evidence based practice, introduction of a model of social care in relation to children with disabilities services.

- What are the main entitlements that patients will be provided under your funding model?

**Response:** Access to early intervention to therapy and rehabilitation

Please provide examples of best practice, or estimated costs of such models if available.

### “10.12 Savings

This report found that many professionals involved in the statutory assessment of need process spent considerable periods of time on relatively routine tasks that could, in some cases be more effectively done by other people or by using appropriate technology.

Efficiencies could be achieved if the Health Service Executive ensured that:

- all agencies conducting statutory assessments of need have access to IT services and appropriate encryption software. This would facilitate the confidential electronic transmission of documentation and ensure that the entire process can be based on electronic based document system
- organisations and teams provide clinicians with appropriate level of administrative support for functions such as typing up dictated assessor’s reports. Such a practice would allow clinicians to devote more time to assessing and providing intervention to children
- organisations and teams have appropriate software to score standardised assessment tests. This would allow clinicians to devote more time to assessing and providing intervention to children”

**National Disability Authority Research 2011 into the Practice of Assessment of Need under Disability Act PAGE 82**

**Please refer to Position Statements from the British Association of Occupational Therapists and N.I.C.E guidelines attached.**

**Any recommendations for action by Government or other actors which the Committee should consider in preparing its report.**

- **Response:** There is no joined up thinking or integrated clinical and financial management systems operating between health and education services and other government departments who impact upon a child’s lifestyle and ability to remain independent –e.g. the departments of education, housing and transport. **This should be a priority action to address this situation.**

Alice Gormley, Occupational Therapist.

## All Ireland Institute of Hospice and Palliative Care

With numbers of older people set to rise in Ireland, it is vital that models of care delivery adapt to enable people to live as well as possible until death. Continued change and innovation is required to future proof the health service in providing the best possible care for those living in Ireland, regardless of underlying diagnosis. This is especially true of the care provided to those living with serious and progressive life-threatening illnesses, such as advanced cancer, advanced dementia, degenerative neurological conditions, irreversible organ failure, or acquired immune deficiency syndrome (AIDS).

AllHPC is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AllHPC advances education, research and practice to improve the palliative care experience of people with life limiting conditions and their families. As the palliative care sector's institute, AllHPC is:

involving service users, carers and communities in palliative care delivery and development working to integrate palliative care across the health system so people are supported as early as possible, supporting the development of specialist palliative care services for everyone who needs them.

### Overview

Now more than ever, society is facing many challenges when it comes to the provision of hospice and palliative care. With numbers of older people set to rise, along with rates of disability, dependence on carers and deaths set to increase over the next decade, it is vital that models of care delivery adapt to cope. Continued change and innovation is required to future proof models of care, enabling health services to provide the best possible care for those living in Ireland, regardless of underlying condition.

In 2014, Ministers of Health at the World Health Assembly<sup>1</sup> supported a ground-breaking resolution driving national action to reduce barriers to the accessibility and availability of palliative care. The Assembly urged Member States (inter alia):

- To develop, strengthen and implement palliative care policies to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care;
- To ensure adequate domestic funding and allocation of human resources for palliative care initiatives, including education and training, and quality improvement initiatives;
- To provide basic support, including through multi-sectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;
- To aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities.

Since the publication of the 2001 NACPC Report<sup>2</sup>, significant initiatives to enhance services have taken place across and between organisations within the palliative care sector in Ireland, as detailed in the report "Palliative Care - The Three Year Development Framework (2016 – 2018)" (produced by the HSE and submitted to the Department of Health for consideration). These include the creation of the HSE's National Clinical Programme for Palliative Care<sup>3</sup> to improve quality, facilitate equitable access and promote efficient use of

resources, and the establishment of the All Ireland Institute for Hospice and Palliative Care (AIHPC)<sup>4</sup> and The Palliative Hub<sup>5</sup>, with the potential to transform and promote palliative care education, research and practice across the island of Ireland.

Principles of rehabilitation are evident as central themes in the philosophy and vision for modern day hospice and palliative care espoused by its founder Dame Cicely Saunders: “All the work of the professional team ... [is] to enable the dying person to live until he dies, at his own maximal potential performing to the limit of his physical and mental capacity with control and independence whenever possible”<sup>6</sup>. Despite this, palliative care services are still considered by both professionals and the public as relevant only to last days of life and hospices are often seen as places of death, dying and bereavement with less of a focus on helping people to live well, and be the best they can be. A model of “total care” has grown up that can in practice disable the patient by taking over and “doing” for or to them<sup>7</sup>. But is this what patients want? The evidence is that most people express a desire to remain as independent as possible for as long as possible in the face of advancing illness. It is paramount to people to be viewed as normal, rather than as an illness, and where possible to be able to do normal things such as wash, dress, shop, cook for themselves. The Let’s Talk About Palliative Care Survey report<sup>8</sup>, commissioned by the AIHPC, revealed that of the 528 responses received:

Over two thirds (68%) of respondents signified that planning for the future was their biggest practical worry.

While 27% felt supported by care provided, 52% indicated that they felt frustrated, helpless or a combination of both.

Forty-eight percent of respondents felt they were communicated to clearly or sensitively by those providing care, while 22% indicated that issues of relevance were avoided completely. Thirty-four percent of respondents experienced information being communicated in a timely or appropriate manner, yet 37% felt they received information too little, too late. Only 24% of respondents felt they were able to make choices they wanted whilst 34% felt control was in someone else’s hands and 21% felt that choices were limited.

Emotional or psychological needs were felt to be less well met than spiritual or physical needs in over half of respondents (51%). Notably psychologists and counsellors were rarely identified as being involved in the care of those reporting their experience.

Forty-two percent of respondents indicated they would have preferred better coordination of care or treatment; 20% signified that better emotional support could have been provided. Half of respondents (50%) felt that family and friends were adequately involved in care plans, or that their views were respected, but 20% felt family and friends were forgotten about or excluded and 18% felt that carers were put under too much pressure.

In moving to new and improved models of care it is vital that patients and families are:  
approached with an ethos of what we enable you to do for yourself rather than what healthcare services do for you;  
asked what matters to you rather than asking what’s the matter with you;  
asked what is your goal rather than what is your problem;  
rather than asked what is the pain stopping you or your loved one from doing, rather than just how bad is the pain,<sup>7</sup>

Sufficient consideration must be given to educating future practitioners in the art and philosophy of palliative care. In doing so we limit the dangers associated with prescriptive care planning which insufficiently considers the unique care needs associated with an individual's personal life preferences and goals<sup>7</sup>. The Palliative Care Competence Framework<sup>9</sup> supports health care professionals in all Irish care settings to self-assess, develop and maintain skills, knowledge and attributes required for the provision of palliative care and delivers a mandate to educators in the delivery of training which addresses these elements.

Research is a vital component of service development. In a systematic process which culminated in a prioritisation in 2015, the top 10 unanswered research questions, or evidence uncertainties, in palliative and end of life care in Ireland as identified by health care providers, patients and carers,<sup>10</sup> were determined to be as follows:

What are the best ways of providing palliative care **outside of 'working hours'** to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families? What are the benefits, and best ways, of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good co-ordination of services affect this?

What are the best ways to make sure that palliative care patients receive adequate **pain and symptom relief** and which drugs for pain management are best in terms of side-effects, such as drowsiness?

What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also **explain the dying process compassionately and honestly**? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?

What are the benefits of **Advance Care Planning** and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?

What are the best ways to make sure there is **continuity for patients at the end of life**, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?

What are the best ways to **support children and young people** when someone close to them is dying or has died? This includes **communicating with them about the diagnosis and dying process**, enabling them to talk about their experience and providing bereavement support.

What **information and training do carers and families** need to provide the best care for their loved one who is dying?

What are the best ways to begin and deliver **palliative care for patients with non-cancer diseases** (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?

Are hospices, hospitals and care homes providing adequate **staff training** to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?

The National Clinical Care Programme (NCCP) for Palliative Care<sup>2</sup> aims to ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis. As a key collaborator of the NCCP, AIIHPC provide a platform for collaborative engagement with key stakeholders, including service users, carers and the wider community, care providers, educators and researchers.

### Recommendations for action by Government

The AIIHPC recommend the following actions by Government:

Continue to strive for a palliative care approach to be delivered equitably to all who need it, alongside provision of other forms of care, regardless of diagnosis or geographical location and as early in treatment planning as would support more positive health and well-being outcomes for patients and their families. A palliative care approach should be provided in any location or setting by all health care professionals and is not solely the remit of palliative care specialists.

Ensure that the findings of the Let's Talk About Survey report and the voices of service users, carers and the wider community are adequately represented in decisions surrounding future palliative care developments.

Support ongoing cross-organisational collaborative networks to ensure questions which matter most are answered in an efficient and effective manner and that research findings are translated into practical guidance for services and incorporated into curricula development for specialist training.

Mandate that the Palliative Care Competency Framework informs the education and development of healthcare professionals across the health and social care sector and is considered within whole service CPD plans. These competencies are of relevance to all health care professionals and are not solely relevant to those working within specialist palliative care settings.

### About the AIIHPC

All Ireland Institute of Hospice & Palliative Care (AIIHPC) is a leading organisation with national and international influence driving excellence in palliative care. We are a collaborative of hospices, health and social care organisations and universities on the island of Ireland, working to improve the palliative care experience of people with life limiting conditions and their families.

Major initiatives led by the AIIHPC include:

**The Palliative Hub**<sup>4</sup> – an online gateway to information and resources about palliative care on the island of Ireland for the public, healthcare professionals, educators and researchers. The Hub offers a central repository for key reports, toolkits and guidance documents and an overview of the latest research and developments taking place in the Republic of Ireland as well as in Northern Ireland. It contains two public facing websites which aim to be portals to

key information about palliative care. It also provides dedicated areas for palliative care professional online education and forums.

**Voices4Care** - an initiative involving people receiving palliative care (service users), carers and the wider community to bring unique and fresh insights about care to those providing or making decisions about palliative care. Voices4Care members supported the Let's Talk About Palliative Care survey<sup>7</sup> which provides a picture of what matters to people when they are living with a palliative condition, and co-produced the Top 10 Research Priorities for the island of Ireland<sup>10</sup>.

**Palliative Care Research Network (PCRN)** – Launched in 2012 the PCRN aims to offer the all-Island palliative care research community opportunities to create and engage within a collaborative environment that supports the development of excellent, high quality, clinically-relevant and innovative research projects that reflect, inform and contribute to AllHPC's programmes of work and the wider palliative care community.

**Education Network** - bringing the providers and consumers of education together to ensure that learning opportunities are available, accessible and of the highest quality and supporting the establishment of core competences for palliative care, this network of 50+ organisation promotes high quality palliative care education

**Chief Executive Officers Network** - forum for the chief officers and Directors from voluntary hospices to meet to discuss issues of mutual interest and to share learning and experience both within and across the island of Ireland.

Response Prepared by Dr Cathy Payrne, Programme Manager, All Ireland Institute of Hospice and Palliative Care

For further information on AllHPC, contact  
Karen Charnley  
Head of Institute  
All Ireland Institute of Hospice and Palliative Care  
Education & Research Centre  
Our Lady's Hospice & Care Services,  
Harold's Cross,  
Dublin 6.  
Tel: +353 (0)1 491 2948.  
Email: [kcharnley@aiahpc.org](mailto:kcharnley@aiahpc.org)  
Website: <http://aiahpc.org/>

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## All Together in Dignity

On behalf of All Together in Dignity (ATD) Ireland I wish to make the following submission for consideration in the development of a new ten year health strategy for health care and health policy in Ireland.

ATD Fourth World is an international non-governmental organisation with no religious or political affiliation which engages with individuals and institutions to find solutions to eradicate extreme poverty. Working in partnership with people in poverty, ATD's human rights-based approach focuses on supporting families and individuals through its grass-roots presence and involvement in disadvantaged communities in both urban and rural areas, creating public awareness of severe poverty and influencing policies to address it.

ATD Ireland is the Irish subsidiary of ATD Fourth World with independent charitable status. ATD Ireland holds that the experiences, views and solutions of people living in poverty should be seen as valued expertise, essential for successful policy-making in at local, national and international levels.

ATD Ireland is currently engaged in a Europe for Citizens of the European Union funded project *Our Voices 2017- Participating and Rethinking Europe from the Margins*. Focused exclusively on the subject of health we have had several workshops among people who are 'on the margins' for example long term unemployed, people from the Traveller Community, people with experience of addiction and mental health difficulties. The attached submission is largely evidence based on some of the transcripts of the 'health' workshops with approximately 40 people identified as living in hardship. A 'diagnostic' phase of the project is now completed and we are now working on a phase that will propose solutions and opportunities for the issues and deficits raised.

This submission is a sample of some of the direct quotes from the transcripts - we will be in a position to forward a deeper analysis of the workshops to the Committee in Spring 2017. We would welcome the opportunity to submit our more complete findings at that stage and believe it will be of value to the development and/or implementation of an effective health strategy.

Thank you for considering this submission.

Pierre Klein, National Co-ordinator

### **Introduction**

ATD Ireland welcomes the establishment of a cross-party government committee on a 10 year strategy for improved health care and health policy and the deficits and challenges recognised by the terms of reference.

The following is a sample of the statements made in the context of Our Voices workshops with people living on the margins of Irish society.

### **Interplay of health with wider societal factors**

A recurring theme throughout the workshops is the view that health and well-being cannot be easily separated from other aspects of one's life, living conditions and wider society.

*Health and other things are all connected- in particular housing, mental health and physical health are all connected to each other. Economic rights are linked to social, civil, cultural and political rights.*

The experience of poor housing, access to housing and homelessness came up. The release of boarded up houses and the implementation of the law in relation to private tenancies were recommendations made:

*I live in a squat because I'm homeless- its hard to get a spot in a hostel and I don't feel safe in the hostels anyway. The accommodation isn't stable – everyday I am afraid that when I go back there it (the squat) will be boarded up. At least there are two us and we help each-other. I wish I had a roof over my head – that would make my life better. The fact that we don't know if we will have a place that night causes your mental health to deteriorate – I'm always worried.*

*Basic amenities for daily living should be available and an entitlement for everyone-what I mean is the things you need for your basic needs – a bed, a place to be able to cook your own meals.*

*Several generations are forced to live together through lack of accommodation -this creates its own problems.*

*What makes it worse is the lack of employment and job opportunities - this creates a situation where so often we then see how the crime rate goes up -people don't have enough food to put on the table; the rate of homelessness rises...*

Investment in general community services, amenities and groups is valued, fostering a sense of belonging, participation and inclusion:

*I volunteer in the garden in the local community development centre ...*

*I like living near the Botanic Gardens and Phoenix Park where there are plenty of plants and trees and I like the quiet. Usually I walk there and I like Dublin and nature  
When I used to live there it was a run down Corporation flat riddled with drugs but now it's more a community place and community run. ...it's more organised*

*Things that make my environment worse for me is my own addiction, self harm, services that have been taken away from us, getting in with the wrong crowd, not enough resources, no treatment available.*

*...to belong where people know you, being involved in a community centre... because when you're isolated you begin to feel depressed so your mental health is at risk, but belonging and feeling you can go somewhere - it actually protects your mental health. ...Having someone to really listen to you.*

People spoke about negative effects of cuts in non-health related welfare allowances and the importance of re-instating them:

*It's the way that the Government spends the money, say for the TV - giving financial support and incentives help. Allowances for payments for electricity, phone, gas, and travel especially is very important as it gets you out and about*

## Communications

Participants of the *Our voices* spoke about communication issues both between health and welfare services and also on the one-to-one health relationship.

A need for (ongoing) consultation and involvement of people at 'grass-roots level' in health and wider government policy is valued:

*when you want change you need to consult with people starting at the bottom*

*I think it all comes down to likes of ATD and Our Voices -if one person does something - it's only one person but when they come together that's when you hear that your voices heard*

There were many reports of lack of effective communication between health systems and suggestions made for improvement:

*see with the police where the pulse system - you just put in this yoke and everything comes up- that's what they should have in the hospitals- they'd put in a pulse system and every appointment no matter what hospital it is- it all comes up*

*The health system would be better if they (health professionals) communicated with each other more”*

Around supporting people make appointments the suggestion was made simply:

*They could send a text*

*If a nurse I knew spoke to me about what the letter (for a scan) meant, I might go*

One-to-one communications can be problematic:

*Every time I go up to him he asks me 'what are you doing?' ...he should know what I am doing but every time I go up he still asks me like 'what are you doing', 'where are you at?' this that and the other and I just told him*

*I feel it is bad for my health to be waiting for answers - often I am not getting a clear message.*

*after building up from asking so many and asking and going to the corporation and going to your clinic and going to your doctors – being misunderstood...and that's where you lose your voice*

*instead of saying... 'we don't know that and we'll get back to you on that' , they are letting you think that you're not good enough to know any more .... 'Ah you wouldn't understand what we have to tell you”*

*Because they take your confidence away because they are sending you from pillar to post so you feel you're nothing; you've no confidence to ask more”*

## Project Phase/ Future Engagement

As outlined in the cover letter the current health-focused project *Our Voices* of ATD Ireland has a important role in exploring the views and solutions presented by people living on the margins of Irish society. The workshops on the subject began in April 2016 and will continue until Spring 2017 and as such the project is mid-course. The above quotes represent a

sample of the contribution that could be followed up on in the future by the Committee or by those involved with the implementation of the strategy. The kinds of themes, proposals and solutions that will be further expanded include:

- Rights awareness
- Support systems in health and social services
- Inequalities in health care
- Education for health service users and professionals/agencies
- Trust
- Local, flexible human service provision
- Addiction Services & Methadone

## **Conclusion**

We recommend that the *Committee on the Future of Healthcare* or any subsequent implementation grouping interested in hearing the voices of people on the margins of society, in relation to healthcare provision, take into consideration the above submission and engage with the future results and solutions offered by the *Our Voices* project.

**ATD Fourth World - Ireland** is a company limited by guarantee not having a share capital, registered in Dublin. Registered Number 475746 - Charity Number CHY 18678

**Directors:** Bernadette Brown, Marie Williams, Isabelle Perrin, Martin Byrne, Ger Doherty, Mark Hogan, Registered Office, 26 Mountjoy Square, Dublin 1, Phone: 01-8558191 E-mail: [pierre@atdireland.ie](mailto:pierre@atdireland.ie)

[www.atdireland.ie](http://www.atdireland.ie)    twitter: @ATDIreland

Facebook: [facebook.com/togetherindignityireland](https://facebook.com/togetherindignityireland)

## Alpha Group

Alpha Healthcare Ltd was founded in 2003 to provide dedicated support to Healthcare Professionals, GP Practices and Primary Care Centres. Alpha formed a Consortium group (Alpha Group) of clinicians and managers from Ireland and the UK to work on large scale projects in the Health Sector and is an approved OGP supplier. The Alpha Group is delighted to deliver this submission to the Committee for consideration.

The Irish Healthcare system is facing many challenges which was brought into sharp focus when the headline news was reported

*'HSE Chief – no plan, no money and no vision for health'.*

The head of the HSE recently warned that there is no clear vision for the future of the health service and added that the HSE was a badly conceived 'amorphous blob that nobody understood' and has been living under a 'death sentence' for years.<sup>47</sup> Waiting lists are at an all-time high with more than 500,000 patients on waiting lists. This is just not acceptable and does not reflect the type of health system Ireland should and can have.

The commitment to developing a 10-year plan for health in the programme for government is a key recognition of this and many other challenges facing the health service. The Minister's appointment of the Oireachtas Committee to examine future models of healthcare in Ireland is a very positive step in this journey, which we welcome warmly.

We set out a series of 12 key strategic objectives we recommend the Committee consider for inclusion in the Future strategy and we give a rationale and context to each of our proposals.

Fundamentally, we propose that we should establish a long term vision to **make Ireland's Healthcare system one of the best in the world** and all objectives, initiatives and funding should focus on making this a reality in the longer term.

**Buy-in and agreement from the Senior leadership teams across the Health Sector – from the Minister, to the DG of the DOH, the DG of the HSE and their Senior leadership teams – will be necessary to deliver on a unified Future vision for Healthcare in Ireland. This relatively small group of people hold the power to transform Ireland's Healthcare system.**

In the short term there is a need to establish integrated improvement programs, that align with the long term vision, to reduce the unacceptably high waiting lists and position the health service such that it can migrate to a universal and equal access system where patients are prioritised on clinical need rather than ability to pay. We must eliminate the two tier system.

***The development of an Integrated whole system approach to reform is essential to deliver an effective and cost efficient health service. We recommend that funding for Primary Care and GP Services be greatly increased in support of the move of services to the Primary and Community environment.***

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<sup>47</sup> Sunday Business Post – 13 December 2015 – Series of Interviews with HSE Head Mr Tony O'Brien.

## Introduction and Background

Alpha Healthcare Ltd was founded in 2003 to provide dedicated support to Healthcare Professionals, GP Practices and Primary Care Centres. Alpha promotes the use of Operational Management and Industrialised techniques, such as LEAN, Total Quality Management and process flow optimisation, within the healthcare environment to deliver improved patient service, optimum patient flow and efficient systems.

Alpha formed a Consortium group (Alpha Group) of clinicians and managers from Ireland and the UK to work on large scale projects in the Health Sector. This submission is made on behalf of the Alpha Group representing Alpha Healthcare and key professionals and organisations. Details of this Group are provided in Appendix 1.

The Alpha Group has a valuable insight into the budgetary and resource constraints within the Health Sector. The Irish Health system faces enormous challenges. Some indicators of the challenges the Irish Healthcare Service faces are:

1. Ireland tops the EU table for percentage spent on health. CSO data published in 2015 showed we paid € 18.4 billion on health in 2013, which was just above 12% of gross national income. This was considerably more than the 9.2% average spent on health by other OECD members.
2. Despite our high expenditure on health, OECD data (2015) shows that Ireland had the worst incidence of asthma and COPD.
3. We have a 'two tier' health system where people are seen based on ability to pay rather than health need.
4. We have unacceptably long waiting lists when benchmarked against other countries and there appears to be a denial within our health system of the crisis that this is creating.
5. Despite producing the highest number of medical graduates (for export), about one-third of doctors working in Ireland are foreign trained.
6. "HSE Chief – no plan, no money and no vision for health'. The head of the HSE recently warned that there is no clear vision for the future of the health service and added that the HSE was a badly conceived 'amorphous blob that nobody understood' and has been living under a 'death sentence' for years.<sup>48</sup> The previous HSE National Lead for Transformation and change recently commented that consistent and sustained improvement was impossible if the direction of the health service changed with every general election.<sup>49</sup>

Let's seize this unique opportunity that is now emerging to make Ireland's Healthcare System one of the best in the world.

## Strategy

### Ten year Priorities

We set out the key strategic priorities we believe should be considered for inclusion in the ten-year strategy and in section below we delve into more details on each recommendation and why we recommend it be treated as a priority.

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<sup>48</sup> Sunday Business Post – 13 December 2015 – Series of Interviews with HSE Head Mr Tony O'Brien.

<sup>49</sup> RCPI's CEO Leo Kearns -who previously served as HSE's National Lead for Transformation and Change from 2013 -2015- speaking at the Paediatrics Spring Conference – Irish Medical Times May 25, 2016.

Set out a **vision** to make Ireland's healthcare system **one of the best in the world**. This overarching vision for health care in Ireland should be to provide a quality, accessible, effective, responsive and affordable health system equally to all of the population.

Patients and service users should be at the core of any service delivery policy and their voices should be listened to and acted upon.

The new health strategy should focus on the delivery of a caring and humane service to the people and not overly focus on metrics and targets.

Set waiting list targets for Ireland that are commensurate with International best practice and establish a timeframe (no of years) to achieve these.

Establish integrated programmes to deliver on these waiting list targets – these would be staged (yearly), clearly defined and there should be clear accountability to deliver on these improvement programs.

Establish models of care and funding models that are appropriate to the Irish Healthcare system needs, that deliver quality outcomes at the most economical cost.

Establish greater accountability for the delivery of health system reform and outcomes in line with the 10 year strategic goals.

Develop a clear strategy to fully utilise innovation and technology to support the effective, economic delivery of health services with improved outcomes.

Develop a transparent and open reporting of the performance of the health system and radically change the current culture which lacks transparency and meaningful performance reporting.

Provide a progressive and rewarding career opportunity and development pathway for all healthcare clinicians – doctors, nurses and healthcare assistants, to keep our excellent graduates to work within the Irish healthcare system.

Establish a 'fit for purpose' regulatory regime that promotes quality and maintains standards in a LEAN manner where all unnecessary bureaucracy is eliminated.

Develop the HSE skills base and ensure that all management and staff work in a service orientated, performance managed environment.

## **Rationale Supporting Proposed Priorities**

### **Vision**

We recommend that the committee establish an agreed vision to make the Irish healthcare system one of the best in the world. This will set the context and focus of how the strategic plan and objectives are developed and annual programmes agreed. In setting the standard for this we point to Ireland's position in other sectors – technology, software etc where we have become world leaders. Why should we demand anything less for our health system only the best in the world. The British people rank their NHS their proudest institution<sup>50</sup>. Let's aim to make our health system Ireland's proudest institution.

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<sup>50</sup> Opinion poll carried out between 15 January and 3 Feb 2016 ranked the NHS their proudest institution

## **Patients and Service Users**

The patients and service users should be at the core of our health service and system. We urge the committee to consider their voice and to ensure it becomes a fundamental part of any future health policy and direction. Aside from it being the right thing to do research on the Ten Key Principles for Successful Health Systems Integration for Canada's healthcare system, has shown that 'organisations that fail to place the patient at the centre of their integration efforts are unlikely to succeed'.<sup>51</sup>

## **Caring & Humane Health Service Delivery**

Health impacts us all and we will all need to avail of the health service at some time during our lives. All healthcare staff should behave in an appropriate and caring manner and safeguarding of vulnerable adults and children should be at the core of our health service delivery.

## **Waiting Lists, Transformation Programs & Accountability (objectives 4,5, & 7)**

This is an area that receives constant headline news and most recent reports summarise the position well –

*'Record 530,000 on public hospital waiting lists. Number waiting long periods continues to soar despite Government promises'<sup>52</sup>.*

Repeated initiatives and investments in this area have failed to show sustainable improvements.

We expect the committee will fully agree that current waiting list numbers and times are just not acceptable and do not feel the need to reemphasise this further or to reference further data. We recommend that the Committee sets the bar high on expectation here and proposed the following, for consideration:

1. Setting out a series of waiting time metrics that should form part of our 'new world' health service.
2. Define an aggressive but pragmatic timeline to deliver on these (no of years)
3. Establish a series of Integrated system change programmes with clear annual deliverables, to deliver on these new waiting lists.
4. Establish a series of 'immediate measures' that align with and support the approach in the integrated system improvements in 3) that start to address the current 'peak numbers' to accelerate the reduction in current waiting list numbers.

## **Models of Care (strategic objective 6)**

This we suggest will be one of the biggest challenges facing the committee – to agree on what the future models of care and funding should be appropriate to Ireland's current changing health sector environment and ageing population demands.

We believe that this must be multi factorial, take consideration of local needs and demographics and models need to be flexible and responsive whilst at the same time they must look at the fully integrated health system and not look at 'pockets' of the service in isolation.

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<sup>51</sup> 'Ten Key Principles for Successful Health system Integration' Esther Suter et al , NCBI Dec 20 2010

<sup>52</sup> 'Record 530,000 on public hospital waiting lists' The Irish Times, Paul Cullen, Sat Aug 6 2016.

We have some good examples of health improvement initiatives that can be built upon and copied. The review of cancer care in Ireland which led to the launch of a Strategy for Cancer Control in Ireland 2006 and the subsequent establishment of the National Screening Service (NSS) by the Minister is one segment of the health system we can be justifiably proud of.

We can also learn a lot from our NHS partners and we would refer the committee to the NHS's 'Five Year Forward Review'<sup>53</sup> published in October 2014, as containing useful reference points, comparators and very useful information that is directly applicable to the committee's review of a 10-year strategy for Ireland's health service. Some of the key points raised in this review are shown in Appendix 3 for reference:

### **Innovation and Technology**

Innovation and technology can provide quantum leap improvements in the delivery of our healthcare system in terms of quality, speed and cost. We recommend that a comprehensive review and inclusion of appropriate technology and innovative solutions be included within the 10-year strategy plan. Many initiatives are underway in this respect and we recommend building on these and introducing more – more rapidly.

### **Professional and Organisational Development**

Our medical institutes are developing some of the best medical graduates – doctors and nurses but we are losing many of these to immigration. In a report by the RCSI in 2013<sup>54</sup> they stated that 47.5% of our doctors are working outside the country and in an IMO survey done in 2011 showed that 61.0% of NCHD's rated morale as low. Further data showed that an important reason the NCHD's leaving the country is due to uncertain career pathway and also difficult working environments.

This phenomenon is not new and in fact in a previous Oireachtas Joint Committee on Health and Children published in February 2010 this was one of the key findings of the committee.

- 'The Committee recommends that HR strategies should be employed that maximise retention of GPs once trained'

We recommend that the organisational structures, roles and reporting mechanisms be reviewed and changed. Our new health service delivery organisation should have a LEAN structure with minimal (but appropriate) levels of management structure.

We recommend greater accountability and responsibility at all levels of the organisation and that staff development programs are put in place to support these.

We believe that such a change will require a major cultural shift within the HSE.

### **Regulatory Regime & Reporting**

It is vital that we have and maintain an independent regulatory oversight on the quality of outcomes and quality of delivery of all our health services. However, equally we recommend that this regulatory and monitoring regime is appropriate and 'fit for purpose' to deliver of these quality standards.

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<sup>53</sup> 'Five Year Forward View' – Shared view of the NHS's national leadership and reflects an emerging consensus amongst patient groups, clinicians, local communities and frontline NHS leaders. Published by NHS England.

<sup>54</sup> RCSI – 'Why are Irish Doctors emigrating?' -Student Medical Journal, 2013 6(1):93.8

Reporting and transparency should be a key feature of our new national health service. Patients and service users should be able to access relevant information about our health system and progress in the delivery of key transformational programs should be reported.

### **Integrated Primary and Community Care**

Primary Care is the first point of contact that people have with the health and personal social services. It is the appropriate setting to meet 90 – 95% of all health and social service needs.

The development of a properly integrated primary care service can lead to better outcomes, better health status and better cost effectiveness.<sup>55</sup> Agencies ranging from the Irish College of General Practitioners to the World Health Organisation have recognised Primary Care as being the most effective and cost efficient way to treat patients.

A Joint Committee on Health and Children already undertook a major consultation exercise, completed research and published an all-party report with recommendations for the delivery of an effective Primary Care service in Ireland as part of the reform of the health service. (Alpha Healthcare was a contributor and presented to the Committee on this).

We would direct the Committee to this report – ‘Report on Primary Medical Care in the Community, February 2010, House of the Oireachtas. The report contains a list of 40 recommendations, some of which have progressed and some have not. We feel that many of the findings of the Committee are today equally applicable to the development of a forward looking 10-year plan for our health system.

We believe that developing an **Integrated Primary Care service model** should be an essential part of any future model of care. Primary Healthcare professionals should be incentivised to keep patients out of hospital (or penalised for high, unnecessary referral rates).

We recommend that more be done to ensure that there is a **whole system approach to Primary and Community Care** and for example the idea of an **Integrated Primary and Secondary Care provider approach** could lead to better care, more care in the community and a more efficient delivery system through better utilisation of resources and less unnecessary duplication of effort.

Ireland is not the only country to have struggled with the implementation of a primary care strategy. We would refer the committee to the WHO report on Primary Care<sup>56</sup> and we show how they highlight the shifting focus needed (see table in Appendix 2) to deliver on an effective integrated Primary Care service.

### **Current Roadblocks**

From our experience of the Irish healthcare system some of the key roadblocks and barriers to the development and implementation of an efficient integrated health system for Ireland are:

1. Lack of investment and development of Primary and Community Care strategy. Ireland. This has restricted the development of GP services which could be delivered more cost effectively in the Primary Care and Community environment.

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<sup>55</sup> Primary Care – A New Direction, Quality & Fairness – A Health System for You – DOH Report 2001

<sup>56</sup> Primary Health Care – Now More than Ever – WHO Report 2008

2. Lack of timely access to diagnostics and consultancy services for public patients – due to the large waiting lists. This barrier inevitably means that patients are sent to A&E to get into the system.
3. The two tier system distorts the availability of services and diagnostics for public patients. If you pay you can have near immediate access, often to the same service provider, as the public patient is waiting for.
4. The lack of a properly integrated whole system approach to the delivery of health care is leading to ‘siloes’ improvement initiatives which unfortunately do not improve the overall performance and delivery of the health system.
5. Our health system remains ‘hospital focused’ and the ‘money follows the patient’ focus remains siloed in its approach. This initiative, we recommend, should extend across the health system.
6. There is a siloed approach to change initiatives rather than a whole system’s approach to deliver sustainable improvements in service delivery and efficiencies.
7. Funding models and cost management do not support the delivery of new services (in the community for example) and there is a lack of rigorous cost control and management.

### **Funding Models**

There is a program underway by the HSE to move towards an activity based accounting system and this is a positive development to give greater transparency and clarity on actual health spending.

We believe that the Irish healthcare system should be freely accessible to all and that the current two tier system should be eliminated. Universal healthcare should be accessible to all and provided on the basis of clinical need rather than ability to pay. A form of National Health Insurance model should be considered in the context of the successes this has had in other countries such as Canada. This would provide the government with a funding model that would allow for a universal type healthcare system to be developed and implemented.

Appropriate models should be developed to provide full access to health care for those that most need it (means tested) with the remainder of the population having a form of co-payment to contribute towards the cost of a single tier system. The performance of this new health system (outcomes and access) will need to match, at a minimum, what is currently on offer via the private health insurance market so as to get widespread buy-in.

We also recommend that funding towards Primary Care and in particular towards GP led services be increased substantially to allow delivery of services from within the community.

We would also suggest that any model would include an ability to commission and then provide new services at a national and local level to meet clinical needs and drive service improvements.

### **Summary**

We have presented this submission to provide the Committee with positive support and views from practical experiences of the Irish Healthcare system and relevant comparisons with our neighbouring, UK NHS system.

We are fully supportive of this initiative to establish a long term all party healthcare vision and strategy, to develop a universally accessible healthcare system.

We are happy to provide any further assistance or input the committee may require and would be available to make a presentation of more specifics if that is required.

**Submission Presented by the Alpha Group:**

Dr Jack Nagle	CEO, Alpha Healthcare.
Mr Keith Davies	CEO, i5 Health
Dr Nick Flynn Dr George O Mahony	GP Partners, Hollyhill Medical Centre, Cork.
Mr Nick Nurden	Managing Partner, The Ridge Medical Centre, Bradford, England
Ms Caroline Kerby	Director of Strategic Dev. & Quality, Harness Care London

**APPENDIX 1**

Alpha Group (Backgrounds of Consortium members supporting this Submission)

The Alpha Group is an approved supplier of services to the Health Sector, DOH & HSE, under the OGP Framework Tender PAS032F - Multi Supplier Framework Agreement for the provision of Business & Management Consultancy and Advisory Services for the Irish Health Sector.

**The Alpha Group (Consortium supporting this submission include):**

**Alpha Healthcare:**

Alpha Healthcare has over 10 years’ experience at the forefront of business management and support services to Healthcare professionals across Ireland and the UK. The company has taken best practice management principles, quality standards and suitable industrial techniques and applied them to the Health Sector environment with outstanding and enduring results.

Director/Partner	Dr Jack Nagle
Director/Partner	Dr Mike Prentice

**Harness Healthcare**

Harness Healthcare comprise of a network of 21 practices in North West London, dedicated to clinical and managerial leadership combined with a patient-centred approach to delivery of high quality services and continuity of care for patients. The company provide a wealth of experience in business and operational strategy, as well as change management, leadership and quality management.

Harness Healthcare provides resources and/or SME’s to Alpha based upon the requirements of a specific project as required.

Alpha and Harness have worked together for over 5 years.

Director /Partner	Caroline Kerby
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**i5 Health**

i5 Health, based in London, has significant expertise in data analytics, demand management, urgent care modelling and information management among others. They have worked extensively across the NHS on numerous projects with significant improvements as a result. i5 Health have analytical tools and benchmarking data which will help provide the team with data extraction and predictive tool analysis.

i5 Health provide additional resources and/or SME's to Alpha based upon the requirements of a specific project as required.

Director/Partner	Mr Keith Davies
Director /Partner	Dr Harald Braun

**Primary Care Team**

The Primary Care Team comprises a team of GP Partners from the Hollyhill Medical Centre, Cork with significant experience and expertise in areas relating to primary care and populations within same. The team have extensive experience with large patient cohorts with differing medical socio economic needs- chronic disease, acute illness, mental illness and addiction treatments.

GP Partner	Dr George O Mahony
GP Partner	Dr Nick Flynn

**The Ridge Medical Centre**

The Ridge Medical Centre, based in Bradford, is a multidisciplinary centre which provides medical services to over 25,000k patients. The team within the Ridge are well known as clinical innovators and have been extensively involved in integrated care and pathway design.

The Ridge provide additional resources and/or SME's based upon the requirements of a specific project

Managing Partner	Mr. Nick Nurden
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## Appendix 2 below

**Table 1** How experience has shifted the focus of the PHC movement

EARLY ATTEMPTS AT IMPLEMENTING PHC	CURRENT CONCERNS OF PHC REFORMS
Extended access to a basic package of health interventions and essential drugs for the rural poor	Transformation and regulation of existing health systems, aiming for universal access and social health protection
Concentration on mother and child health	Dealing with the health of everyone in the community
Focus on a small number of selected diseases, primarily infectious and acute	A comprehensive response to people's expectations and needs, spanning the range of risks and illnesses
Improvement of hygiene, water, sanitation and health education at village level	Promotion of healthier lifestyles and mitigation of the health effects of social and environmental hazards
Simple technology for volunteer, non-professional community health workers	Teams of health workers facilitating access to and appropriate use of technology and medicines
Participation as the mobilization of local resources and health-centre management through local health committees	Institutionalized participation of civil society in policy dialogue and accountability mechanisms
Government-funded and delivered services with a centralized top-down management	Pluralistic health systems operating in a globalized context
Management of growing scarcity and downsizing	Guiding the growth of resources for health towards universal coverage
Bilateral aid and technical assistance	Global solidarity and joint learning
Primary care as the antithesis of the hospital	Primary care as coordinator of a comprehensive response at all levels
PHC is cheap and requires only a modest investment	PHC is not cheap: it requires considerable investment, but it provides better value for money than its alternatives

### WHO Report on Primary Care – 2008 Appendix 3

- Sustainability of the NHS – radical upgrade in prevention and public health
- NHS plans to take hard-hitting national action on obesity, smoking, alcohol and other major health risks. Planned introduction of incentives.
- When patients need care – they will gain far greater control of their own care.
- NHS plans to take decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between health and social care.
- The report suggests models of 'Multispeciality Community Provider' -where GPs, nurses, other community health services, hospital specialists and perhaps mental health and social care to create integrated out-of-hospital care.
- A further option is an integrated hospital and primary care provider – Primary and acute systems.
- Urgent and emergency care services will be redesigned to integrate between A&E departments, GP out of hours' services, urgent care services and ambulance services.
- The foundation of the NHS will remain list-based Primary Care.

### Key Points from NHS's 'Five Year Forward Review'<sup>57</sup> published in October 2014

<sup>57</sup> 'Five Year Forward View' – Shared view of the NHS's national leadership and reflects an emerging consensus amongst patient groups, clinicians, local communities and frontline NHS leaders. Published by NHS England.

## Alzheimer Society of Ireland

### **ASI recommend three priority actions for the ten-year strategy:**

- Strategic policy and shared principles including a follow-on to the National Dementia Strategy.
- Integrated policy and practice including case management and a collaborative approach to care.
- Social care model and entitlement to community care to ensure that people can remain living in the community for as long as possible.

Providing adequate levels of funding for social and community care including home-based care.

Our ageing population and subsequent increase in number of people living with dementia needs to be factored into a ten-year strategy.

Adequate dementia data collection, recording and sharing needs to be developed.

### **Integrated Care:**

**ASI recommends five steps to an integrated care model, including (i) putting policy into practice; (ii) leadership; (iii) recognising the vital role of the community and voluntary sector; (iv) legislative change and (v) appropriate funding.**

Many of the most effective management approaches are provided by primary level healthcare professionals from multiple disciplines.

Best practice examples includes Multidisciplinary Team approaches; the Alzheimer Scotland<sup>58</sup> Eight Pillar model for integrated health and social care; and the PREPARED project.

### **Funding:**

Financing of care for people with dementia must be co-ordinated across the trajectory of the disease with adequate funding at each stage of progression.

Early diagnosis and early intervention, for example, can deliver cost savings to public services as well as delivering a better quality of care for people with dementia.

In recent years the financing of long-term residential care has increased, while investment in home care has gone down. There is growing consensus that home or community-based care can be a cost-effective alternative to long-term residential care for some older people.

### **Introduction**

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make this submission to the Committee. It is based on our experiences working with people with dementia and their family carers. There is growing public support for strategic action on dementia care with over

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<sup>58</sup> [http://www.alzscot.org/assets/0000/4613/FULL\\_REPORT\\_8\\_Pillars\\_Model\\_of\\_Community\\_Support.pdf](http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf)

20,000 people signing our petition for increased Government investment into home-based care for people with dementia.

Dementia is one of the major causes of disability among older people worldwide (WHO, 2012<sup>59</sup>). It places a high demand on the health and social care system. People with dementia are extremely high users of services whilst experiencing high levels of unmet need (Cahill et al. 2012<sup>60</sup>), with services under-resourced and under-funded.

The majority of people with dementia would like to stay in their own homes for as long as possible, however our current system is failing to provide adequate home-based supports to enable this. This submission will present evidence and solutions to the on-going gaps in services<sup>61</sup>. Combined with an ageing population and a growing need for a strategic approach to dementia care, this means dementia must be a priority in a ten-year strategy for the health service.

## **Recommendations under Theme One: Strategy**

### **Key priorities for the ten-year plan**

We have identified three priorities which we feel must be included in the ten-year strategy, namely:

1. Strategic policy and shared principles
2. Integrated policy and practice
3. Social care model and entitlement to community care

Each will be addressed in turn below.

### **Strategic policy and shared principles**

The health system requires shared values and principles to underpin actions. Drawing on those outlined by the Health Reform Alliance<sup>62</sup>, this includes a focus on equity, entitlement, adequate funding, integration and person-centredness.

In addition, planning must be underpinned by strategic policy. The implementation of the National Dementia Strategy (NDS<sup>63</sup>) (2014), it is hoped, will lead to systemic change including changes to Primary and Community Care, Mental Health, Acute and Long-Term Care; improving rates of diagnosis<sup>64</sup> and improving pathways to enable people to access care.

The lifespan of the current NDS is limited, coming to an end in 2017. The strategy too has limitations, namely:

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<sup>59</sup> World Health Organization (2015) Dementia: A Public Health Priority available via [http://www.who.int/mental\\_health/neurology/dementia/dementia\\_thematicbrief\\_executivesummary.pdf](http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_executivesummary.pdf)

<sup>60</sup> Cahill, S. O'Shea, E. and Pierce, M. (2012) Creating Excellence in Dementia Care report. Trinity College Dublin/NUI Galway.

<sup>61</sup> Please also see table in Appendix 3 which outlines gaps in services for people living with dementia.

<sup>62</sup> <http://healthreformalliance.ie/wordpress/health-reform-alliance-principles/>

<sup>63</sup> Department of Health (2014) National Dementia Strategy. Available via <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

<sup>64</sup> In the UK, it is estimated that only about 40% of people with dementia have a diagnosis. Formal diagnosis of dementia in Ireland is not common place and there is no national register of people with dementia.

- A lack of priority to the needs of people with younger onset dementia<sup>65</sup> and the maintenance of the discriminative age barrier to access some health and social care services.
- Little focus on residential care.
- Little priority given to a Dementia Friendly Community model as a measure to address social and community care.
- No attention given to dementia risk reduction and/or prevention.

These issues can be addressed in a follow-on Strategy and built into wider strategic reform of the healthcare system.

### **Integrated policy and practice**

The NDS states that dementia policy, service delivery and development should be guided by the principles of chronic disease management as set out by the Department of Health (2014)<sup>66</sup>. However, dementia is not part of the chronic disease prevention and management programme. A gap arises as a result to enable GPs to give time and appropriate attention to pro-actively manage dementia.

Evidence from other jurisdictions shows that health promotion, pro-active care and better outcome measures rely on incentivisation and resourcing of chronic disease management (Savage et al., 2015<sup>67</sup>). The Chronic Care Model (CCM) is widely adopted and cited as a model on how to organize chronic care programmes in primary care. The CCM<sup>68</sup> is an excellent resource to plan primary care services for dementia care.

In addition, people with dementia, especially those under 65, would benefit from strategic developments arising from the neuro-rehabilitative strategy.

Integrated policy should, in turn, lead to more integrated working across the health and social care system. Case management and a collaborative approach to care are effective in organising care for people with dementia at home. This requires leadership and designated personnel to support people to navigate a care pathway (Trepel, 2015<sup>69</sup>).

Currently, people with dementia are one of a core group who are caught in the delayed discharge cycle. It's estimated 25% of all patients in a typical general hospital have dementia (Timmons et al, 2015<sup>70</sup>). Worryingly 51% of delayed discharges between May 2013 and February 2015 were a result of delayed access to appropriate community supports (HSE, 2016). Targeted approaches to reduce the length of time people with dementia stay in hospital must be a priority:

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<sup>65</sup> There's an estimated 4,000 people under 65 years currently living with dementia in Ireland.

<sup>66</sup> This includes the development of a model of shared care that is integrated across organisational boundaries; planning care that is delivered in the appropriate setting; and using multidisciplinary teams in the provision of care.

<sup>67</sup> Savage et al (2015) Clinical and Economic Systematic Literature Review to Support the Development of an Integrated Care Programme for Chronic Disease Prevention and Management for the Irish Health System. UCC Available via <https://www.hse.ie/eng/about/Who/clinical/SystematicLiteratureReviewSupportDevtofIntegratedCareChronicDiseases2015.pdf>

<sup>68</sup> See: [http://www.improvingchroniccare.org/index.php?p=The\\_Chronic\\_CareModel&s=2](http://www.improvingchroniccare.org/index.php?p=The_Chronic_CareModel&s=2)

<sup>69</sup> See: <https://www.alzheimer.ie/getattachment/About-Us/Policy/Expert-Policy-Paper-Series/Trepel,-D-2015-An-Economic-Analysis-of-Home-Care-Services-Final.pdf.aspx>

<sup>70</sup> Timmons, S. et al (2015) Dementia in older people admitted to hospital: a regional multi-hospital observational study of prevalence, associations and case recognition. Age and Ageing. September 28.

- Average length of hospital stay for a person with dementia admitted and discharged to and from their home is 22 days (de Suin and O'Shea, 2014<sup>71</sup>)
- Average length of stay for the general population is 5.43 days and 12.3 days for someone aged over 65<sup>72</sup>

Evidence from the UK<sup>73</sup> shows that a strategic approach to dementia care saves money by reducing the need for unplanned admissions to long-term care and unnecessary admissions to hospital.

### **Social care model and entitlement to community care**

A social model of care recognises that people living with dementia utilise social and community care in addition to health services. To meet the preferences of people living with dementia to live in the community, and recognising the broader societal impact of the condition such as that on family carers, a key priority in a ten-year strategy is entitlement to care, particularly entitlement to home-based care such as home help, post-diagnostic (e.g. cognitive stimulation and rehabilitation therapies, counselling), information services, social clubs, befriending, respite, day care etc. with appropriate options for supported/assisted living.

The Report of the Seanad Public Consultation Committee on the Rights of Older People (2012<sup>74</sup>) identified (i) the rights of older people to be enshrined in a formal way and (ii) the need to support and encourage independent living at home for as long as possible.

A social care model and an entitlement to community and home-based care would place an obligation on Government to make certain choices about the use of existing resources within a ten-year strategy. This, in turn, will ensure that community care:

- (i) meets needs by addressing current blockages in the delivery of care to people with dementia,
- (ii) ensures care assessments takes account of needs arising from cognitive impairment as well as personal care requirements,
- (iii) has regulations to ensure consistency of care and safeguards against risk,
- (iv) greater integration of community care across all health and social care system.

### **Challenges in achieving a universal single tier health service**

People with dementia require a continuum of flexible innovative care, individual needs-led approaches; appropriate to changing and complex needs arising from the condition. This means providing lower levels of care and support in the earlier stages and high levels of care as the condition progresses.

In the majority of cases, dementia can be addressed at the level of primary and community care provision (Cahill et al, 2012<sup>75</sup>). There is growing consensus that home or community-

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<sup>71</sup> de Suin, A. and O'Shea, E. (2014) Report of the National Audit of Dementia Care in Acute Hospitals 2014.

<sup>72</sup> Department of Health (2015) Review of the Nursing Home Support Scheme.

<sup>73</sup> See <https://www.hsj.co.uk/Journals/2015/02/19/a/a/w/Dementia-Today-and-Tomorrow.pdf>

<sup>74</sup> Available via <http://www.oireachtas.ie/parliament/media/committees/seanadpublicconsultationcommittee/reports/FinalReport.pdf>

<sup>75</sup> Ibid

based care can be a cost-effective alternative to long-term residential care for some older people (Review of the Nursing Home Support Scheme, 2015<sup>76</sup>; OECD, 2005<sup>77</sup>)<sup>78</sup>.

A key challenge then is the provision of adequate levels of funding for social and community care including home-based care. Recent research (Donnelly et al., 2016<sup>79</sup>) shows that Ireland is slipping below international standards for the proportion of the population aged 65 and older receiving home help as recommended by the OECD (HSE, 2016 in Donnelly et al., *ibid*).

Due to the financial cost of dementia and the health benefits of having a medical card for people with the condition, the ASI maintains that it is critically important that people living with dementia have access to a medical card or system of care that allows them to access care based on their needs regardless of income.

## **Future demographic pressures**

### **Ageing population**

There is a significant and rising number of people currently living with dementia in Ireland; approximately 55,000 individuals<sup>80</sup>. If current trends continue, and within the lifetime of a ten-year strategy, this number will increase to 77,460 people by 2026 (Pierce et al., 2014<sup>81</sup>). Although the majority of people with dementia are over 65, as age is the main risk factor, there is a significant proportion under 65, an estimated 4,000 people.

Many of those caring for people with dementia are older people; 84% of those in a caring role are over 45 and 37% are over 65 (ASI, 2007<sup>82</sup>). Changing demographics of families mean that women, traditionally the main carer, are now more likely to work outside the home. We need to respond with strategic planning to appropriately address this demographic change.

## **Data collection and evidence based service planning**

Reliable information on dementia is largely absent in Ireland. Information is not currently being recorded on national databases. This has implications for policy and the provision and planning of evidence-based services and supports and for ensuring that resources are targeted effectively.

## **Integrated Primary and Community Care**

A strategic approach to dementia care within the health system must include integrated and multi-disciplinary care across primary, secondary and long-term care.

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<sup>76</sup> *Ibid*.

<sup>77</sup> OECD (2005) Ensuring Quality Long-term Care for Older People.

<sup>78</sup> European analysis of average costs in dementia care for example found that residential long-term care costs €4,491 per month compared to €2,491 for aggregate costs from home care (Wübker et al, 2014).

<sup>79</sup> Donnelly, S. O'Brien, M. Begley, E. and Brenna, J. (2016) Older People's Preference for Care: Policy but what about practice. University College Dublin/Age Action/Alzheimer Society of Ireland/Irish Association of Social Workers.

<sup>80</sup> Department of Health (2014) National Dementia Strategy. Download from: <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

<sup>81</sup> Pierce, M, Cahill, S. and O'Shea, E. (2014) Prevalence and Projections of Dementia in Ireland, 2011-2046. Dublin: Trinity College Dublin/NUI Galway/Genio.

<sup>82</sup> The Alzheimer Society of Ireland (2007) Living with Dementia – The Experience of Carers with Dementia (unpublished)

The ASI advocates for community/home-based care and the need for an integrated care pathway with a multi-disciplinary case management approach to dementia. This is against the current backdrop of a home care service, often experienced as impersonal, inflexible, underfunded and poorly integrated with other health and social care services (SCIE, 201483).

People living with dementia and their carers find it increasingly difficult to negotiate complex pathways of care (Pratt et al., 200684). The delivery of integrated care for people with dementia has challenges across a range of areas, including:

- Lack of an integrated IT systems;
- Lack of appropriate data collection and sharing;
- Poor dementia education and training;
- Lack of leadership;
- Inappropriate legislation for community/home-based care;
- Inadequate levels of funding for community/home-based care.

### Steps to an integrated model of primary, secondary and community care

<b>Step 1</b>	<b>Putting Policy into practice</b>	National policy is underpinned by a commitment to support people to age-in-place, in their own homes <sup>85</sup> . Yet, research shows that this policy is not being implemented (Donnelly et al, <i>ibid</i> ). There is no official policy framework for integrated home-based care service and supports for older people (Timonen, Doyle and O'Dwyer, 2012 in Donnelly et al. <i>ibid</i> ).
<b>Step 2</b>	<b>Leadership</b>	Good dementia care involves multi-disciplinary working and case management (Trepel, 2015 <sup>86</sup> ), requiring designated personnel at different levels in the health and social care system and effective inter-agency and interdisciplinary communication. The National Dementia Office has been established as part of the NDS implementation plan. There is a need to build and further develop

<sup>83</sup> Social Care Institute for Excellence (2014) Commissioning Home Care for Older People. Available at: [www.scie.org.uk/publications/guides/guide54/files/guide54.pdf](http://www.scie.org.uk/publications/guides/guide54/files/guide54.pdf)

<sup>84</sup> Pratt, R., Clare, L. and Kirchner, V. (2006) "It's like a revolving door syndrome": Professional perspective models of access to services for people with early-stage dementia', *Aging and Mental Health*, 10(1), 55-62.

<sup>85</sup> National Positive Ageing Strategy, 2013; Irish National Dementia Strategy, 2014; Future Health: A Strategic Framework for Reform of the Health Service 2012-2015

<sup>86</sup> *Ibid*

		<p>this infrastructure to embed clinical and policy leadership for dementia into the Department of Health and HSE.</p>
<b>Step 3</b>	<b>Vital role of the community and voluntary sector</b>	<p>The community and voluntary sector must also be considered critical in supporting the success of an integrated model. The wider strategic policy context of building towards a sustainable health system is complimented by a model that recognises the innovative and cost-effective role that the community and voluntary sector play in responding to emerging needs and community/home-based care for people.</p>
<b>Step 4</b>	<b>Legislation</b>	<p>The need for a statutory basis for community care has been outlined above. Overall, all developments relating to dementia care and support should be underpinned by a human rights legislative framework, to which providers should be accountable. People who use services should be involved in the decisions that affect their lives and they should be empowered to exercise choice and control over the care and support they receive.</p>
<b>Step 5</b>	<b>Funding</b>	<p>Funding for community/home-based care should be a priority step moving to an integrated system with a social model of disability.</p> <p>In recent years the financing of long-term residential care has increased, while investment in home care has gone down.</p> <p>Home-based community supports should be equal in status to clinical care. This requires an increased level of professionalisation of staff in the social care sector with a focus on career paths and accreditation.</p> <p>Factoring in a social care model will also involve putting a value on family care. The current system relies heavily on family members to provide care, which means that burdensome aspects of care are</p>

		extremely significant in terms of balancing the provision of care for people with dementia (Trépel, 2012 <sup>87</sup> ). One of the main reasons people with dementia enter long-term care is due to family carer burnout (Brodaty and Donkin, 2009 <sup>88</sup> ).
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### How to achieve these steps

With respect to dementia, many of the most effective management approaches are provided by primary level healthcare professionals from multiple disciplines<sup>89</sup> (Grand et al., 2011<sup>90</sup>). Primary care is the point of first medical contact and hence the cornerstone of ensuring early detection, timely intervention, and effective ongoing management of care for people with dementia (UK Department of Health, 2001<sup>91</sup>).

### Ensuring buy-in from health care professionals

There is an international evidence-base that points to the cost effectiveness and efficiency offered by a more integrated system.

Active involvement of key professional groups and clinicians and other health and social care professionals from the beginning of the process can also ensure buy-in. Providing space to communicate and discuss issues can enable different disciplines to identify common gaps and possible solutions. The ASI used a roundtable model<sup>92</sup> of consultation to bring health and social care professionals together in the lead-up to the National Dementia Strategy and in efforts since its publication to monitor the implementation of the Strategy; this has proved beneficial.

### Example of best practice for consideration by the committee

Multidisciplinary Team approaches are good practice in responding to the care needs, required supports and preferences of older people (Donnelly et al, *ibid*).

<sup>87</sup> Trépel, D (2012) Financing Dementia: What money is available, what does dementia need and will the required resources be received? The Alzheimer Society of Ireland Expert Policy Paper Series.

<sup>88</sup> Brodaty, H. and Donkin, M. (2009) family Carers of People with Dementia. *Dialogues in Clinical Neuroscience* 11(2).

<sup>89</sup> General Practitioners, Public Health Nurses, Occupational Therapists (OT), Speech and Language Therapists, Mental Health Nurses and other key healthcare professional play a significant and frequent role in the management of dementia care.

<sup>90</sup> Grand et al (2011) Clinical features and multidisciplinary approaches to dementia care. [J Multidiscip Healthc](#). 4: 125–147.

<sup>91</sup> Department of Health. National service framework for older people. London: Stationery Office, 2001.

<sup>92</sup> Reports available from this link [http://alzheimer.ie/Alzheimer/media/SiteMedia/Living-with-Dementia\\_NDS-Roundtable-report\\_September-2013\\_The-Alzheimer-Society-of-Ireland.pdf](http://alzheimer.ie/Alzheimer/media/SiteMedia/Living-with-Dementia_NDS-Roundtable-report_September-2013_The-Alzheimer-Society-of-Ireland.pdf)

Alzheimer Scotland<sup>93</sup> has produced an Eight Pillar model for integrated health and social care. This model addresses the social implications of dementia, demonstrating how these can be tackled most effectively by coordinating the full range of health and social care interventions to meet individual needs.

Irving and McGarrigle (2012<sup>94</sup>) as part of the ASI's expert policy series, conclude that a move towards more integrated working in terms of planning and service delivery could help achieve better outcomes for those with dementia and make the best use of current resources. Achieved through close integrated working across health and social care systems, the delivery of GP-led memory clinics in association with specialised support from community mental health teams, proactive case management as well as strengthening community networks and support.

The PREPARED<sup>95</sup> project, a primary care focused national research and service development initiative run by the Department of General Practice at UCC, funded under the National Dementia Strategy, aims to develop, deliver and evaluate training and education interventions for primary care clinicians. Key elements include multidisciplinary management, registries to collect data and appropriate resourcing of primary care, which are in line with the core aspects of the Chronic Care Model referenced earlier.

### **Funding Model: Which health service funding model would be best suited to Ireland?**

Financing of care for people with dementia must be co-ordinated across the trajectory of the disease with adequate funding at each stage of progression. State spending on dementia to date has been low and inadequate. Dementia continues to lag behind other chronic diseases in terms of budget allocation in most countries, particularly relative to the disease burden (Cahill et al, 2012). The initial joint investment by Atlantic Philanthropies and the Government to support the implementation of the NDS has limited lifespan. Longer-term thinking and investment is required.

### **Financing, payment methods and service delivery (purchaser and provider)**

Equality of access and outcome should be a guiding principle for any funding model. Refocusing policy on quality of care rather than solely cost-effectiveness. There is also a

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<sup>93</sup> [http://www.alzscot.org/assets/0000/4613/FULL\\_REPORT\\_8\\_Pillars\\_Model\\_of\\_Community\\_Support.pdf](http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf)

<sup>94</sup> Available at this link <https://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/Integrated-Care-Pathways.pdf>

<sup>95</sup> More information available [here](#)

need to ensure that financial reform in the healthcare sector<sup>96</sup> does not negatively impact on health service users such as people with dementia.

The National Economic and Social Council (2013)<sup>97</sup> found that cuts to health spending resulted in reductions in grants to outside agencies, which affect service provision on the frontline.

A concern for the NGO sector is that quantitative measurements of financial savings do not take into account the effect on service provision at a ground/micro level. NGOs can make an important contribution to health system reform in Ireland. They provide an input that is complementary to political forces, and they have interests primarily for society rather than commerce.

### **Best practice, or estimated costs of funding models**

There is underinvestment in dementia research and care infrastructure, relative to its social and economic impact. Given the demographics of an ageing population, this gap will only increase. Evidence from the UK also shows that achieving better outcomes for people with dementia and achieving greater value for money in dementia care is possibly through changes to service provision or adopting new ways of working (House of Commons, 2011<sup>98</sup>). Early diagnosis and early intervention, for example, can deliver cost savings to public services as well as delivering a better quality of care for people with dementia (House of Commons, *ibid*).

### **Conclusion**

Under the current health and social care system, people with dementia and their carers face serious barriers in equity of access and outcomes from the point of diagnosis to end of life. A key challenge in establishing an integrated health service based on need rather than ability to pay is ensuring that the service is person-centred, integrated and based on quality of life outcomes within a wider human rights and social model framework.

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<sup>96</sup> European Commission. Europe 2020: A strategy for smart, sustainable and inclusive growth, COM(2010). Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PD>

<sup>97</sup> NES (2013) *The Social Dimensions of the Crisis*

<sup>98</sup> House of Commons (2011) The £20 billion question An inquiry into improving lives through cost-effective dementia services. All-Party Parliamentary Group on Dementia. available via

[file:///C:/Users/MCrean/Downloads/The %C2%A320 Billion Question - an inquiry into improving lives through cost effective dementia services from the All-Party Parliamentary Group on Dementia 310811.pdf](file:///C:/Users/MCrean/Downloads/The%20A320%20Billion%20Question%20-%20an%20inquiry%20into%20improving%20lives%20through%20cost%20effective%20dementia%20services%20from%20the%20All-Party%20Parliamentary%20Group%20on%20Dementia%20310811.pdf)

A ten-year plan for the health service must be informed by strategic policy and shared principles, integrated policy and practice on the ground, and a social model of care that ensures a right to community/home-based care.

Moving to an integrated health and social care system requires leadership, policy implementation, legislative change, appropriate levels of funding and a recognised role for the NGO sector. Funding must be underpinned by equality of access and outcomes and rebalanced in a way that recognises the need to resource primary and community care to provide a foundation for more integrated and strategic healthcare.

<http://www.alzheimer.ie/Home.aspx>

## Arthritis Ireland

Rheumatic and Musculoskeletal disorders (RMDs) are a group of more than 200 different conditions that affect 1 in 4 people of all ages, equivalent to 1.2 million Irish citizens ([www.eular.org](http://www.eular.org)). It is estimated that 2% of the EU GDP is spent on direct medical care of RMDs. RMDs are the leading cause of disability in Ireland. RMDs cause the single greatest socioeconomic cost of any disease group due to lost productivity from long-term work absence and due to the payment of disability benefits.

There will be a dramatic increase in the prevalence of RMDs in the next decade due to an increasing and ageing population. RMDs impede the ability of people to remain economically and socially active when becoming older. The social and economic impact of RMDs will be accentuated by the necessity to maintain the larger, ageing Irish population in work to a later age.

Many RMDs, such as rheumatoid arthritis, have seen major advances in specialist treatment in the past decade, effective in preventing joint damage and patient disability. The need to develop Rheumatology services for the provision of better care for patients with RMDs in Ireland is recognised by the Health Service Executive (HSE). In 2010, a National Clinical Programme for Rheumatology (NCPR) was established with the overarching aim of: *“Adopting a chronic disease model of care so as to facilitate a right person, right place, first time approach to patients with RMDs.”*

In 2016 the NCPR produced a model of care for Rheumatic and Musculoskeletal Diseases in Ireland(

<http://www.hse.ie/eng/about/Who/clinical/natclinprog/rheumatologyprogramme/modelofcare.html>). The model of care notes that Ireland has one of the lowest ratios of rheumatologists to population in the EU and when implemented will bring service provision for RMDs in line with evidence-based practice and international standards of care.

The model of care envisages expansion of rheumatology services in a hub-and-spoke model of tertiary centres operating within 6 rheumatology networks coterminous with the new hospital groups and integrated with Community Healthcare Organisations (CHOs). This will provide co-ordinated care and uniform standards of service delivery for patient across the networks supported by the development of clear referral protocols, pathways and therapeutic standards. The cost of implementing this model can be realised through the prevention of RMD disability and its high direct and indirect costs and by implementing efficiencies in current utilisation of specialist services such as high technology drug expenditure.

## **Recommendations and Key Priorities for 10 Year Plan:**

1. Rheumatic and Musculoskeletal disorders (RMDs) to be formally acknowledged as one of the largest direct healthcare costs in Ireland today.
2. Rheumatic and Musculoskeletal disorders (RMDs) to be formally acknowledged as the single largest indirect cost due to disability in Ireland.
3. Implementation of the National Clinical Programme Rheumatology Model of Care as the basis of a 10 year healthcare plan for integrated medical care (eg non-surgical) of RMDs.
  - i. Establish one consultant rheumatologist per 79,000 population (WHO)
  - ii. Establish a multidisciplinary team to work with each consultant in delivering care of RMDs
  - iii. Provide appropriate facilities for each Rheumatology MDT to deliver care of RMDs
  - iv. Rheumatology centres to work as networks across each hospital group to optimise clinical services, education and research.
  - v. Establish a Treat to Target model for disease management in RMDs that will result in maximal disease outcomes and maximal economic benefits
  - vi. Sustain and develop self-management programmes for RMDs in collaboration with patient organisations such as Arthritis Ireland
  - vii. Further develop the specialist physiotherapist triage scheme for RMDs
  - viii. Further develop RMD management in primary care with appropriate access to diagnostic and therapeutic modalities for GPs
  - ix. Implement recommendations of Fit to Work coalition to effect reductions in work disability
  - x. Implement a National Fracture Liaison Programme to prevent fractures from Osteoporosis
  - xi. Establish RMD units in each network to provide inpatient care for RMDs
4. Acknowledge that investment in and development of RMD treatment will reduce disability and that this will reduce indirect costs from disability.
5. Acknowledge that due to the chronic nature of RMDs cost effective strategies aimed at reducing disability in large populations can only be realised through long term planning and investment such as envisaged in the 10 year Irish healthcare plan.
6. Acknowledge that the short term nature of Irish Healthcare funding to date is one of the reasons why RMD services in Ireland are so underdeveloped.
7. Recommend integrated primary, secondary and community health care of RMDs to be led through the HSE Rheumatology Model of Care.

## What are Rheumatic and Musculoskeletal disorders?

Rheumatic and Musculoskeletal disorders (RMDs) are a group of more than 200 different conditions which may result in damage to the muscles, bones and joints of the body. The European Union League against Rheumatism estimates that RMDs affect 1 in 4 Europeans of all ages, equivalent to 127 million Europeans and 1.2 million Irish citizens (www.eular.org). Table 1 lists the most common and important RMDs.

**Table 1: Common Rheumatic and Musculoskeletal disorders (RMDs)**

<b>Osteoarthritis (OA) and Regional MSK pain</b>	500,000 people affected in Ireland. 1 in 4 adults in the UK are affected by longstanding Musculoskeletal problems that limit everyday activity and 30% of all GP consultations are about MSK complaints (Department of Health (UK), 2006).
<b>Rheumatoid Arthritis (RA)</b>	At least 40,000 people in Ireland have RA. 70% of people with RA cannot work outside of home due to RA, costing the state €1.6 billion (Bevan et al., 2009a). Early intervention can prevent joint damage and disability in patients with RA.
<b>Spondyloarthropathy (SpA)</b>	Over 44,000 people in Ireland are affected (Bevan et al., 2009a) by this inflammatory disease predominantly affecting the spine including ankylosing spondylitis & psoriatic arthritis. Early intervention prevents disability in patients with SpA.
<b>Osteoporosis</b>	1 in 5 men and 1 in 2 women > 50yrs will develop a fracture due to osteoporosis. Hip fracture is fatal for 20% of patients with permanent disability for 50% (Stafford et al., 2004). Fractures can be prevented by treating osteoporosis.
<b>Systemic Rheumatic Disease: Connective Tissue Disease and Vasculitis</b>	2,000 people in Ireland affected. Multisystem diseases with high morbidity and mortality. Specialist multidisciplinary care improves outcomes and quality of life.
<b>Juvenile Idiopathic Arthritis (JIA)</b>	1,200 children in Ireland affected (Arthritis Ireland, 2016) - early specialist care within months of diagnosis prevents

permanent joint damage, growth retardation and disability.

<b>Fibromyalgia and Soft Tissue Rheumatism</b>	2% of women, aged 20-55. One of the most common reasons for patients to visit a GP is widespread MSK pain attributed to abnormal pain processing (Department of Health, 2006)
<b>Gout</b>	Gout is the commonest inflammatory arthritis and prevalence is increasing – in line with obesity - with 1 in 40 of the UK population now affected (Kuo et al, 2014)

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Arthritis is the leading cause of disability in people aged 55 years and over and hence is the greatest cause of health service usage (Vos et al., 2015). Over 1 in 5 Irish people have some form of arthritis (Arthritis Ireland, 2015a) and the condition accounts for over 30% of all general practitioner (GP) visits (Bevan et al., 2009a). A recent report from the Central Statistics Office (2008) confirmed that chronic back pain is the second commonest condition among adults, after hypertension. The Institute of Public Health MSK briefing document in September 2012 found that 169,000 adults (5.1% of the population) had rheumatoid arthritis in the previous 12 months, which had been clinically diagnosed.

### **The Economic impact of RMDs**

RMDs give rise to major health resource utilisation – the direct costs of RMDs are estimated to account for 2% of the European GDP making it one of the top 4 disease groups in terms of healthcare costs (www.eular.org). Effective health resource utilisation for RMDs is achieved by providing a population health approach providing preventative, self-management and primary care services for most patients with RMDs and specialist services for more complex and serious diseases which comprise 15-20% of RMDs. RMDs cause the single greatest socioeconomic cost of any single disease group due to lost productivity from long-term work absence and due to the payment of disability benefits. They represent 39% of all occupational diseases and are the main cause of early retirement, impeding the ability of people to remain economically and socially active when becoming older.

### **Population Growth and Ageing in Ireland 2016-2016**

As the demographic profile in Ireland changes, with increased life expectancy and rising numbers of the population moving into the middle and older age groups, it is expected that the prevalence of RMDs will increase dramatically in the next decade. RMDs impede the ability of people to remain economically and socially active when becoming older. An effective strategy to treat RMDs will be critical to maintain patients in social independence

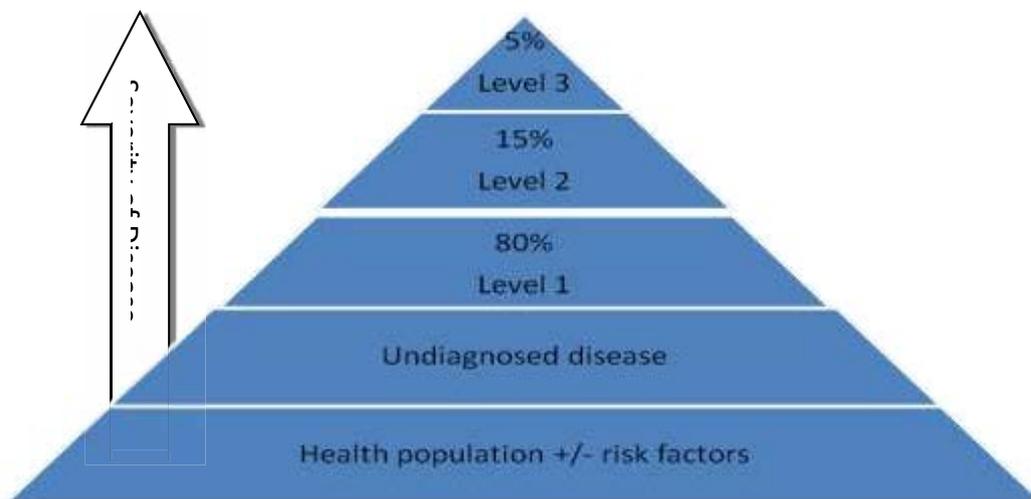
thus reducing nursing home care demands in the future as well as maintaining patients in work to a later age.

### The New Therapeutic Strategy for RMDs

New medical therapies are radically changing the approach to RMD management and are significantly affecting clinical outcome, preventing disability and maintaining patients' social and economic independence. For example the introduction of improved therapeutic strategies and biological medications for rheumatoid arthritis and spondyloarthropathy, means that lasting disease remission is the new therapeutic goal (Emery et al., 2008) for up to 100,000 Irish patients. Preservation of work status, maintenance of quality of life and prevention of joint damage and disability result from successful treatment. Previously up to 70% of RA patients were unable to work outside of the home.

Not all RMDs require intensive specialist services and a population health approach is the most appropriate model for service delivery. Figure 1, which applies to all chronic conditions, shows the segmentation of complexity (levels 1-3) as it relates to RMDs. It is important to appreciate that these three levels are not distinct cohorts of patients; people in each level can improve or deteriorate and move between levels.

*Figure 1: Population Health approach as it relates to Musculoskeletal health (Taylor, 2007, HSE, 2008b, Minnock et al., 2012)*



**Level 1:** Individuals who have RMDs that are well controlled by the patients themselves. It is assisted by self-management participation and as required primary care support (approximately 70-80% of patients).

**Level 2:** Individuals with more complex illness. They may have one or more chronic illness of varying severity, but are not at risk of hospitalisation if they are well managed in the community (approximately 15-20% of patients). These patients can be monitored by self-management participation and identified via achievement or non-achievement of specific treatment goals.

**Level 3:** Individuals with complex conditions, often with complications. They require specialist care, intensive intervention and are at high risk of hospitalisation (Approximately 5-7% of patients).

### **National Clinical Programme for Rheumatology Model of Care**

*“To develop a chronic disease model of care to facilitate a right person, right place, first time approach to patients with rheumatic and MSK disorders.”*

### **Achievements to date**

Rheumatology is the medical specialty dedicated to the treatment of RMDs. The NCPR was established in 2010 and comprised of representatives of all health professionals involved in Rheumatology care in Ireland. To date it has delivered:

- The appointment of seven additional Consultant Rheumatologist posts. This significantly increased the number of posts from 26.5 WTE to 33.5 WTE representing a 25% growth in Rheumatology Consultant numbers.
- The establishment of a Musculoskeletal Physiotherapy Initiative in collaboration with the National Clinical Programme for Trauma and Orthopaedic Surgery, with twenty-two Clinical Specialist Physiotherapists in place nationally. To date, this initiative has removed 71,714 patients from Rheumatology and Orthopaedic waiting lists. On foot of this success an additional six Clinical Specialist Physiotherapists were allocated through the 2016 service planning process.
- Endorsement by the National Director for CSPs of the Irish Rheumatology Nursing Forum Business Proposal for Advanced Nurse Practitioner and Clinical Nurse Specialist Posts to implement ‘Treat to Target’ as standardised care for patients with inflammatory arthritis. Further, the national director and the Chief Information Officer confirmed their co-sponsorship for the associated rheumatology electronic patient record pilot to capture essential treat to target outcome data.

### **National Clinical Programme Rheumatology Model of care**

Based on European Action Towards Better MSK Health (European Bone and Joint Health Strategies Project, 2004) and The MSK Service Framework (Department of Health (UK), 2006), a patient centred model of care for Rheumatology Services in Ireland was agreed by

the NCPR, RCPI, the Rheumatology Clinical Advisory Group representing consultant rheumatologists throughout Ireland and Arthritis Ireland representing patients (<http://www.hse.ie/eng/about/Who/clinical/natclinprog/rheumatologyprogramme/modelofcare.html>)

## **Recommendations of the Model of Care**

### **Quality Solutions**

- Establish Rheumatology Clinical Networks (RhCNs) that are underpinned by robust clinical and corporate governance structures
- Develop/agree/implement national clinical guidelines, standards of practice, care pathways with all partners that move from prevention and self-care through to hospital care and ensure that the use of primary and secondary care is appropriate to patients' needs
- Care pathways to include detailed and agreed clinical audit measures and all services must engage in clinical audit.
- To agree and implement disease specific and patient focused quality outcome measures
- To enhance and develop self-management and patient education programmes that are tailored to particular levels of complexity and risk e.g. those developed by Arthritis Ireland
- To further develop “fracture-liaison” programmes so as to ensure that patients with osteoporosis are identified and treated in a timely manner
- A national arthritis registry to be established
- To utilise the International Classification of Functioning, Disability and Health (ICF) as a framework to develop these measures. Activity and participation outcomes to be measured in tandem with outcomes that focus on body structure and function

### **Quality Solutions: Education and Research**

- To develop an accredited Continued Professional Development (CPD) programme in the assessment and treatment of MSK conditions for all disciplines. This programme to include e-learning modules
- To promote service-related and translational research programmes related to rheumatic diseases

- Develop and agree an integrated competency framework for each discipline working in rheumatology services across primary, secondary and tertiary services
- To review and develop, in partnership with the Higher Education Authority and Universities, MSK training programmes in the undergraduate courses in all the relevant disciplines

### Access Solutions

- Provide access to a Multidisciplinary Team (MDT) at community level which will enable individual and population-based self-management support, education, optimal clinical and social care in the most appropriate setting, education, avoidance of complications, improved outcomes and optimal quality of life
- Facilitate care across the chronic disease spectrum e.g. a falls clinic in primary care can be used to identify those at risk of osteoporosis and could also be used for health promotion in patients at risk
- Increase consultant rheumatology time by 40% within 1 year – this to be achieved by taking all rheumatology consultants off General Internal Medicine (GIM) call and by appointing new consultant rheumatologists.
- Develop and increase extended scope role in nursing, occupational therapy pharmacy and physiotherapy and to enhance multidisciplinary/interdisciplinary management
- Provide full MDT access to all dedicated rheumatology services, only one third of the recommended nurse specialists, occupational therapists and physiotherapists are in post nationally. An integrated workforce planning exercise needs to be completed on MDT staffing levels requirements in implementing the proposed model of care. Secondary care services to have an outreach component
- Developing educational programmes and liaising with community MDTs will facilitate optimal management of MSK conditions in the community and avoid “inappropriate” referrals
- To examine the possibility of integrated care protocols for patients on biologic therapies

### Value Solutions

- To develop and agree an evidence-based national guidelines for use of biologic therapies, including biosimilars, in a cost-effective manner in conjunction with the Medicines Management Programme

- To develop cost effective (eg:- community based, protocolised, etc.) infusion programmes which will provide economies of scale and substantial savings (vial sharing savings of €100,000/yr/100 patients treated or savings associated with use of biosimilars)
- To review usage of drugs within the General Medical Scheme, in particular those where efficacy is unproven
- To work with the OPD programme to ensure that all patients seen at OPDs are appropriately referred and have all the pre-assessment work-up completed prior to attending outpatient clinics in secondary care
- To reduce the 'did not attend' (DNA) rate to 12% as per National OPD performance improvement programme
- To liaise with Department of Social Welfare and to reduce MSK work-related disability costs (estimated €350m/year) by 10% in 2 years
- By introducing/rolling out an effective fracture-liaison programme including a falls risk assessment, to substantially increase the numbers of patients with fractures assessed to 90% within 1 year

Prof David Kane, Consultant Rheumatologist & Clinical Lead  
 HSE National Clinical Programme for Rheumatology  
 Royal College of Physicians Ireland, Setanta House, Setanta Place, Dublin 2.  
 Email: [GaryKilleen@rcpi.ie](mailto:GaryKilleen@rcpi.ie) Tel 01 8639620

Mr John Church, Chief Executive Officer,  
**Arthritis Ireland**

Mr Derek Deely, Honorary Chairperson  
**Irish Rheumatology Health Professionals Society**

Ms Louise Moore, Honorary Chairperson  
**Irish Rheumatology Nursing Forum**

Dr Alexander Fraser, Honorary President  
**Irish Society for Rheumatology**

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## Arts Council & HSE Arts and Health Working Group

The Arts Council & HSE Arts and Health Working Group welcomes the opportunity to contribute to the deliberations of The Oireachtas Committee on the Future of Healthcare.

### Introduction - Arts and Health practice

Arts and Health practice has been taking place across all disciplines and settings in the health service since the early 1990's. Broadly speaking, Arts and Health practice involves the development of arts events, projects and programmes by professional artists and arts organisations working in partnership with healthcare staff.

Initiatives take place in a range of healthcare settings including hospitals, residential units, day care centres, hospices, primary care centres, community-based health and arts settings; and can involve staff, service users, carer's, family members, visitors and volunteers.

Projects aim to achieve a range of health and artistic goals. For example, Arts and Health programmes may aim to:

- enhance health and wellbeing of service users through improving quality of life and access to the arts<sup>99</sup>
- enhance the built environment
- convey health messages
- improve staff morale, skills and working environment

Health service users involved in Arts and Health initiatives have reported:

- feeling more empowered to make choices in relation to health
- greater capacity to cope with illness
- reduced sense of fear, isolation and anxiety
- increased confidence, sociability and self-esteem
- transformation of the experience of being in hospital / ill health

Other outcomes can include:

- improved communication between staff and patients
- reduced drug consumption
- reduced length of stay
- improved staff recruitment and retention
- improved atmosphere in healthcare settings

Arts and Health practice has continued to develop and expand throughout the country over the last 25 years, primarily because healthcare staff have found that high quality engagement with the arts can add value to the working and healthcare environments and many of the services they provide.<sup>100</sup>

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<sup>99</sup> The Arts Act 2003 defines the arts as 'any creative or interpretative expression (whether traditional or contemporary) in whatever form including, visual arts, theatre, literature, music, dance, opera, film, circus, architecture, and any medium when used for those purposes.'

<sup>100</sup> Please see Appendix 1 for an overview of Arts and Health practice in Ireland.

## Policy and research

The approach, practice and impact of Arts and Health practice aligns with many of the goals and objectives outlined in *Healthy Ireland*, and has relevance to other key Department of Health and HSE policy and strategies such as *Future Health*, the *National Positive Ageing Strategy* and *Vision for Change*.

However, while there is a high level of partnership between the health and arts sectors locally, there is no formal arts policy within the Department of Health or the HSE and no joint Arts and Health policy at national level.<sup>101</sup> In the absence of a policy and strategy at national level, Arts and Health projects and programmes are developed and resourced in an ad-hoc manner. Consequently, the impact and learning from a wide range of valuable work is not being maximised.

As the statutory bodies with national responsibility for health and the arts respectively, the HSE (Health Promotion and Improvement, Health and Wellbeing Division) and the Arts Council, jointly commissioned a piece of research to explore the establishment of a formal framework to support the development of Arts and Health practice in Ireland. The purpose of the research was to examine what form such a framework might take and to consider the most strategic and effective options in this regard.

The research was led by Dr. Catherine McCabe, Trinity College Dublin, and included an extensive literature review, an audit of existing projects and programmes, interviews with stakeholders and a review of international arts and health models at national level.

The report will complete in September. It was designed as an internal report to inform further deliberations by the HSE and Arts Council in regard to Arts and Health. However, the findings and other elements of the report such as the literature review will be made available in due course. Full details can be made available to the Oireachtas Committee should further information be required.

## Future of Healthcare

With regard to the Committee's consideration of the future of healthcare, we acknowledge that the area of Arts and Health is just one component of a much larger and more complex review of healthcare models. However, Irish and international research has shown that the arts can add value to healthcare provision across all services<sup>102</sup>, and we believe that the arts have a particularly vital role to play in the development of an integrated, patient centered model of healthcare.

Arts and Health practice has particular relevance to the following Oireachtas Committee Objectives and Terms of Reference:

- *vision for the health service with an emphasis on quality of patient care* (Objective 1)
- *development of a model of integrated healthcare with an emphasis on primary and community care* (Objective 6)

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<sup>101</sup> The Arts Council published an Arts and Health Policy in 2010 - [http://www.artscouncil.ie/uploadedFiles/Arts\\_and\\_health\\_policy\\_2010\\_2014.pdf](http://www.artscouncil.ie/uploadedFiles/Arts_and_health_policy_2010_2014.pdf)

<sup>102</sup> A wide range of case studies, research and evaluation are available on the national Arts and Health website <http://www.artsandhealth.ie>

- *a changed model of healthcare that advocates the principles of prevention and early intervention, self-management and primary care services as well as integrated care (g, ToR)*
- *re-orientation of the health service on a phased basis towards integrated, primary and community care, consistent with highest quality of patient safety, in as short a time-frame as possible. (i, ToR)*

The Arts Council | HSE Arts and Health Working Group encourage the Committee to include the area of Arts and Health practice in their considerations of future models of healthcare in Ireland. The working group would be pleased to provide more specific details on any aspect of this proposal at any time.

**For further information please contact:**

Ann O'Connor, Arts Participation Adviser, Arts Council | An Chomhairle Ealaíon,  
ann.oconnor@artscouncil.ie or

Michael Shemeld, Special Projects Manager, Health and Wellbeing Division, HSE,  
Michael.Shemeld@hse.ie

Submitted on behalf of The Arts Council | HSE Arts and Health Working Group. The Working Group was established in 2015 in order to oversee research into the establishment of a formal framework to support the development of Arts and Health practice in Ireland.

Members include:

- Dr. Cate Hartigan, Head of Health Promotion and Improvement, Health and Wellbeing Division, HSE
- Stephanie O'Callaghan, Arts Director, Arts Council
- Ann O'Connor, Arts Participation Adviser, Arts Council
- Caroline Peppard, Senior Health Promotion Officer, Health Promotion and Improvement, HSE
- Michael Shemeld, Special Projects Manager, Health and Wellbeing Division, HSE
- Karen Whelan, Arts Participation Officer, Arts Council

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## Appendix 1

### ***Brief outline of Arts and Health practice in Ireland***

This appendix is intended to give an indication of the scope of Arts and Health practice in Ireland. It is not attempting to be fully comprehensive.

Arts and Health involves a wide range of stakeholders, each with their own aims, objectives, priorities and approaches. The following all play a role in the development and delivery of Arts and Health practice in Ireland.

#### *Health Service Executive*

Although there is currently no national HSE policy, strategy or dedicated budget line in place for the arts at national level, the HSE still fund a large percentage of the Arts and Health practice that is taking place. Funding is not automatically ring-fenced for the arts, but is allocated to Arts and Health practice by managers and staff at regional and local level. Individual clinical, administrative, and service staff, champion Arts and Health practice at all levels and are involved in the planning, delivery, and evaluation of practice in partnership with local artists and arts organisations. The HSE also employ many of the Arts and Health Coordinators that currently initiate and manage arts programmes in HSE hospitals and other healthcare settings around the country. [www.hse.ie](http://www.hse.ie)

#### *Arts and Health Coordinators Ireland*

Arts and Health Coordinators are employed (or work on contract basis) in hospitals and other healthcare settings throughout Ireland. Coordinators programme and manage arts initiatives in a range of health contexts and play an important role at local level, championing the arts in their respective settings and ensuring good practice and artistic quality. Coordinators set up a national network in 2003 called Arts and Health Coordinators Ireland. The network meets regularly and has over 20 members. <https://artsandhealthcoordinatorsireland.wordpress.com>

#### *The Arts Council*

The Arts Council has promoted the value of the Arts and Health and supported individual artists and arts organisations working in the field, through the provision of funding and the development of strategic capacity building initiatives. Initiatives include the commissioning of research, development of information resources and delivery of regional, national and international events. The Arts Council developed a formal *Arts and Health Policy* in 2010, following consultation with the arts and health sectors. In 2011, the Arts Council initiated and continues to support the development of *artsandhealth.ie*, the national Arts and Health website, now managed by Waterford Healing Arts Trust. [www.artscouncil.ie](http://www.artscouncil.ie)  
[www.artsandhealth.ie](http://www.artsandhealth.ie)

artsandhealth.ie is a national website that provides an important focal point and resource for the field of Arts and Health in Ireland, through resource documents, case studies, a directory of contacts, perspectives on a range of issues and current news. The site is managed by Waterford Healing Arts Trust and is supported by an Editorial Group that includes representation from the HSE, Arts Council, Arts and Health Coordinators Ireland and individual artists. [www.artsandhealth.ie](http://www.artsandhealth.ie)

#### *Independent / specialist Arts and Health organisations*

Alongside the many arts programmes and departments that are managed by Arts and Health Coordinators and embedded within HSE hospitals and other healthcare settings throughout Ireland<sup>103</sup>, there are also a small number of independent specialist Arts and Health organisations. These include:

- *Anam Beo* (established in 2009), is an independent organisation that delivers an Arts and Health programme in Offaly. It is supported by Offaly County Council and HSE Dublin Mid-Leinster.
- *Helium* (established in 2008), is a puppetry and performance based Arts and Health organisation, working nationally with children, their families and health care communities. <http://www.helium.ie>
- *Galway University Hospitals Arts Trust* (established in 2006), delivers a multi-disciplinary arts programme in University Hospital Galway and Merlin Park University Hospital. In 2015, GUHATs brief expanded to include the wider Saolta Hospital Group (6 hospitals across 7 sites in the West and North West). <https://www.facebook.com/guharts/>
- *Kids Classics*, a not-for-profit organisation that provides high quality music making opportunities in educational, healthcare and community settings. <http://kidsclassics.ie>
- *MusicAlive*, specialises in the provision, development and promotion of music in healthcare and community settings. <http://www.musicalive.ie/>
- *Vivartes* (formerly known as 4<sup>th</sup> Promise, established in 2005), developed the *Open Window* multimedia project in St. James Hospital and adapted it for use in other hospitals and residential health settings. Vivartes is currently involved in the development of an arts programme at the new Mercer's Institute for Successful Ageing in St. James Hospital.
- *Waterford Healing Arts Trust* (WHAT, established in 1994), is based in a dedicated Centre for Arts and Health in the grounds of Waterford Regional Hospital. WHAT works in a variety of health contexts locally and provides a multi-disciplinary arts service. WHAT also manages the national website artsandhealth.ie, and an annual national Arts and Health networking event. <http://www.waterfordhealingarts.com>

#### *National arts and other resource organisations*

National arts resource organisations such as Create, the national agency for collaborative arts, and Music Network have developed opportunities and resources for information, training, networking and practice development in the area of Arts and Health. Create were involved with the development of artsandhealth.ie in partnership with WHAT and also manage the Artist in the Community Scheme on behalf of the Arts Council, numerous Arts

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<sup>103</sup> For example, programmes such as the HSE Cork Arts and Health Programme, the Centre for Arts and Health at Tallaght Hospital, The Twilight Arts and Health Programme at St Patrick's University Hospital, West Cork Arts for Health Partnership and many others are key components of the Arts and Health infrastructure in Ireland.

and Health projects are supported through this Scheme annually. Age & Opportunity has also developed arts programmes with older people in a range of health settings, in particular through Bealtaine, the national festival that celebrates creative ageing.

#### *Local Authorities*

Local Authority Arts Officers are key in the development of Arts and Health practice. They support individual artists and arts organisations through the provision of funding and development of strategic initiatives. For example, Sligo County Council developed an Arts and Health programme in 1998 and agreed an Arts and Health strategy with the HSE West in 2007, Mayo County Council developed an Arts and Health Programme in partnership with the HSE West in 1999, Offaly County Council developed an Arts and Health programme in partnership with HSE Dublin Mid Leinster in 2005, and Kildare County Council launched an Arts and Health strategy in 2009.

#### *Regional arts organisations and festivals*

Regional Arts Centres have also been to the forefront of work in this area. West Cork Arts Centre, for example, has developed a long-term partnership with the HSE South, the VEC and Cork County Council, which support professional artists to work in local community hospitals and daycare settings. Other regional arts organisations and festivals, such as Inisceiltra Festival in Clare, Phizzfest in Dublin 7 and others have also developed Arts and Health strands to their work.

#### *The Creative Arts Therapies*

The Creative Art Therapies (e.g. music, drama, dance / movement, visual arts therapies) are a valuable component of the broad area of Arts and Health and many Creative Art Therapists are employed by the HSE. The Creative Arts Therapies and Arts and Health practice differ in focus however. Creative Arts Therapists utilise the arts in order to achieve clinical goals. Artists working in partnership with health professionals have a focus on artistic goals, processes and outcomes, alongside any other goals that health partners may have (such as health, wellbeing, inclusion etc). The primary purpose of the arts in healthcare contexts is to promote health and wellbeing by improving quality of life, the healthcare environment and access to the arts, particularly among a sector of the population that is often excluded from mainstream arts provision (Arts Council, 2010).

<http://www.artsandhealth.ie/directory/the-arts-council-an-chomhairle-ealaion/>

## Association of Hospital Chief Executives (AHCE)

The Association of Hospital Chief Executives (AHCE) representing the Senior Management of the State's voluntary hospitals welcome the opportunity to input to the Joint Oireachtas Committee on the Future of Healthcare.

Nationally, voluntary hospitals account for almost 30% of all inpatient care. They are governed independently of the HSE either through historic charters, companies limited by liability or bodies established through the Health Corporate Bodies Act. Each provide services on a non-profit basis right across the continuum of healthcare including acute care, maternity, paediatric, specialist hospitals, rehabilitation, old age, hospice, long term and psychiatric services.

A third of State funding for hospital services is granted to voluntary hospitals (approximately €1.3bn) and the sector employs a comparable number of staff at approximately 22,000.

Voluntary hospitals have strong service brands that are trusted by their communities both locally and nationally. They have strong links with third-level education, a proven track record in health research and innovation, attract strong philanthropic support, and have professional fundraising bodies that foster close relationships with the communities they serve. Voluntary hospitals through their clinical and quality monitoring, track key trends across all aspects of healthcare and are ideally positioned to offer timely, accurate and informed advice on policy and service development.

The voluntary hospital structure has been in existence in Ireland many years before the introduction of the public health service and many of these voluntary hospitals are still providing care today. Over the last 2 centuries, the voluntary hospitals have led in developing healthcare in Ireland, through their leadership in risk management, research, clinical education and service development. The Voluntary hospital system enhances state provided care in areas of speciality and expertise as in the specialist oncology and haematology services, cardiothoracic surgery, solid organ transplantation and other areas.

The unique structure of voluntary hospitals with their voluntary boards allows knowledge and expertise from outside the healthcare sector to influence and guide the hospitals in their daily work, lead out on emerging improvements in healthcare provision and initiate longer term strategies.

The AHCE believe there are three key areas of focus for the ten year plan, they are:

- Healthcare Structure
- Healthcare Demographics
- Investment for the Future

### Healthcare Structure

The AHCE's vision for the future of the Irish health system is to design a system which treats everyone fairly, provides equal access to a defined level of health service, taking account of specific needs. Is flexible to reflect changing demographics provides care, at the point of need, in the most efficient manner and where appropriate in a community setting. The structure of healthcare management should support the daily living experience of everyone.

Much time has been devoted to discussions on the funding of the healthcare system and funding models, comparing one country against another. Funding comparisons against other EU countries are not reflective of the Irish healthcare system and do not give an accurate reflection of the investment and funding required for the Irish system, both current and future demands.

We believe that some of the funding concerns within the system would be addressed through a change in the current healthcare structure.

- We believe there should be an independent commissioning of health providers. This will secure better outcomes for service users, better match services to the needs of the population and will secure greater efficiency from services.
- Services should be commissioned from statutory, voluntary and private institutions depending on the urgency of the care required and availability of the service.
- Funding of activity should be separate to investment in overall strategic services. Funding should reflect agreed services in line with patient needs and patient centred, i.e. money follows the patient.
- A system covering all bodies within the healthcare system should have a quality frame of reference, for example, the European Foundation for Quality Management to measure quality across different Healthcare organisations irrespective of size, structure or acuity.
- Good quality performance should be rewarded and poor performance should be managed through an agreed process. Performance should be measured in the context of quality of patient outcome in the context of available resources.

## Healthcare Demographics

Ireland's population grew by 23% in the last 15 years; this was a combination of high immigration and birth rates. Statistics show that in the next 25 years, Ireland's population will grow by 30%.

Certain age groups will grow at a faster rate over the next fifteen years - there will be a 33.5% increase in the 55-64 age groups, a 44.4% increase in the 65-74 age group and 82.4% in the 75+ age group. Over this same period the demographic profile of Ireland will change with 74.3% of the population under 60 and over a quarter (25.7%) of the population over 60 years of age.

The Irish birth rate of 14.9 per 1,000 residents is higher than the EU average of 10.1. Relative to other EU countries the Irish death rate is falling and we actually live longer than the average in Europe, and the increase in these additional years of life continues. That, and a younger than average population, explains our low death rate in recent times.

While this is positive for the individual, these changing demographics pose challenges for the health service now and in the coming years. Based on trends, the current model of acute hospital care is unsustainable particularly in relation to bed capacity. Improvements in the long term health of the population will ultimately alter the acute hospital model and will be assisted by the following:

- Increased co-ordinated health education, awareness programmes and effective public health measures aimed at pre-birth to old age. These include vaccination programmes which would improve the general health of the population; programmes to address obesity, heart disease, and many other chronic illnesses that currently impact on the health service.
- The Healthy Ireland initiative should be expanded to all parts of the social and economic environment, through education, housing, environment and capital development. All initiatives

should support and encourage a healthy lifestyle with a focus on preventative measures to reduce future demands on the healthcare system.

## Investment for the Future

The AHCE strongly believe that through focused investment greater efficiencies can be gained within the healthcare sector. Investing in effective public health measures and awareness campaigns will improve the general health of the population and place less demands on services into the future.

However future investment will need to reflect

- Development of the IT infrastructure within the healthcare system which will support new connected health solutions and allow healthcare providers adopt and gain full advantage of the technical and data advances which are transforming the healthcare environment. Connected IT infrastructures - within an agreed data protection framework - will facilitate greater information sharing and facilitate patient access to specialised advice. It is likely that this investment will ultimately change the locus for the delivery of the majority of healthcare away from large acute centres towards local and more easily accessible health care providers.
- The demand for, and cost of, healthcare is rising, which is challenging. There is no doubt that adopting new forms of technology will help meet some of these challenges; however, other models will be needed to drive greater building and equipment investment, efficiencies and flexibilities to the sector as well as deliver services demands and higher quality patient outcomes. This could be delivered through developing greater industry links and the healthcare "system" becoming an ecosystem of interconnected stakeholders, each one focused on improving patient safety, quality of care and patient outcomes, while delivering efficiencies and savings.

A world class healthcare system demands world class talent. It is vital that the sector retains and attracts workers at all skill levels. It is critical that the talent pool is trained to adapt to a rapidly changing healthcare environment. As all levels of healthcare are, and will continue to be, person delivered, Investment is needed in the following areas:

- Recruitment of high calibre, trained individuals.
- Adequate funding for upskilling and a strategic education plan for current healthcare workforce to allow greater recruitment, career paths and retention of staff. Development of vocational or apprentice models could be considered for the sector.
- Conduct a future skills need analysis for the healthcare sector, being mindful of the changing business environment, in particular the impact of technology on the skill requirements of the future.

The voluntary hospital model has delivered high quality healthcare, in some instances for over two hundred years. This model has established a model of governance which places the patient services proximate to the governing Board. The vast experience, technical knowledge and up-to-date service information makes the Voluntary Hospital system ideal partners/resources in planning future health services.

The AHCE have worked with the Department of Health on the development of healthcare policy and will continue to engage fully with the Department on future policy developments.

We believe this sector has a lot to offer in driving the important changes that are required in delivering a future healthcare plan that will be developing better patient outcomes and a sustainable healthcare system. The sector has a lot to offer to drive this important change. The AHCE look forward to working with the Committee and Government.

Mr. Fearghal Grimes  
Chairman  
Association of Hospital Chief Executives  
Chief Executive  
St John's Hospital  
John's Square  
Limerick V94H272  
Tel: 061 462295

## ASSERT Centre, College of Medicine and Health, UCC

Medical progress is evident by new and better treatments. We propose a new and better method of training medical personnel to deliver healthcare in a better and safer manner. Consequently, delivering the advantages of both novel and currently available treatments quickly with a major early return on investment.

Medical procedures are fundamental effectors of modern healthcare, performed for diagnostic, therapeutic or preventative purposes; all are associated with risk of failure and harm to the patient. Fifty percent of adverse events result from an invasive procedure. Fifty to 66% of hospital adverse events are attributable to surgery and surgical care. The nature of surgery and interventional procedures make them more error prone. Clinical learning opportunities available to trainee doctors and healthcare workers are much fewer than previously. To date, the challenges posed by these changes not being addressed or are addressed in a disparate way by different stakeholder groups. This heterogeneity of approach is itself an obstacle to optimizing the patient benefit available through safe, effective and appropriate procedural care.

The **ASSERT** (Application of Science to Simulation-based Education and Research on Training) Centre at UCC is a new innovative facility which will deliver better and safer healthcare, through quality assured education and training, incorporating Technology Enhanced Learning (TEL). The authors of this submission particularly emphasise that although ASSERT represents a valuable national resource dedicated to improve patient safety, it is the innovative and effective methodology that it has developed that is relevant to the work of the Committee. The method (outlined below) has attracted the interest of leading health providers around the world; it represents the future of evidence-based training and maintenance of competency by health professionals. Therefore, Ireland's healthcare system can benefit from a new, cost effective and outcome-centred approach to training its professionals, thus ensuring that the Irish people receive safer, better healthcare. Secondary benefits include reduction and mitigation of the human and financial costs of certain clinical risks and a more engaged, high performing and stable workforce. It would be a disappointment to the authors if, through our international engagement, other early adopting countries and health services benefit from this approach to training before Ireland does.

The overall goal of the ASSERT approach is the development, implementation and validation of education and training programs to improve patient safety and to reduce avoidable harm with quality assured, evidenced based and benchmarked education and training. This approach takes as its starting point the competencies that are demonstrated by competent practitioners, currently in practice. These competencies in the domains of knowledge, practices and skills are derived from a comprehensive procedure characterisation by competent and experienced practitioners. This process draws on international, national and professional guidelines, published scientific evidence, and clinical experience. The metrics identified from this characterisation are then subjected to an objective, transparent validation process. Validated performance metrics are then used to assess the performance levels of experienced and competent practitioners. On the basis of these objective assessments performance, benchmarks (or proficiency levels) are quantitatively defined which trainees (no matter how senior) must demonstrate before training is deemed completed.

Fundamentally, training in healthcare must become more than an educational experience. Training should offer some guarantee of the performance level that the graduating trainee is able to consistently demonstrate. Furthermore, these performance benchmarks must be

derived from clinically meaningful sources. ASSERT derives these proficiency benchmarks from context specific healthcare practitioner's performances. Evidence from prospective randomised and blinded clinical studies has shown that 'proficiency-based progression' (or PBP) offers significant performance advantages over the traditional approach to education and training in healthcare. These studies demonstrate PBP delivers over a 30% - 83% reduction in intra-operative errors and between 17% and 58% reduction in operating times.

## **Background**

Medical procedures are fundamental effectors of modern healthcare, performed for diagnostic, therapeutic or preventative purposes; all are associated with risk of harm to the patient and of failure. Fifty percent of all adverse events are the result of an invasive procedure<sup>1</sup> and this number has not decreased since publication of the Institute of Medicine's "To err is human" in 2000.<sup>2</sup>

Regenbogen et al.,<sup>3</sup> indicate that between one half and two thirds of hospital adverse events are attributable to surgery and surgical care. The nature of surgery and other procedures makes them more error prone. During procedures, operators are constantly making decisions in real time and acting on them. Most procedural errors that occur are technical in nature and concern manual skills and errors of judgment or knowledge.

The number of clinical learning opportunities available to trainee doctors and healthcare workers is much fewer than previously. To date, the challenges that these changes pose are not being addressed or are addressed in a disparate way by different stakeholder groups. This heterogeneity of approach is itself an obstacle to optimizing the patient benefit available through safe, effective and appropriate procedural care and to comparing studies of effectiveness.

## **Traditional Education and Training**

Nurses, doctors and healthcare workers acquire their skills from repeated experience working with patients. While this is effective, though patients are exposed to increased risk of harm during the early part of the trainees' learning curve. Concurrently, work experience has changed considerably and training organizations have become cognisant of patient safety, partly because of high profile medical errors.<sup>4-6</sup> The Kennedy Report (UK) on the Bristol surgical errors, concluded that there can be no more learning curve on patients.<sup>4</sup> Although primarily about learning and performance of surgery, the response to it has impacted on training and clinical performance in ALL of medicine and healthcare.<sup>7</sup> One of Kennedy's main recommendations was that training should be competency based. This resulted in a transformation in medical education and training, which is still impacting on education, training and competence assurance today. A major implication of this report has been a steady move away from an assumption of competence based on the demonstration of 'knowing what to do', as in a knowledge exam for demonstration of a requisite performance. Initially this impacted greatest on post-graduate training but it is now impacting on education and training at an undergraduate and intern level. For example, the Greenaway<sup>8</sup> Report recommended that doctors should be 'licensable' on graduating from medical school. The implications of this recommendation are profound. For instance, competency in 15 core clinical and procedural skills for provisionally registered doctors is already a compulsory part of medical education and training.<sup>9</sup> The implication of the Greenaway<sup>8</sup> report recommendation is that a competence level would have to be verified before graduation and would mean a considerable change in the high-stakes nature of skills assessment at medical school. Furthermore, assessment of these skills would have to be validated for what would now be a high stakes assessment.<sup>10</sup>

## Training for surgery and procedure based medicine

The adoption of minimally invasive surgery (MIS) and the reduction in work hours for trainees coincided with a growing concern amongst the surgical leadership that graduating surgical trainees appeared to have significant knowledge and experience gaps in important operative areas in general surgery. Furthermore, graduating trainees themselves expressed concern about their readiness to enter independent clinical practice, 80% at completion of general surgery training programs opted for additional training. In 2009 Bell et al. quantitatively confirmed that surgical trainees lacked exposure, never mind training to competency, in many surgical procedures, which Program Directors considered fundamental to general surgery training. Overall, the take-home message from the Bell et al., study is not good news. For the best part of a century, surgery (and other interventional disciplines in medicine) have relied on repeated practice of surgical skills *in the operating room* for training the next generation of clinicians. Reduced work hours and changing work practices have caused a reduction in clinical and operative exposure during residency with a consequent requirement for new approaches to training. The same is true for other procedure based disciplines such as cardiology, radiology and gastroenterology. Ironically, the changing work practices that to some extent have caused the problems faced by surgical training also appear to offer a viable solution.

Trainees have diminishing opportunities to acquire their skills in the operating room and the opportunities that do remain must be used optimally. The argument should now move on from 'should we train open procedure skills outside the operating room' to 'how should we optimally train open procedure skills outside the operating room'? The operating room must change from being a basic skills learning environment for trainees to a finishing school where procedural skills are integrated and refined, and procedural wisdom is acquired from the master clinician before progressing into independent practice.

### Simulation Training

Satava<sup>11</sup> suggested an alternative strategy to acquire surgical skills that would minimise risk to patients particularly during the early part of the learning process, namely virtual reality (VR) simulation. However, Medicine has long held to the belief that surgical skills can only be learned whilst working on real patients. Other high-risk, high-technical skills sectors for example the aviation, nuclear, military and space sectors have developed an approach to learning practical skills based on surrogate model training, which was developed by Thorndike and Woodworth in the early 20th century<sup>12</sup>. They proposed that what individuals learned in one context could be transferred to another sharing similar characteristics. By natural progression, VR simulation training is the late 20th century's adaption of that earlier training concept.

Simulations and technology enhanced learning (or TEL) have been used in healthcare training for decades but heightened awareness of patient safety and training efficacy forced a re-examination of their use. The Department of Health UK proposed that the first time a procedure is performed by a healthcare trainee it should not be on a real patient.<sup>13</sup> They have recommended that technologies such as simulation and e-learning (i.e., TEL) should be harnessed to better prepare the trainee for more effective and safer healthcare. Although there has been considerable investment in TEL training the same variability in the approach to training also exists in skills laboratory training, largely relying on repeated practice for skill acquisition. However, simulation based training when optimally applied, relies on *deliberate* practice,<sup>14</sup> meaning that the trainee learns what to do and what not to do with the appropriate instruments while also receiving formative feedback on their performance preferably in real

time.<sup>15</sup> Used optimally, simulation based training should ideally require the trainees to train until they demonstrate a quantitatively defined performance level which is benchmarked on experienced and proficient practitioners; this is the essence of proficiency-based progression (PBP).<sup>16 17</sup>

Simulation training affords the opportunity for the trainee to rehearse their skills in a safe environment with no risk to patients. It allows the trainee to rehearse procedural performance and it also gives them proximate performance feedback which means they can learn to use the correct devices, in the correct order, safely. This approach to training is much more flexible than traditional *in vivo* clinical training but does not compromise on the quality of knowledge and skill that a trainee acquires as this is benchmarked and training is not completed until this knowledge and skill level have been unambiguously demonstrated. This benchmarked approach to training, PBP, produces the best training outcomes,<sup>16 18 19</sup> however the studies validating it have mostly been in surgery, in single educational sites and with small trainee numbers.<sup>20</sup>

Training on simulation that currently exists in the health services and medical educational institutions around the world is mainly used as a training experience that is guided by local practices and expertise rather than a national, coordinated, curricular approach. In contrast, PBP training is an approach that utilises trainer-configured TEL platforms to deliver a standardized training experience which affords a trainee the opportunity to learn the clinical context, procedure performance sequence, the correct instruments and how they are appropriately used and then integrate these different aspects of learning on a simulation platform which allows them to rehearse and sequence their performance. This approach also provides the opportunity for them to engage in deliberate practice<sup>14</sup> and receive proximate performance feedback whilst rehearsing performance, thus facilitating learning.<sup>17</sup> Training is only completed when a quantitatively defined performance level is attained. This allows trainees to advance at different rates but ALL will have demonstrated the same performance level BEFORE progression. As benchmarking is defined on the objectively assessed performance of experienced and proficient practitioners this approach also increases the overall performance level of trainees. At the same time PBP training with TEL reduces performance variability between trainees, thus increasing the quality and safety of treatments.

### **What are metrics?**

Based on the task analysis process outlined above, the units of performance that have been identified (and validated) as integral to skilled task performance are the metric units of task execution. This means that these performance units should be used to define and shape the configuration of any simulation developed to train skilled task performance. Metric units must be unambiguously defined so that they can be scored as occurring or not occurring. These metric units should capture the essence of procedure performance and might include the steps that the procedure should be performed in, the instruments used and what should be done with them. Crucially, the metrics should also describe for each procedure step what should not be done thus characterising performance that deviates from optimal performance (or errors).<sup>21</sup> Metric errors are some of the most important performance units for simulation based training.<sup>17</sup> Training should concentrate on what should be done and the order in which it should be done, but it should also target performance errors for at least reduction, preferably elimination. This means that operational definitions of performance units or metrics need to be unambiguous. Metrics thus define how the simulation should be characterised and performed by the trainee and must afford the opportunity for meaningful performance assessment.

## Evidence Based Training

Clinically effective and safer patient care will only be achieved with an outcome based rather than process-based approach to education and training across the entire healthcare spectrum. In prospective, randomized and blinded clinical studies it was found that a PBP and outcome based rather than process based training was associated with a 10% - 58% faster operative performance and between 30% and 83% fewer objectively assessed intra-operative errors.<sup>16 18 19 22-24</sup> Although much of the evidence to date provided by us and others relates to surgery, it is likely that such improvements will also be realised across other technical and non-technical skills. In particular, this will apply to critical communication, diagnostic and drug prescribing skills fundamental to the practice of medicine and healthcare in the community as well as in the hospital.

Amongst the medical community there appears to be no problem accepting that a PBP training methodology leads to improved intra-operative performance and 'skill'. There is considerably more debate about whether improved intra-operative performance and 'skill' leads to better patient outcomes, i.e., reduced morbidity and mortality. A study by Birkmeyer et. al.,<sup>25</sup> goes some way to answer this question. Very experienced surgeons were objectively assessed by their peers. On the basis of this performance surgeons were banded into four quartiles e.g., worst performing, two middle quartiles and best performing surgeons. The outcomes of procedures they subsequently performed were then followed prospectively and morbidity and mortality data collected for the procedures they performed between 2006 – 2012 were assessed. They showed that surgeons assessed as performing in the 4<sup>th</sup> Quartile (i.e., best and most skilled) had significantly lower morbidity and mortality than those surgeons assessed as performing in the 1<sup>st</sup> (i.e., worst and least skilled). These differences ranged from 52% for rates of re-operation to 81% differences in mortality.

## Funding Model

Anaesthesiologists at Harvard affiliated hospitals were charged lower malpractice premiums by CRICO (captive Harvard insurer) on condition that they had successfully completed training at the Centre for Medical Simulation in Boston.

Specifically, the "outcomes based" training methodology used at ASSERT has been shown to result in

- 10% to 58% faster operative performance, which enables more productive use of facilities, specialist staff and reduced associated costs.
- 30% to 83% fewer objectively assessed intra-operative errors which enables reduction of risk of complications and reduced associated costs.

By way of example, two specific areas where the ASSERT approach could potentially play a role include:

1. **Day Cases:** Hospitals are treating more patients, including those undergoing operations, on a day-care basis -- up from 314,971 in 2001 to 857,596 in 2010. This is not just cost effective (hysterectomy can be done on a day-case basis for €2,618 vis a vis €6,748 once the patient has a stay in hospital), but it can reduce the risk of patient complications, like hospital infection, leading to further substantial cost saving.

The HSE has a "basket" of 24 procedures that can be carried out without admitting a patient to hospital. The ASSERT approach will ensure that healthcare professionals are trained to proficiency in each of these 24 procedures to meet the rigorous level of

care under demanding timelines required for day cases, with consequent savings in time and costs.

- Hip Arthroplasty:** The July 2014 HIQA “Health Technology Assessment of Scheduled procedures”<sup>26</sup> reported an annual national cost of elective hip arthroplasty in Ireland of €37.3 million, with an average weighted cost per case of €11,403. Demand for this procedure will increase due to changing demographics and the cost per “episode of care” will also increase due to the increasing incidence of obesity. Based on our work, one could reasonably project the effect of a national evidence-based training programme in hip arthroplasty would decrease the number of intraoperative errors by > 40% and lead to a shorter duration of surgery (more efficient surgical performance). A conservative estimate of the resultant cost savings of 20% would result in an annual saving to the Irish Exchequer of c.€7.5m.

Costs for hip fracture in the over 65s is currently estimated at €600 million,<sup>27</sup> our work would deliver a saving of an estimated €180 million and projected savings of €300 million in 2020 and €700 million by 2030. It should be noted that the training methodology used at ASSERT aligns perfectly with the Medical Council’s “roadmap in safeguarding standards and fostering improvement 2015-2020” to “foster an outcome-based approach to medical education, training and lifelong learning in Ireland”. We have confirmed this excellent alignment in our meetings with the MCI’s leadership.

Clearly, the implementation of evidence based training (and maintenance of competence) will require time and investment. We propose that the skills and domains which disproportionately account for tragic and costly claims of €1.16 billion in clinical claims to the State Claims Agency are those to which the approach is first applied. This will mitigate a set of current and substantial clinical risks within Irish Healthcare and the resultant savings will offset implementation costs. Furthermore, much of the infrastructure and human capital to implement evidence based training already exists in the form of the accredited training bodies, the hospitals and primary care centres, and ASSERT itself.

The Irish Healthcare Service must respond to very significant increases in demand driven by an ageing and changing population, a significant growth in the incident of chronic illness, new health technologies as well as a training/education for medical professionals that is outcome driven. The Medical Council’s “Doctors Education, Training and Lifelong Learning in 21<sup>st</sup> Century Ireland” states that “a robust system of medical education training and lifelong learning, which effectively contributes to a strong health system for the benefit of patients, must be properly resourced and supported at a political level”. The evidence based and benchmarked approach adopted at ASSERT is a key part of that support.

## **Conclusions**

Fundamentally, training in and maintenance of competence in healthcare must consistently deliver safe and effective practice in a manner, which is practicable and cost effective. Evidence based training such as we have outlined (and implemented internationally) is now feasible in the Irish setting. It will depend of the establishment of clear national policy driven goals for the performance of health professionals. Much of the organisational and regulatory infrastructure already exists within the universities, healthcare credentialing and training bodies and state agencies. The timeframe across which the Committee’s recommendations will be implemented (10 years) is more than sufficient to realise the clinical (patient outcome and safety) and financial benefits of approach we are proposing in this submission.

Briefly,

- i) Training should offer some guarantee of the performance level that the graduating trainee is able to consistently demonstrate.
- ii) These performance benchmarks must be derived from clinically meaningful sources. These proficiency benchmarks will be derived from context specific healthcare practitioner's performances.
- iii) We have demonstrated that the form of outcome based training described above results in superior performance, 30% - 83% reduction in errors<sup>16 18 19 22 28</sup> and 17-58% reduced operating times compared to the existing standard approach.

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<https://www.ucc.ie/en/assert/>

**Professor Anthony G. Gallagher**

**On behalf of: - Professor Paul C. Neary** (Surgery, Tallaght & TCD), **Professor George C. Shorten** (Anaesthesia, CUH & UCC), **Dr. Peter P. Kearney** (Cardiology, CUH & UCC), **Dr. Patrick Henn** (Medical Education, UCC), **Professor Henry P. Redmond** (Surgery, CUH & UCC), **Angela Crowley** (ASSERT, UCC)

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## Association of Occupational Therapists of Ireland

***“Although no single group of professionals holds the key to the future of the health and social care system, it is arguable that one has more influence than most. It is not doctors, not nurses, not even social workers – but occupational therapists, or OTs.”<sup>104</sup>***

David Brindle, Public Services Editor for The Guardian Newspaper, outlined in 2015 how occupational therapists are 'Punching above their weight'. In the same article Richard Humphries, Assistant Director at the King's Fund Health and Care Think-tank noted: *“If you talk about care closer to home, and reducing people’s need for formal health and care services, then OTs are right on the front line. They may be only a tiny percentage of the health and care workforce, but they punch well above their weight in terms of their impact on people’s lives.”*

The World Federation of Occupational Therapists (WFOT) defines occupational therapy as *“a client-centred health profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement.”<sup>105</sup>*

Occupational Therapists help “people to do the everyday things that they want to do and need to do when faced with illness, injury, disability or challenging life events”<sup>106</sup> in their work across the full life span in all areas of physical and sensory, intellectual and psychosocial disability to maximise the potential for individuals in their daily lives.

The AOTI is the professional body for occupational therapists in the Republic of Ireland. Historically occupational therapy has been historically significantly under resourced in Ireland. The AOTI is concerned about the significant shortfall in the recommended number of occupational therapists in Ireland. The latter has a significant impact on the quality of care received by service users, including delayed discharge, greater dependence on in-patient services and the loss of the valuable outcomes to individuals including engagement in meaningful occupation / activity, greater independence, lifestyle re-design, recovery support and life skill acquisition.

### Recommendations

Occupational Therapy staffing for all services including those outlined below on pages 3 – 7.

Specific ***Recommendations for Action*** are outlined below.

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<sup>104</sup> David Brindle, The Guardian Newspaper, 'Punching above their weight': the impact of occupational therapists, 27th January 2015 <http://www.theguardian.com/social-care-network/2015/jan/27/impact-of-occupational-therapists>

<sup>105</sup> WFOT, 2012

<http://www.wfot.org/aboutus/aboutoccupationaltherapy/definitionofoccupationaltherapy.aspx>

<sup>106</sup> The Association of Occupational Therapists of Ireland, 2016.

<https://www.aoti.ie/page.aspx?contentid=51>

## Promoting Independence

***Occupational therapists are experts in the interaction between the person, occupational performance, and the social, cultural and physical environment to optimise inclusion and participation.***<sup>107</sup>

Research demonstrates that occupational therapy improves physical health, mental health, social well-being and life satisfaction<sup>108</sup> improves the quality of life, mood and health status of both patients and caregivers<sup>109</sup> and improves functional mobility, self care and home management activities.<sup>110</sup>

The AOTI supports the development and roll out of self management programmes for patients with chronic conditions. Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with the medical management, role management and emotional management of their conditions.<sup>111</sup>

As experts in enabling occupation; occupational therapists are ideally qualified to address the physical, cognitive, psychosocial, psychological performance and environmental aspects of self management issues. The use of adaptation and negotiation and the development of an adapted / new role facilitate the reestablishment of the patient's life roles and engagement in society.

## Universal Design

***Occupational therapist assesses the person, their environment and their everyday occupations and how the interplay of all three elements influences their function.***

The AOTI acknowledges and supports *“the principles of universal design as a prerequisite for participation and inclusion in society. Universal design is a strategic approach to planning and design for human diversity, social inclusion and equality, defined as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.”*<sup>112</sup>

Products, buildings and exterior spaces should be designed to be usable by all people to the greatest extent.

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<sup>107</sup> World Federation of Occupational Therapists (WFOT), Position Statement on Universal Design. (2012)

<sup>108</sup> Clarke Florence et al., June 2011. “Effectiveness of a lifestyle intervention in promoting the well-being of independently living older people: results of the Well Elderly 2 Randomised Controlled Trial”, J Epidemiologic Community Health 2012;66:782-790 doi:10.1136/jech.2009.099754  
<http://jech.bmj.com/content/early/2011/06/01/jech.2009.099754.abstract>

<sup>109</sup> Graff M., et al (2007). “Effects of community occupational therapy on quality of life, mood and health status in dementia patients and their caregivers: a randomized controlled trial”, The Journals of Gerontology Series A: Biological Sciences and Medical Sciences 62: 1002-1009.Graff et al. 2007

<sup>110</sup> AOTA 2012, <http://www.aota.com>

<sup>111</sup> Institute of Medicine (IOM). Priority areas for national action: transforming health care quality. Adams K, Corrigan JM, eds. Washington (DC): National Academies Press (US), 2003.

<sup>112</sup> Connell, B.R., et al The principles of universal design (1997) NC State University, The Center for Universal Design, an initiative of the College of Design. Version 2.0 4/1/97. Cited by WFOT, Position Statement on Universal Design. (2012)

## Falls

***“In a randomised controlled trial among elderly people with visual impairment an occupational therapy based home safety programme was found to be the most effective programme in reducing falls among the participants. The programme was home based and focussed on home environment modification and behaviour change.”***<sup>113</sup>

Occupational therapy practitioners conduct falls risk assessments and environmental / safety / hazard risk assessments which are effective in decreasing falls in older people<sup>114 115</sup> thus reducing the risk fractures and consequently is effective in increasing functional ability,<sup>116 117 118</sup> reducing risk of falls<sup>119 120 121</sup> and reducing the risk of early readmission.<sup>122</sup>

The NICE UK guidelines on falls assessment and prevention<sup>123</sup> states that: *‘older people who have received treatment in hospital following a fall should be offered a home hazard assessment and safety interventions/modifications by a suitably trained healthcare professional’.*

Such assessments are part of the occupational therapists remit and research<sup>124</sup> concluded that a home assessment by an Occupational Therapist targeted at environmental hazards reduce the risk of falls can prevent falls among older persons at increased risk.

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<sup>113</sup> Campbell, A. J., (2005). Randomised controlled trial of prevention of falls in people aged >75 with severe visual impairment: the VIP trial. *BMJ*. 331, 817 et al cited by Stapleton, T., Swanton, T. Falls and Fractures Prevention, 2007, cited in Health Service Executive, Department of Health and Children (2008); ‘Strategy to Prevent Falls and Fractures in Ireland’s Ageing Population’. [http://www.hse.ie/eng/services/publications/olderpeople/Strategy to Prevent Falls and Fractures in Ireland%E2%80%99s Ageing Population - Full report.pdf](http://www.hse.ie/eng/services/publications/olderpeople/Strategy%20to%20Prevent%20Falls%20and%20Fractures%20in%20Ireland%E2%80%99s%20Ageing%20Population%20-%20Full%20report.pdf)

<sup>114</sup> Gillespie, L.D. et al (2003). Interventions for preventing falls in elderly people. *The Cochrane Database of Systematic Reviews*. 2003, Issue 4. Art. No.:CD000340. DOI: 10.1002/14651858.CD000340

<sup>115</sup> Close, J., et al (1999). “Prevention of falls in the elderly trial (PROFET): a randomised controlled trial”. *The Lancet*. 353, 93-97

<sup>116</sup> Cameron, I. et al (2000). N Hip protectors improve falls self-efficacy”, *Age Ageing* 29: 57-62.

<sup>117</sup> Hart, D., et al (1990). Locomotor disability in very elderly people: value of a programme for screening and provision of aids for daily living”, *British Medical Journal* 301: 216-220.Hart et al. 1990

<sup>118</sup> Liddle, J., et al (1996). “Can occupational therapy intervention play a part in maintaining independence and quality of life in older people? A randomised controlled” trial”, *Australian and New Zealand Journal of Public Health* 20: 574-578.Liddle et al. 1996

<sup>119</sup> Cumming, R.G., et al, (1999). “Home Visits by an occupational therapist for assessment and modification of environmental hazards: a randomised trial of falls prevention.” *Journal of the American Geriatrics Society*. 1397-1402.

<sup>120</sup> Pardessus, V., et al, (2002). “Benefits of home visits for falls and autonomy in the elderly: A randomized trial study”. *American Journal of Physical Medicine and Rehabilitation*, 81, 247-252.

<http://dx.doi.org/10.1097/00002060-200204000-00002> [Article] [PubMed]

<sup>121</sup> Gitlin, L., et al, (2001). “A randomised controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia”, *Gerontologist* 41: 4-14.

<sup>122</sup> Cornelissen, H. (2015), cited in National Clinical Programme for Trauma and Orthopaedic Surgery, Model of Care for Trauma and Orthopaedic Surgery, HSE, RCSI, IITOS. 2015.

<sup>123</sup> National Institute for Clinical Excellence (NICE), Falls the assessment and prevention of falls in older people. Clinical Guideline 21, November 2004.

<sup>124</sup> See 19 above

## Acute Hospitals

***“Because of the critical challenges facing the NHS and social care – the ageing population, the need to keep people out of costly hospital beds and care homes, the imperative to integrate services – occupational therapy has the potential to play a decisive part in ensuring the survival of the system deep into the 21st century.”<sup>125</sup>***

Occupational therapists play a critical role in the assessment and treatment of patients in Emergency Departments and acute hospital settings.

Once the patient is medically cleared for discharge the occupational therapist is the primary therapists to determine if the patient is functionally suitable for home or not. If the latter is the case the occupational therapist determines what the most suitable discharge location should be and the levels of support required.

There is a strong evidence base that supports investment in multi-disciplinary teams (MDTs) to reduce lengths of stay. Research highlights the trend in reduced ‘index length of stay (7.3 days vs. 7.8 days)’ for patients treated by a full MDT in acute care.<sup>126</sup>

Mudge also reports reduced mortality (6.4 to 3.9%), less functional decline of the patients in hospital and improved patients’ ratings of their health status.

## Therapy Led Clinics

***Therapists are improving patient outcomes, reducing costs and waiting times by altering care pathways through therapist led clinics for assessment and treatment of hand injuries.*<sup>127</sup>**

Over the past decade specialist occupational therapists working as hand therapist have facilitated the development of Extended Scope Practitioners (ESP) clinics within the UK and Ireland. Review of the literature<sup>128 129 130 131 132 133 134</sup> on ESP in the area of hand therapy

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<sup>125</sup> Brindle, see 1 above

<sup>126</sup> Mudge, A. et al, (2006). Controlled trial of multidisciplinary care teams for acutely ill medical inpatients: enhanced multidisciplinary care. *Internal Medicine Journal*, 36:558-563.

<sup>127</sup> Katherine Rundus, 2012. The Winston Churchill Memorial Trust of Australia.

[https://www.churchilltrust.com.au/.../Katherine\\_Rundus\\_Fellowship\\_Report\\_2012.pdf](https://www.churchilltrust.com.au/.../Katherine_Rundus_Fellowship_Report_2012.pdf)

<sup>128</sup> Hand Therapist led management of mallet Injury: Southampton University Hospital (Katsoulis, et al 2005)

<sup>129</sup> Extended scope Hand Therapist led acute traumatic wrist injury clinic: St Thomas Hospital (Branstiter et al 2010)

<sup>130</sup> The Introduction of Practitioner-led Hand Clinics in South Manchester, 2000 *Hand Therapy* 06/2001; 6(2):41-44.

<sup>131</sup> Lee- Rose et al, (2009). Development and implementation of a hand therapy extended scope diagnostic clinic for both elective and trauma hand conditions to enhance patient care. Guy’s and St Thomas’s NHS Foundation Trust.

<sup>132</sup> Warick, D., Belward, P., (2004) Hand Therapist Carpal Tunnel clinic. *British Journal of Hand Therapy*, 9 (1).

<sup>133</sup> Innovation in practice: One-stop Carpal Tunnel Clinic: Imperial College Healthcare NHS Trust (presented at the International Federation of Societies for Hand Therapy (IFSHT) 8th Triennial Congress Orlando 2010.

identifies a series of clinical audits and research that indicate that ESP clinics have the potential to improve the patient pathway by providing earlier access to a specialist opinion for a diagnosis and management of both trauma and elective hand conditions thereby improving service delivery.<sup>135</sup>

### **Facilitating Earlier Discharges and Reducing Readmissions**

The Occupational Therapist plays a key role in the safe and successful discharge of patients and reduces length of stay within the acute setting and facilitates early discharge.<sup>136</sup>

### **Frail Elderly**

AOTI supports initiatives such as the Healthcare Improvement Scotland<sup>137</sup> initiative to improve the identification and management of frailty. This report focuses on work to identify frailty and ensure rapid comprehensive geriatric assessment (CGA) in four NHS boards in Scotland. Occupational therapy was identified as a key to improving “the flow of patients through the hospital”.

In Ireland, occupational therapists have been appointed with excellent outcomes in several locations to Frail Elderly teams. AOTI recommends replicating this model across all acute care hospitals.

### **Seating & Positioning**

Seating, posture management, and wheeled mobility are a right for all. Currently there is considerable shortage of occupational therapists in all settings to provide this service. There is inequity in service provision, funding structures and access to services.

Adequately resourced occupational therapy services should be provided to assist with the client journey through every stage from identifying need to provision of seating and posture systems. Patients should receive the right equipment at the right time in the right place from the right clinician regardless of their address.

### **Nursing Home Residents / Extended Care Facilities**

Residents in Nursing Homes and Extended Care Facilities in Ireland do not have automatic access to occupational therapists. The HSE does not employ occupational therapists in all of its own facilities despite HIQA and other Guidelines.

Occupational therapy promotes independent living the absence of such intervention increases the risk of falls in nursing home residents. “Nursing home residents have the highest risk of falls, fractures and osteoporosis, rate of hip fracture is 3-11 times greater than community dwelling.”<sup>138</sup>

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<sup>134</sup> An evaluation of the influence of practitioner-led hand clinics on rupture rates following primary tendon repair in the hand, Department of Burns and Plastic Surgery Outpatient, Wythenshawe Hospital, Southmoor Road, Wythenshawe, Manchester M23 9LT, UK. *British Journal of Plastic Surgery* (Impact Factor: 1.29). 02/2004; 57(1):45-9.

<sup>135</sup> Cornelissen, H. 2015, cited in National Clinical Programme for Trauma and Orthopaedic Surgery, Model of Care for Trauma and Orthopaedic Surgery, HSE, RCSI, IITOS. July 2015.

<sup>136</sup> AOTA, (2012). <http://www.aota.org/>

<sup>137</sup> Robertson, H., 2014. Think Frailty Improving the identification and management of frailty; A case study report of innovation on four acute sites in NHSScotland. <http://www.healthcareimprovementscotland.org/>

<sup>138</sup> American Geriatrics Society, British Geriatrics Society and American Academy of Orthopaedic Surgeons Panel on Falls Prevention (2001) *Journal of the American Geriatrics Society*, 49, pp. 664-672.

## Mental Health

Numbers of occupational therapists working in the mental health service are not at the recommended per population levels and service user access to Occupational Therapy is inequitable throughout the country. In adult community mental health teams there are very significant gaps with only 42% of the minimum staffing level of occupational therapists recommended by *A Vision for Change* in post and only 28% of the higher staffing level occupational therapists in post on January 1st, 2010.<sup>139</sup>

## Paediatrics

Policies and practices between the Department of Health, Education, the Environment and Children and Youth Affairs are inconsistent in relation to services for children. The HSE is working towards a needs-led model of intervention, in which children receive services based on their presenting needs, rather than based on their diagnosis. The Department of Education continues to require diagnoses in order to obtain resources for children in education.

The Assessment of Need (AON) process, as required under The Disability Act, places additional pressures on therapists to provide assessments within a limited timeframe. This process leads therapists to highlight needs in children which cannot be addressed immediately. Children referred through the AON process are prioritised for assessment over other children due to the legal obligation to see them within a strict timeframe.

There is an excessive focus on assessment rather than intervention. Determining the health needs of children is difficult to ascertain and not consistently measured across Community Health Organisations (CHOs). The AON simply highlights if a child meets the criteria for a list of diagnoses. There is a duty of care to meet the needs once they are highlighted however this does not occur in all cases under the current system resulting in parents privately funding the required intervention.

There is an over-emphasis on quantitative outcomes (eg. how many clients have been seen within what time frame etc.) and no qualitative drive for therapists to provide a quality service with measured outcomes for children.

In May 2016<sup>140</sup>, there were 2,159 children on waiting lists for Occupational Therapy in the HSE (O'Regan, 2016). Children continue to wait long after the recommended times to access occupational therapists in the community.

Inequitable geographical service provision is clearly evident as some counties have established Progressing Disability Services whilst others have not. Meanwhile, Tusla the

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<sup>139</sup> Boland, L., et al (2010). Occupational therapy staffing levels in mental health services in Ireland. Dublin: AOTI Mental Health Advisory Group. cited in Association of Occupational Therapists of Ireland, Submission to: A Vision for Change Independent Monitoring Group February 2012

<sup>140</sup> O'Regan, M., 29/05/2016. Independent Newspaper.

<http://www.independent.ie/irish-news/health/over-2000-underfives-on-therapy-waiting-list-34754836.html>

Child and Family Agency, in a workforce of 4000 staff, employs one occupational therapist nationally (Co. Galway).<sup>141</sup>

There are currently six paediatric acute and sub-acute rehabilitative beds allocated for four days per week nationally. Consequently children remain in the acute system with limited access to therapeutic service

### Recommendations for Action:

Strategic	
General	
1	Ethical leadership and management of all health service resources (human, capital, non-pay) - honesty, fairness, conscientiousness, excellence. <sup>142</sup>
2	Access to services within a reasonable time frame for : <ul style="list-style-type: none"> <li>• an emergency</li> <li>• a diagnostic investigation and</li> <li>• treatment of a long term condition</li> </ul>
3	Adopting the World Health Organisation definition of health and orienting our health service to assist with all aspects of this not only the absence of disease element.
4	The establishment of a Health IT system – Electronic Patient Record (EPR) with a Unique Patient Identifier (UPI).
5	Promote greater implementation of Integrate Care Pathways (ICPs).
6	Need to reinstate the Therapy Representative Position in the Department of Health to advance therapy professions. Currently more than one position for Nursing and none for the 36+ professions represented by the Health and Social Care Professional Alliance (HSCPA).
7	Create a Therapy Professions Representative in the HSE.
8	Reinstate HSCP involvement in the Clinical Care programme structure in the HSE. The HSCP grouping was sidelined, without consultation, when the HSE Reformed the Programme Structure in 2015.
9	Review Task Allocation – According to the OECD “Approx 77% of physicians, 79% of nurses and 83% of other occupations “report being over-skilled for some of their tasks, suggesting a waste in human capital”.
	Establish what aspects of a physician’s workload could be assigned to occupational therapists to free up physicians and surgeons doing only those tasks which they are highly specialist in.
10	Design and delivery of specialist services must be informed by ongoing research to monitor best practice. Ensure: <ul style="list-style-type: none"> <li>• Ongoing research with application to practise of evidence based interventions.</li> <li>• Protected time for research</li> <li>• Career opportunities for qualified clinicians in Research</li> <li>• Clinical academic positions in University Hospitals.</li> </ul>
11	Develop partnerships with academia to ensure that an evidence-based approach is adopted.

<sup>141</sup>Tusla, 2016. <http://www.tusla.ie/>

<sup>142</sup> Ho & Pinney, 2016

12	Switch emphasis from specialist physicians to generalists. The OECD Average for 2015 has 34% of physicians categorised as generalists (66% Specialists).
13	Increase focus on pre-operative assessment in advance of elective surgery
14	Eliminate top heavy structure in the HSE. New Hospital groups have created additional duplicate administrative posts. Unacceptable when there are insufficient front line clinicians delivering the service.
15	Reinstate clinical front line posts that were lost in the recession (some services lost up to 50% of their staffing on March 29 <sup>th</sup> 2009 and have not been backfilled).
16	Utilise census data for planning

	<b>Strategic</b>
	<b>Occupational Therapy</b>
1	Need to undertake a gap analysis on occupational therapy input into multidisciplinary teams. Currently the majority of acute hospitals / PCCC / Paediatric / Mental Health teams have considerably shortage of occupational therapists.
2	Review of the current grading structure in the profession.
3	Ensure equity on grading and remit as current inequities based on local arrangements prevail
4	Establish Clinical Specialist Occupational Therapy positions as is currently happening for Clinical Nurse Specialists.
5	Roll out Therapy -Led clinics in line with International Evidence Based Best Practice (EBBP).
6	Provide funding for occupational therapists in Emergency Departments and High Dependency / Intensive Care Units.
7	Protected time for education and clinical supervision by a more experienced / specialist occupational therapist.
8	Protected funding streams similar to that for physician and nurse continuing professional development.
9	<b><i>Multiple examples of best practice – restricted by word count – happy to provide.</i></b>

	<b>Integrated Primary and Community Care</b>
1	Establishment of a central referral, coordination and evaluation system – eliminate local restrictive practises which restrict seamless care.
2	Establish and promote a system support for self-management in conjunction with hospital based clinicians, GPs and PCCC based clinicians.
3	Establishment of Regional Seating Clinics staffed by clinical specialist occupational therapists to guide prescription and research into evidence based best practise guidelines.
4	Input and guidance from all stakeholders, clients, families, therapists and disability organisations to shape and make policy changes regarding the right to access to seating, posture care and wheeled mobility for all.
5	Establish Therapy Director positions at regional level similar to nursing and medicine.
6	Establish Clinical Integrate Care Pathways between Acute Hospital and PCCC services

	Funding Model
1	Allocate funding for services based on the Clinical Care Programmes Model of Care Documents.
2	Undertake a cost benefit analysis of the National Recruitment Service (NRS) in Manorhamilton and reinstate the practice of HSE services recruiting their own staff.
3	Promote Home Care Packages which should be reviewed by occupational therapists to determine if hours need to be decreased / increased.
4	Reinstate the Bacon Fund for all occupational therapists (Student Training).
5	Medical cards for individuals with lifelong rare genetic disorders.
6	Allocate funding for training for occupational therapists prescribing / issuing adaptive equipment and wheeled mobility. It should be employer funded and similar to current training for CPR.
7	Focus on Vocation Rehabilitation to return injured employees to work. Advanced system in Australia.

**Submitted By:**

Helen Cornelissen  
On behalf of The AOTI

<https://www.aoti.ie/>

## Asthma Society of Ireland (ASI)

- ✓ **470,000 people in Ireland have asthma**
- ✓ **Ireland has the fourth highest prevalence of asthma in the world**
- ✓ **60% of people in Ireland have uncontrolled asthma, meaning they are at risk of an asthma attack**
- ✓ **Approximately 1 person dies every week in Ireland from asthma**
- ✓ **Every 26 minutes someone visits the Emergency Department because asthma**
- ✓ **90% of asthma deaths are preventable**
- ✓ **1 in every 10 adults has asthma**
- ✓ **1 in every 5 children has asthma**
- ✓ **Adults miss an average of 12 days at work each year due to asthma**
- ✓ **Children miss an average of 10 days at school each year due to asthma**
- ✓ **The economic burden of asthma in Ireland estimated €500m per year**

**The Asthma Society's mission is to save lives and improve the lives of people with asthma.**  
**While asthma cannot be cured, it can be controlled.**

**However, issues such as the high cost of preventative medication, inadequate primary care services and poor air quality mean that 60% of Irish asthmatics don't have their asthma under control.**

**As a result, someone ends up in A&E every 26 minutes and fifty people die every year from the condition.**  
**Our key recommendations would change this and dramatically improve the lives of the 470,000 Irish people with asthma and their families.**

### Key Recommendations

- 1. Expand Primary Care services to support to all people with asthma**
- 2. Address the high cost of medication in Ireland compared to other EU countries**
- 3. Improve Secondary Care services for all people with asthma**
- 4. Develop E- medicines and surveillance systems to allow us better plan and deliver services more effective**
- 5. Explore ways to fund our Health and Social care services through a progressive tax based model**

As a member of the Health Reform Alliance, Asthma Society of Ireland (ASI) are committed to helping policy makers and others move toward an improved health and social care system that can deliver affordable, quality care for all. Accordingly, some of our responses are shared with the HRA. Following the request for submissions on the future of health care in Ireland, we are advocating on behalf of people with asthma in Ireland to have equitable access to health and social care, not based on where they live or what they can afford. We

believe with proper investment, a collaborative approach, and a commitment to implementation, a ten year plan for a universal health and social care system will reduce asthma mortality and morbidity and greatly improve the quality of life for asthma patients.

**1) What are the key priorities for the inclusion in a ten year plan for the health service?**

The ten year plan should focus on what the outcomes the health and social care system should achieve by 2026. Three key areas to focus on are costs, quality of services covered and who should be covered.

Currently, people with asthma have to pay regular out of pocket payments for healthcare. The personal expenditure on asthma goes far beyond just medication and GP visits. People with asthma face other direct costs such as emergency visits, inpatient care, ambulance use, bloods and diagnostic tests. There are also a number of indirect costs people with asthma face including days lost at work or school, traveling, waiting times and loss of productivity for the caretakers of children with asthma. These costs are acting as barriers and are inhibiting people with asthma reaching their full health potential. We believe healthcare services should be free at the point of access and should be funded through general taxation.

A move towards a universal, single tiered healthcare system should mean that all Irish citizens are treated equally and equitably. The availability of services varies greatly between Irish citizens based on location and finances. Keeping in line with the National Clinical Programme for Asthma, our objectives are to improve the standard of patient care across all sectors of the health services. This includes improving asthma control, reducing exacerbations and ensuring that everyone with asthma is enrolled in a structured asthma programme. We believe services in both primary care and secondary care should be covered. Services in areas such as health promotion, protection and disease prevention should also be considered.

Target 3.8 of the Sustainable Development Goals is to achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all. Access to health and social care should be based on need and not ability to pay. We believe all citizens should be covered for health and social care in Ireland.

**2) What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?**

The current Irish healthcare system is a regrettably unique two tier, if not three tier when medical cards are included, that combines public and private services, operating mainly through the public system. The vast majority of people with asthma fail to fall into any form of universal coverage in the current health care system, despite asthma being the most common chronic illness. This means the availability of services varies greatly between Irish citizens based on location and finances. Many people with asthma from lower socioeconomic backgrounds, for example, do not have the resources, information, or finances to manage their condition properly. People with asthma have to pay regular out of pocket payments for their healthcare.

A recent member's survey found that 31% rate the care they have received from the Irish health service for their asthma as poor. Children are waiting on average up to half a year to see a respiratory consultant after a GP referral. 23% of parents decided to go private to avoid these long waiting periods and therefore have to pay unnecessary expenses to seek treatment, highlighting the dysfunctionality of our current system.

Ireland is the only European country that does not provide universal access to primary care. A move towards a universal, single tiered healthcare system should mean that all Irish citizens are treated equally and equitably. Finding the appropriate funding system will be challenging but it should mean everyone pays into one system and everyone receives equal care from that system.

### **3) What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?**

Asthma is having a huge economic burden to the health system. Currently there are over 470,000 people in Ireland living with asthma. 60% of which have uncontrolled asthma.

In 2011, it was estimated that asthma related hospital care cost the state €6.5 million and asthma specific day cases cost a total of €0.6 million. Many of these cases could have been treated more efficiently in a primary care setting. Adults miss an average of 12 days of work each year due to asthma and children miss an average of 10 days of school. Our study, Case For Change (2014)<sup>1</sup> estimated that 1.4 million work days are missed each year due to asthma related illness, costing the economy approximately €194.6 million in lost earnings. The overall economic burden of asthma in Ireland is estimated to be €500 million per year. The cost of asthma does not need to be this high.

Although asthma is a chronic disease it can be managed with proper medication and supports in place. Following the National Clinical Programme for Asthma, improvements in the standard of patient care across all sectors of the health and social services is needed to

improve asthma control and reduce asthma exacerbations. Everyone with asthma should also be enrolled in a structured asthma programme. The burden of asthma can be well managed in the primary care setting and a commitment to increasing the quality and access to primary care services will be vital in reducing the impact of asthma on the health system and the economy.

When considering the future of health in Ireland the Asthma Society believes that a great deal of focus needs to be placed on the upgrading of our Health service's ICT capabilities with greater collaboration between Government Departments and agencies. Telenursing and telemedicine practice and standards have developed internationally and there is evidence to support these approaches, particularly for people with access problems and living remotely. It is also seen more generally as an intervention that helps reduce health system costs. The crucial piece of this intervention is to ensure that there is continuity of care and that the protocols are in place to facilitate this. One such example in this space is the Asthma Society Nurse Advice line which offers tailored care over the phone free of charge to asthmatics. This type of service could be expanded to embrace developments in technology like video for instance and be replicated right across the health and social care service.

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<sup>1</sup> Asthma Society of Ireland (2014) *Case for Change, Implementing the National Clinical Programme for Asthma*

Another area where Ireland has no established system is around Real time "syndromic surveillance systems" which has become common place across Europe. These systems illustrate a partnering up of Environmental agencies and Health departments designed to aid people with respiratory conditions and allow authorities plan and react to health needs. Real time "syndromic surveillance systems" set up between GPs, Emergency Departments etc. that report diseases like asthma and link the cases to air pollution events need to become established in a coherent national network. Recording deaths is easier than establishing numbers of asthma cases. The roles of the EPA and HSE would need to be substantially increased, particularly regarding an expansion of air monitoring activities, healthcare reporting and their full coordination in order to help develop an early warning system for Ireland's at-risk population with respiratory diseases.

**4) What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care? What key barriers to achieve this, and how might they be addressed?**

WHO define integration as “ the organisation and management of health services so that people get the care they need, when they need it, in ways that are user friendly achieve, the desired results and provide value for money”.

A move towards a universal, single tiered healthcare system should mean that all Irish citizens are treated equally and equitably. The services covered can also no longer just be a free GP visit; full access to primary care teams is vital. However, universal access to services should not end there. People with asthma often require specialist consultations, lung function testing and asthma nurses. Services in areas such as health promotion, protection and disease prevention should also be considered for reaching full health potentials. An important point the Health Reform Alliance argues is that although there should be universal access to health care, the services it provides should be of equitable quality.

The evidence base for asthma is well established and much of asthma care can be delivered at primary care level, approximately 90% of people with asthma can be taken care of in primary care. Most health systems have developed a “primary level” of care whose functions include health promotion and disease prevention, managing new health complaints, as well as long term conditions and referring patients to hospital based services when appropriate. A key aim is to keep people well by providing a consistent point of care over the longer term, tailoring and coordinating care for those with multiple health care needs and supporting the patient in self education and self management. A high performing primary care system can reduce acute deterioration in people with asthma and prevent their admissions to hospital.

Not all asthma can be managed at primary care however and access to respiratory specialists is often required. However, Ireland has the lowest number of respiratory consultants in Europe after Macedonia at 1.3 per 100,000 populations while the mean for Europe is 4.4. This is extremely worrying as we also have the highest rate of respiratory hospital admissions in 32 OECD countries surveyed (Health at a Glance 2015)<sup>2</sup>. For children, there are currently only 6 respiratory paediatric centers, three children’s hospital (Tallaght, Crumlin and Temple Street) and three regional centers (University Hospital Galway, University Hospital Limerick and Cork University Hospital). Each of which should ideally have two consultants, however this is not the case. An asthma nurse is also a critical part of the model of care for asthma. Again there is an alarming shortage of them across the nation. For instance there are no paediatric asthma nurses in any of the regional centers (Cork, Galway or Limerick). There are also no dedicated paediatric lung function labs with pediatric trained lung function physiologists outside the Dublin children’s hospitals. It would be unheard of for a respiratory consultant looking after adult patients to try to do so without

appropriate lung function assessment. This is even the case with children who have severe poorly controlled asthma. There is a definite need to increase these fundamental services for people with asthma across Ireland.

**5) In your experience, what are the key roadblocks you encounter in your particular area of the health service?**

Our member's survey found that the vast majority of people with asthma are spending more than €250 per year for GP visits. As asthma is a disease that runs in families GP and medication costs can skyrocket. A recent member's survey found that 23% of parents have gone private to avoid waiting times; increasing their out of pocket payments greatly. This highlights the dysfunctionality of our current two tier system!

Asthma medication is expensive in Ireland. A survey of our members highlighted the scale of the problem with 40% of respondents saying that they don't take their medication as prescribed because of cost. On average, a person with asthma spends between €100 and €144 a month which is a huge financial drain on their income.

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<sup>2</sup> OECD (2015), *Health at a Glance 2015: OECD Indicators*, OECD Publishing, Paris

A further 25% said they travel outside of Ireland to buy their medication because they can't afford to buy it here. If we are serious about the future health needs for Ireland we need to tackle the cost of medication. The committee needs to consider the reasons why multiple medications, including asthma medication, are three to four times cheaper in other countries as apposed to Ireland.

We also know that 60% of people with asthma in Ireland do not have their asthma under control. That means that they have regular symptoms, such as coughing, wheezing, shortness of breath and chest tightness. Without regular medication these people risk worsening symptoms potentially progressing to an asthma attack, hospitalisation and even death. Cost should not be a barrier to health and people with asthma deserve better.

**6) How would you ensure buy-in from health care professionals to progress towards an integrated health care model?**

This is a difficult question for a patient group to answer fully. However, the Asthma Society has a strong relationship with the Health Care Professional community across many of its Health Promotion services. The majority of these programmes have been developed to plug gaps in the primary and secondary care system. As such, our interactions with Health Care

Professionals suggest strongly that Health Care Professionals are open and willing to embrace integrated care provided it is properly resourced and planned. As stated previously 90 per cent of people with asthma can be treated and managed well at primary care level. However, for instance the lack of a new GP contract is a major block on the role out of a structured annual review for everyone with asthma as envisaged in the National Clinical Programme for Asthma agreed by the HSE in 2011. Until we properly fund and resource primary care services across Ireland we are going to continue to see avoidable hospital admissions and deaths as a result of asthma. It is our hope that the presence of this future health committee marks the start of a process which will engage all stakeholders including Health Care Professionals on the journey to delivering integrated care in Ireland.

**7) Are there any examples of the best practice that the Committee should consider? Please refer to any evidence you have to support this.**

With regards to best practice, Finland and Australia both have successfully implemented a model of asthma care which has reduced the burden of asthma to individuals and the state drastically<sup>1</sup>. Between 1994 and 2004, Finland implemented an effective and results-orientated asthma programme which saw reductions in hospital admissions, overall cost of up to €300 million in one year and cost per patients reduced by more than 50%. The Australian model by developing a detailed model of care, creating an implementation strategy, resourcing the model appropriately, and focusing on specific areas to obtain 'quick wins' to help sustain momentum.

The total commitment over that period, some \$97.1 million has had a huge impact in improving asthma care across Australia, a country that has a similar prevalence rate as Ireland at approximately 10% of their population (23 million people).

**8) Do you have any views on which health service funding model would be best suited to Ireland?**

The HRA, with which we concur, "believes that a universal and publicly funded health system is the most effective and financially sustainable way to provide universal access to health and social care based on need and not on ability to pay.

Universal health care describes the depth and breadth of coverage of health and social care services, ranging from health promotion, prevention, primary care, secondary care to palliative care services. Plans to introduce Universal Health Insurance have been abandoned due to unacceptable estimated costs.

A system where payment is to be according to ability would be better delivered through progressive taxation or through pay-related social insurance.<sup>3,4</sup>

**9) Please outline the specific of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating.**

To echo the submission of the HRA, “we believe in a tax funded system (for example UK, Denmark, Norway, Sweden) everyone who pays taxes contributes to financing healthcare. General revenues are generally the most equitable way to pay for care, depending on the progressivity of the taxation system. Advantages of taxation funded systems are that they have a large scope for raising resources and the potential for administrative efficiency and cost control. However, the level of funding may be subject to annual budget negotiations.

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<sup>3</sup>Wren, M.A. and Connolly, S. (2016) *Challenges in Achieving Universal Healthcare in Ireland*  
<https://www.esri.ie/pubs/BP201701.pdf>

<sup>4</sup> Health Reform Alliance (2016) *Oireachtas Submission Future of Healthcare*

Advantages of SHI systems are that they deliver an earmarked fund for healthcare, with transparency between contributions and expenditure<sup>5</sup>.

The HRA believes that the 10-year plan for the future of the health service should focus on the public system and should pragmatically deal with the system as it currently exists - a primarily tax-funded system.

It is worth exploring the merits of taking a pragmatic approach and using our current tax-based system to provide universal access. A significant amount of the Irish population currently receives free access to primary care under the medical card and GP visit cards systems. This access could be extended to cover the rest of the population. Theoretically, universal access to hospital care exists but access to private health insurance results in some groups being able to access initial specialist appointments of treatment ahead of others. The introduction of a single waiting list for elective treatments for public and private patients in public hospitals could address this<sup>5</sup>.”<sup>4</sup>

**10) What are the main entitlements that patients will be provided under your funding model?**

The Health Reform Alliance and the Asthma Society believes that “...no two countries health and social systems are the same and the extent of universality provided varies. The Alliance believes that curative, rehabilitative, long-term nursing, ancillary and prevention services as well as medical goods should be free at point of access. Services should include

- Primary care - access to all allied health team members, i.e. not limited to GP access
- Acute care, including diagnostics
- Multi-disciplinary team rehabilitation and re-ablement in acute, step-down and community settings
- Chronic disease management (including medications)
- Step-down care and community services (home care)
- Preventative care, e.g. diet, smoking, blood pressure, cholesterol, etc
- No charges at the point of access (such as 'nominal' fees for GP services) should be introduced

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<sup>5</sup> Ibid

<sup>6</sup> Wren, M.A., Connolly, S. and Cunningham, N. (2015) *An Examination of the Potential Costs of Universal Health Insurance in Ireland*. Dublin: Economic and Social Research Institute, <https://www.esri.ie/pubs/RS45.pdf>.

- Mental health services including social inclusion supports
- Long-term care

Of particular importance is the inclusion of both primary and secondary care services. For example, the roll out of free GP to all citizens and reduction in the €750 charge for inpatient stays in public hospitals will be important milestones on the road to a single tier health and social care system.<sup>7” 4</sup>

**Please provide examples of best practice, or estimated costs of such models if available.**

“Estimating the costs of different models is a complex process and depends on many variables such as the what health and social care services are to be covered, the out of pocket expenses citizens are expected to pay, the level of additional tax revenue available.

The ESRI is currently researching the costs of reforming the health system based on different models. The Trinity College Pathways project is also modelling what universal healthcare would mean in Ireland and will indicate what parts of the system need further development.

The Health Reform Alliance and the Asthma Society recommends that the committee’s decisions in relation to the proposed funding model are informed by this research.”<sup>4</sup>

<sup>7</sup> Wren, M.A., Connolly, S. and Cunningham, N. (2015) *An Examination of the Potential Costs of Universal Health Insurance in Ireland*. Dublin: Economic and Social Research Institute, <https://www.esri.ie/pubs/RS45.pdf>).

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For further information please contact:

Kevin Kelly (Advocacy and Communications Manager)

Asthma Society of Ireland

[kevin.kelly@asthma.ie](mailto:kevin.kelly@asthma.ie)

+353 (0)1 554 9212

<https://www.asthma.ie>

## Cancer Trials Ireland

Cancer Trials Ireland has a 20 year history of successfully opening and running cancer trials.

This submission focuses on cancer trials within Ireland's long-term vision for health care and health policy. It seeks a national health policy decision to mainstream cancer trails as a cancer treatment option and their inclusion in Ireland's strategy to further develop its Life Science industry.

Cancer trials provide patients with free access to new promising treatments which can only be accessed through a trial. These treatments have the potential to enhance and extend their lives. Cancer trials offer hope for thousands of patients each year and save the HSE millions of euro annually in treatment costs; the €3 million the State will invest in cancer trials in 2016 will save €6.5 million in treatment costs that year alone<sup>143</sup>.

Cancer trials also contribute millions of euro each year to the Irish economy by generating inward investment from pharmaceutical companies and international research groups. For example for every €1 its research units receive in State funding they can generate up to €3 from other sources.

Ireland has the opportunity and capability to take full advantage of the opportunities conducting cancer trials in Ireland affords patients and the wider economy.

To assist in exploiting these opportunities it is recommended that Ireland's national health policy commits to mainstreaming cancer trials in two ways.

- I. Cancer Trials should be integrated into the National Cancer Control Programme at a national policy level and promoted to all clinicians as a mainstream treatment option. Consideration of a cancer trial as an option should not be seen as a last resort or reliant on a patient's treating clinician's awareness of available cancer trials. In addition, the target for the number of people participating in cancer drugs trials should be 5%, up from the current participation rate of 3%.
- II. The opening of more cancer trials in Ireland by pharmaceutical companies and international collaborative groups should be an objective integral to Ireland's strategy to further develop its Life Science industry.

Denmark's population size is similar to Ireland's and its achievements<sup>144</sup> as a world leader in both of these areas illustrate the potential for Ireland.

Both strands of this recommended policy are interdependent. If, as part of Ireland's national health policy, cancer trials are treated as an integral part of the available cancer treatment modalities, more patients will be available to participate in trials. It will then be possible to open more trials and provide more patients with access to new promising treatments. It will be possible develop further our expertise in this area and attract more investment from pharmaceutical companies and international collaborative groups. If we can attract this investment we can open more trials, and the cycle repeats itself. This submission provides the evidence to support this recommendation. It draws on the data compiled by the independent analysis of cancer trials carried out in 2016 DKM Economic Consultants.

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<sup>143</sup> Health and Economic Impacts of Cancer Trials in Ireland (<http://www.cancertrials.ie/news-events/health-economic-impact-report-of-cancer-trials-in-ireland>)

<sup>144</sup> Start with Denmark - The Heart of Life Sciences for Research and Business. [http://www.investindk.com/~media/Files/Sheets/Life%20Sciences/Start%20With%20Denmark%202015\\_Full%20Report.ashx](http://www.investindk.com/~media/Files/Sheets/Life%20Sciences/Start%20With%20Denmark%202015_Full%20Report.ashx)

## Introduction

Cancer is a global health issue.

In 2012, there were 14.1 million new cancer cases and 8.2 million cancer-related deaths worldwide.

The World Health Organization projects that by 2035 the world could see 24 million new cancer cases and 14.5 million cancer-related deaths a year.<sup>145</sup>

The number of new cases of cancer diagnosed each year in Ireland is 20,454<sup>146</sup>. The number of people who die each year of cancer is 9,056. This is just slightly below the numbers who die of cardiovascular disease, which is currently the biggest cause of death in Ireland<sup>147</sup>.

While significant progress has been made in the fight against cancer, the Department of Health's 2015-2017 Statement of Strategy predicts that the incidences of cancer in Ireland are projected to double by 2040. It states that *“a key task in the coming years will be to work to prevent cancer occurring in the first place as far as possible and to tackle cancer early when it does occur”*.

Reflecting this commitment, the 3rd National Cancer Strategy, due to be published in 2016, is expected to include the following key elements<sup>148</sup>:

- Plan for growth in incidence, prevalence and complexity
- Resolve the gaps in clinical and allied health staffing
- Invest in molecular diagnostic and personalised medicine
- Emphasise research: infrastructure, innovation & productivity
- Foster prevention and screening
- Focus on survivorship

This submission recommends that cancer trials be mainstreamed within Ireland's national health policy and National Cancer Strategy as a central part of the available cancer treatment modalities and integral to the development of Ireland's Life Science industry. The target set within the National Cancer Strategy for the number of people participating in cancer drugs trial should be 5%, up from the current 3% participation rate.

## Background to cancer trials in Ireland

Cancer Trials Ireland was set up in 1996 and has a 20 year history of successfully opening and running cancer trials in Ireland, and latterly in Europe. It has two main objectives; (i) to open more quality and relevant cancer trials to provide patients with access to new and promising diagnostics and treatments not yet available and (ii) make Ireland a more attractive location to open cancer trials.

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<sup>145</sup> <http://www.cancer.gov/research/areas/global-health>

<sup>146</sup> National Cancer Registry Ireland.

<sup>147</sup> CSO

<sup>148</sup> Source: Presentation by Dr Jerome Coffey MD FRCPI FRCR FFRCSI, Director, National Cancer Control Programme (NCCP) to the conference Cancer Immunotherapy 2016 and beyond hosted by Cancer Trials Ireland 24<sup>th</sup> June 2016.

Since it was established in 1996, more than 15,000 patients have participated in more than 350 Cancer Trials Ireland cancer trials.

Almost all cancer treating specialists in Ireland are members of Cancer Trials Ireland.

Its cancer trials are carried out in 14 hospital based cancer trials units across the country that are supported by a central team of clinical researchers, project managers, data managers and other experts.

Cancer Trials Ireland works with global pharmaceutical companies and international collaborative research groups from around the world which generates substantial inward investment. It not only manages trials in Ireland on their behalf but also manages trials which are underway in other European countries<sup>149</sup>.

Cancer Trials Ireland has grown rapidly in recent years. The number of trials, open and in follow up, has been increasing.

During 2015, its 14 hospital based research units around the country were working on 154 trials involving 6312 patients; 66 were recruiting patients and 88 were in the follow up stage.



35% of these trials involved collaboration with cancer research groups around world and 37% involved working with international pharmaceutical companies.

### **Benefits of cancer trials**

At a broad level conducting cancer trials in Ireland delivers two benefits: (i) health and welfare benefits for patients and the wider community and (ii) economic benefits for the wider economy.

If the recommendation outlined in this submission is adopted it will pave the way to broaden the reach of these benefits.

#### *(i) Health and welfare benefits for patients and the wider community*

Cancer Trials Ireland trials provide patients with access to treatments that they would not be able to access if they were not taking part in a trial. Due to Ireland's relatively small population size, opening cancer trials in Ireland in partnership pharmaceutical companies and international research groups, is sometimes the only way that a treatment, available in other parts of Europe and the USA, can be made available to Irish patients. This is why the work of Cancer Trials Ireland and the associated research teams and their leadership around the country is critically important for so many people.

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<sup>149</sup> Examples include ENZAMET and ENZARAD & NeoAEGIS trials.

Evidence shows that cancer trials have given participants many quality-adjusted life years (QALYs<sup>150</sup>). Based on a small sample of case studies of trials<sup>151</sup> (TAILORx, Monotherapy in Untreated Melanoma, BCIRG 006, PALOMA-1) it is estimated that the health benefits of each trial (considering only the Irish patients who participated in the trials, for the period of follow-up), ranges from 6 to 16 QALYs per trial. The equivalent economic benefits of these QALYs range from €0.28 to €0.72 million per trial. Subsequent benefits, when therapies become available to the generality of patients, would be a multiple of these values.

When Irish cancer centres and patients participate in a successful trial, the treatment in question has a local familiarity and a readymade advocacy during the approval process. This means that the benefits of the diagnostic or treatment for patients and the economy can be made available more rapidly than in countries where trials are not available. For example Ireland's strong involvement in the TAILORx Trial resulted in it being the first in Europe to introduce the test, OncotypeDX<sup>152</sup>, that was the subject of the trial. Its early introduction generated a considerable return for patients in quality of life terms and the health service. It is estimated that every year the test generates an economic benefit of €1.06 million and treatment costs saving to the HSE of €0.56 million in chemotherapy costs.

#### *(ii) Economic benefits for the wider economy*

In 2016 Cancer Trials Ireland will receive from the Exchequer just over €3 million to fund resources in participating hospitals to run trials. It will leverage this investment and generate an additional €4.5 million from other sources such as the pharmaceutical industry, international research groups and granting agencies. As a direct result of its work, it will add a total of €16.5 million to Irish GDP per annum, and generate tax revenues for the Exchequer of €5.8 million per annum. Almost 200 people will be employed working on cancer trials in Ireland. Taking into account supply chain and other multipliers, this number rises to over 230.

Participating hospital-based cancer trials research units have confirmed that the grants they receive enable them to secure funding from non-Exchequer sources. One found that for every €1 in grant funding they received, it generated a further €3 in income from industry for trials.

Over the years cancer trials have also saved the HSE tens of millions of euro in treatment costs. For example as a result of the 110 patients on the TAILORx Trial who could avoid three months of chemotherapy and approximately three months recovery from the effects of chemotherapy, the HSE saved approximately €766,000 (ex VAT) because it did not have to provide these patients with chemotherapy.

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<sup>150</sup> A QALY measures every year of perfect health gained.

<sup>151</sup> Health and Economic Impacts of Cancer Trials in Ireland (<http://www.cancertrials.ie/news-events/health-economic-impact-report-of-cancer-trials-in-ireland>)

<sup>152</sup> Oncotype DX is a test which can help doctors decide if a patient would benefit from chemotherapy as part of their treatment.

Conservatively, Cancer Trials Ireland saves the HSE in the region of €6.5 million annually in cancer drugs costs. This excludes the costs of experimental drugs, avoided treatment costs (as in the case of the Oncotype DX test), and the benefits of improved health and longer lives for patients, leading to lower future healthcare costs.

By this metric alone for every €1 the Exchequer invests in cancer trials it will save more than €2 in cancer treatment costs. If the costs associated with monitoring and tests and contributions to staff are added in, the impact would be greater. By applying the findings of a UK study<sup>153</sup> to the number of people on an open trail during 2015, the savings to the HSE would be calculated at €10.7 million in that year alone.

## Summary

The evidence provided in this submission shows that opening cancer trials in Ireland and managing cancer trials in other European countries delivers many tangible benefits for patients, their families and the economy.

Cancer trials not only contribute to the well-being of patients, they contribute to Ireland's economy and intellectual capital.

The recommendation that this submission puts forward does not involve a commitment to funding more cancer trials. It involves making a national health policy decision to mainstream cancer trials as a cancer treatment option and their inclusion in Ireland's strategy to further develop its Life Science industry.

We are confident that with this national policy direction the business case for further Exchequer funding for cancer trials, given their benefits to patients, the savings they make and the inward investments they attract, coupled with Ireland's track record in this area, will be compelling.

### **Cancer Trials Ireland**

Charity No. CHY12492

60 Fitzwilliam Square Dublin 2, Ireland

Tel: +353 (0)1 6677211

info@cancertrials.ie

[www.cancertrials.ie](http://www.cancertrials.ie)

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<sup>153</sup> Liniker, E., et al., 2013, "Treatment costs associated with interventional cancer clinical trials conducted at a single UK institution over 2 years (2009–2010)", in *British Journal of Cancer* (2013) 109, 2051–2057, <http://www.ncbi.nlm.nih.gov/pubmed/24064969>.

## Care Alliance Ireland

There are approximately 187,000 Family Carers in the Republic of Ireland, made up of those individuals who provide care and support to a family member or friend with a long-term illness, disability or mental health difficulty (Central Statistics Office, 2011). Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

The focus of the Care Alliance Ireland submission to the Oireachtas Committee on the Future of Healthcare in Ireland is to highlight the integral part that Family Carers play in the Irish health system, and how vital their contribution is. It is also essential to note that Family Carers are more likely than non-carers to themselves be customers of the health system, given the higher likelihood that they will experience poorer mental, physical and emotional health compared to non-carers.

Whilst challenges abound in the establishment of a complete and well-functioning healthcare system in Ireland, two key overarching challenges experienced by Family Carers are identified and possible solutions articulated in this document. Those challenges and solutions may be summarised as:

- 1) The added cost of disability and caring, including the increased need for access to services and supports due to this higher financial impact.
- 2) The requirement for sectoral budgets to be unified to provide a single functioning and responsive health service which responds to the needs of its users in a timely fashion, thus saving money and time overall.

We are available to the Committee to give more detailed oral evidence on any aspects of our submission or on topics relating to Family Carers.

### **Introduction**

There are approximately 187,000 Family Carers in the Republic of Ireland, being those individuals who provide care and support to a family member or friend with a long-term illness, disability or mental health difficulty (Central Statistics Office, 2011). Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and other organisations who support carers as part of their response to individuals with specific conditions. The need for Family Carers to provide support to people in the home is continuing to grow both in Ireland and internationally, and will continue to do so over the coming years. A number of factors are at play, including increasing life expectancy, an ageing population, declining family size and higher rates of

labour market participation by women. Census 2011 data point to a significant increase in the number of those providing unpaid care in the home, with a particular growth in the number of older carers (Central Statistics Office, 2012). The ongoing significant increase in Family Care provision, which we expect to continue to be borne out in data from Census 2016, points to an ageing population with an overall increase in care needs.

The cost of the State providing the same level of care as that provided by Family Carers is estimated to be between €2.5 billion and €4 billion annually (Care Alliance Ireland, 2015). As government policy on community-based care strengthens, so too does the requirement for Family Carers to provide care to relatives in the home. In addition, it is clear that the primary desire of people who need care is to receive that care in their own home and community (Donnelly, O'Brien, Begley, & Brennan, 2016). One of the key challenges for health provision in Ireland going forward is to support this majority of individuals who wish to receive care from a family member in their own home, and to support that family member in their responsibilities.

However, it could be strongly argued that at present various governmental policies are in direct conflict with each other. On the one hand, the focus has been on developing supports for Family Carers with respect to the actions contained in the National Carers' Strategy (Department of Health, 2012) and the Programme for Government (Government of Ireland, 2016). On the other hand, there has been a clear priority to increase the availability of and funding for residential care via the Fair Deal Scheme, corresponding with a decrease in availability of home care supports (when accounting for demographic changes) (Care Alliance Ireland, 2016a; Donnelly et al., 2016).

Providing care can be enriching and rewarding when expectations placed on Family Carers are reasonable and adequate supports are provided. Research evidence has identified the satisfaction that Family Carers may feel in being able to support the people they care about (Brand, Barry, & Gallagher, 2016). It is, however, crucial that they are given adequate assistance to sustain them in their role. Caring can also be a source of burden and stress. Whilst care to a loved one may be willingly given, there can be costs to many aspects of the Family Carer's life, including emotional, physical, social and financial costs.

Family Carers experience significant impacts due the nature of their caring role. Family Carers are much less likely to rate themselves in good health than are non-carers (O'Sullivan, 2008), and are more likely to experience both poor

physical (O'Sullivan, 2008; Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009) and poor mental health (OECD, 2011; O'Sullivan, 2008). Recent (2015) work in the UK has found that up to 20% of Family Carers consider themselves to have a mental health condition, with 15% considering themselves to have a condition which limits basic physical activity (Tinder Foundation, 2015).

However, Family Carers are in many ways unique consumers of health services, **as they are not only "patients", but also function as carers and patient advocates** for their loved ones. As such, ensuring a robust and well-functioning health service, which takes accounts of these multi-faceted issues, is critical.

This submission focuses on articulating the key needs of Family Carers, which in many ways are unique to that cohort of individuals. This submission also articulates some of the challenges and possible solutions.

### **Key Issues for Family Carers**

#### 1) The Cost of Disability and Caring

According to research published recently, the estimated economic cost of adult disability is between 35.4% of income (or about €207 per week) and 54.5% (or €276 per week) on average (Cullinan, 2015). These figures highlight the amount of money that disabled households at median income levels need in order to have the same standard of living as a similar non-disabled household.

In multiple studies Family Carers have been identified as far more likely to experience poverty than other sectors of society (Carers UK, 2011; OECD, 2011), with the impacts of providing significant levels of care clear. Recent Irish research discovered that 64% of Family Carers to an individual with a neurological condition reported a significant fall in family income since the onset of the condition (Neurological Alliance of Ireland, 2014). There is evidence that the additional costs of caring for someone include higher waste and water charges, increased heating and lighting bills (due to the use of specialised health equipment) and the cost of specialised aids and appliances, all of which add to the financial burden.

Member organisations of Care Alliance Ireland have given us details of instances where families have been forced to use up savings and large percentages of weekly incomings to provide for such items, due to the fact that the Department of Health and HSE budgets do not provide help with such costs, or due to increased waiting lists.

## 2) Access to Vital Health Services and Supports

Family Carers act as advocates for those they care for, and often face an uphill battle to access the vital supports and services which, if available, would enable them to care for their loved one with dignity at home<sup>154</sup>. As discussed at the **beginning of this submission, Family Carers in Ireland provide an estimated €4 billion worth of care annually, significantly reducing the State's outlay in 1-to-1 care costs.** However, Family Carers are rarely trained professionals, and in order for their loved ones to remain at home (which, as discussed, is overwhelmingly the wish of the majority of people receiving care (Donnelly et al., 2016)), Family Carers need these supports to be readily available. Unfortunately, they are not always available or available at adequate levels in the current formulation of the health service.

In the case of Home Care Packages (recently the topic of a number of comprehensive research and briefing documents (Care Alliance Ireland, 2016a; Donnelly et al., 2016), it is clear that at the most basic level, investment in the scheme is not sufficient to meet current needs. The HSE spent 3% less on home **care in 2015 (€320 million) than it did in 2008 (€331 million), despite a 25%** increase in the population aged over 65 years over the same period (Donnelly et al., 2016). People are finding it increasingly difficult to access appropriate Home Care Packages for their loved ones, and there is wide disparity in relation to availability at local level. Our figures suggest that an additional resourcing of **€31m over and above current published targets would simply reach the 2011** target level of public provision of home care per person aged 65+. In order to **reach 2008 targets, an additional €72 million would be required in 2016, rising to €116m in 2019** (Care Alliance Ireland, 2016a, 2016b).

This is an illustrative example of the challenges facing Family Carers in relation to accessing services and supports. Similar examples can be found in the areas of respite, accessing suitable residential care (for loved ones with and without intellectual disability or cognitive impairments), accessing speech and language therapy, physiotherapy, occupational therapy, etc. The scope of this submission **does not allow for more detail; however, many concrete examples of carers' experiences are available from our member organisations, such as Family Carers Ireland**<sup>155</sup>.

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<sup>154</sup> These services/supports include adequate home care, respite care, aids, appliances, mental health support, etc.

<sup>155</sup> <http://familycarers.ie/about-us/carers-stories/>

### 3) Focus on Wellbeing not on Illness

As outlined above, Family Carers can experience serious health consequences arising from their caring role (O’Sullivan, 2008; Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009; Tinder Foundation, 2015). These health issues are exacerbated by a healthcare system which in practice focuses on illness rather than wellness. Many Family Carers have experienced being told that **the person they care for is not “ill” enough or “disabled” enough to avail of supports and services which would ensure they continue to live as independent a life as possible.** Often families have no choice but to wait until their loved one is debilitated in some way before they can access these supports. Moving from a focus on illness to a focus on wellness enables supports to be put in place at an earlier stage of the ageing or illness process, ensuring that small, short-term outlay translates to increased savings in the long term.

**A good example of this is highlighted in the case study of “Joan”<sup>156</sup>, an older lady who was expected to need long-term care as she was unsteady on her feet and unable to care for herself. Before entering the long-term care which her family thought was inevitable, Joan was able to access two weeks of respite and rehabilitation, and along with a small allowance of two hours of home care over five days a week, has remained happily in her own home. It is clear that the short-term expense of two weeks of respite and rehabilitation, coupled with a relatively modest allocation of home care hours (at a cost of approximately €40 per week<sup>157</sup>), has drastically improved the lives of Joan and her family, and saved the State thousands of euros by avoiding her entry into long-term care at a cost of upwards of €1000 per week<sup>158</sup>.**

In addition to the focus on wellness for the person receiving care, it is vital that any new health plan includes steps to ensure that the wellness of Family Carers is prioritised. Family Carers cannot continue to care indefinitely without access to respite, time off, appropriate health interventions, etc. A key step towards **ensuring that Family Carers’ own health and wellness needs are met is to ensure that, when rolled out nationally, the recommendations for Family Carers who**

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<sup>156</sup> This case study is included in the report entitled “‘I’d prefer to stay at home but I don’t have a choice.’ Meeting older people’s preference for care: Policy, but what about practice?” (Donnelly, O’Brien, Begley, & Brennan, 2016; p33).

<sup>157</sup> See figures in “Briefing Paper 1: Analysis of Home Care Supports Funded by the HSE 2008–2016” (Care Alliance Ireland, 2016a).

<sup>158</sup> See figures in “Nursing Homes Support Scheme Maximum Agreed Prices with Private and Voluntary Nursing Homes”, available on the HSE website and updated July 2016 (Health Service Executive, 2016b).

have been assessed as having a specific need in a Carers Needs Assessment have a right to support for that need.

An example of such a system is in place in the UK. The Care Act 2014 (Government of the United Kingdom, 2015) lays out specific criteria for assessment and eligibility for support arising from a Needs Assessment. This Act focusses on “wellbeing”, as outlined above.

## **Key Strategy Issues**

### 1) Unification of Sectoral Budgets

One of the key difficulties which Family Carers and those they care for face is the fragmented nature of funding of health services by the State. Currently, there are multiple discrete funding streams which should interact seamlessly along the journey of care for an individual; however, it is increasingly becoming clear that this is simply not the case. A person receiving care can easily become “stuck” at the interaction points, causing a disruption to their journey through the system. Care Alliance Ireland has become aware, through consultation and discussion with member organisations, of a number of these sticking points. We are aware from concrete examples of the challenges this creates for families. Not only do **these “sticking points” create tangible periods of distress and difficulty for families**, but they also put undue pressure on the various budgets.

A prime example, introduced above, is the case of Joan, taken from the report **into home care by Donnelly et. al. (2016)**. Joan’s preference was for care in her own home, which was the most economical option, and the preference of all involved; the cost was approximately €40 per week. A long-term care placement for Joan, in the absence of this modest home care, could have cost upwards of **€1000 per week. It is clear where the best budgetary use in this instance lay.**

Likewise, attention can be drawn to a recent (August 2016) individual case highlighted in the media of a woman in Co. Mayo who had been admitted to hospital with a fractured pelvis and was ready for discharge. However, funds were not available within the community care budget and so she has remained in an acute setting **for over 300 days, at a total cost of approximately €280,000** (Crawford, 2016). Discharging her with the full home care package she had been approved for would have cost **€16,000 in the same timeframe. Care Alliance Ireland** is aware of similar cases which are costing the HSE multiples of thousands from the acute health budget, yet where the individuals involved cannot be discharged into the community or into the disability sector as those

budgets cannot supply the correct support. Flexibility between sectoral budgets is crucial for a streamlined and cost-effective health service which can meet the needs of individual patients and their Family Carers. Anecdotal evidence shows that even when care recipients do enter long-term or acute hospital care, the **“carer burden” does not significantly diminish, and may in fact increase, due to** the need for support in dealing with medical staff, the need for the Family Carer to communicate information which only he/she may be able to supply.

We welcome recent moves towards the provision of home care on a statutory basis, a standalone flexible and responsive system which reflects current (and also preferred future policy) of enabling people to remain in, and receive care in, their own homes and communities. This element is crucial to a health system which truly acknowledges the contribution of older people and their Family Carers.

## 2) Funding a New System

We understand that the funding of such a new system, which ensures equal access to all regardless of ability to pay, will not be easy. However, as the possibility of people either needing care or having to provide care to a loved one increases with our increasing population age profile, it is clear that a functioning and responsive health system and related policies which patients can rely on as they age or as they develop a mental health condition or disability is crucial. This is an issue which cuts across age, gender, social class and income, and as such is best achieved via a system of increased taxation.

**A single GP visit in Ireland costs on average €50. Reports indicate that Family Carers may allow their own health to worsen due to the cost of accessing healthcare, and instead prioritise the costs of care provision. Whilst many Family Carers may hold a medical card or a GP visit card, there are many who do not. As discussed, these are individuals who may be significantly worse off than their contemporaries, both in health and financial terms, because of their caring responsibilities. One immediate recommended policy change would be to provide all full-time Family Carers with a medical card. This could be implemented at a modest enough cost. At the minimum, this cohort should be prioritised in consideration of the further expansion of free GP care. In the long term, a system of Universal Health Care, free at point of use, should be considered.**

## Conclusion

This document has outlined some of the key issues which face Family Carers and their loved ones in relation to health policy and provision in Ireland. The focus of the document has been to illustrate the vital need to include the issues which Family Carers see as concerns and which impact their role as Family Carers. It bears repeating that Family Carers contribute up to €4 billion worth of care every year – which is equivalent to about one-third of the entire HSE budget for 2016 (Health Service Executive, 2016a). Ensuring that these issues are planned for within any evolving integrated health policy is vital to the success of that plan. Without Ireland's 187,000 Family Carers, the health system would be under considerably more strain than it already is in 2016.

We are available to the committee to give more detailed oral evidence on any aspects of our submission or on topics relating to Family Carers.

<http://www.carealliance.ie/>

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## Celgene

Over the next ten years, the treatment of serious acute and chronic conditions (including those of specialist interest to Celgene, such as cancer and lifelong immune-inflammatory conditions) will be an important aspect of the services provided by the health service. Current models predict that by 2025 there will be an increase of 50% in the number of cancer cases in Ireland<sup>159</sup>. Annually, the risk of developing cancer is increasing at a rate of 1%, while the risk of dying from cancer is decreasing at a rate of 1%. Further, 86% of deaths and 77% of disease burden are now caused by chronic disease.<sup>160</sup> This picture is creating increasing pressure on the health service with a growing patient population<sup>161</sup>. A 10-year strategy for healthcare must create an environment which future-proofs against these expected health service requirements.

Commitment and action from Government will be matched with innovation and a patient-first collaborative approach from industry. Our submission focusses around two strategic areas which we believe will support the development of a 10-year plan to alleviate the current pressures on the health service; build a better and more manageable service for the future; and deliver better patient outcomes, while taking into account industry and demographic trends and future requirements.

## Recommendations

### ➤ Medicines Access

- There should be greater opportunity for **patient and clinician engagement** in the Irish medicines appraisal system to expand on current evaluations of cost effectiveness.
- The **commercial pricing of medicines must be flexible**, allowing for emerging technologies, and accommodating both large and small patient groups. Mechanisms for flexible commercial models should be considered, to ensure patients' have access to the best medicines.

### ➤ Making Medicines Work

- An end-to-end integrated approach to **helping patients make the most of medicines** (medicines optimisation) should be developed and implemented, alleviating the pressure on acute care by maximising medicines' value to patients
- Investment in the **development of a national IT system** or systems with the ability to collect real world health outcomes data to support the adoption and optimal use of medicines as well as other health care interventions.
- Establishing a **strategic engagement group** between the pharmaceutical industry and the health service to identify areas where we can improve patient outcomes, drawing on best practice in medicines introduction and use.

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<sup>159</sup> National Cancer Registry, Ireland (2014). Cancer projections for Ireland 2015-2040 .

<sup>160</sup> [http://health.gov.ie/wp-content/uploads/2014/03/tackling\\_chronic\\_disease.pdf](http://health.gov.ie/wp-content/uploads/2014/03/tackling_chronic_disease.pdf)

<sup>161</sup> National Cancer Registry Ireland (2013). Cancer in Ireland 2013: Annual report of the National Cancer Registry.

Within these recommendations we have sought to address the following questions within the calls for submission and the committee's terms of reference:

- *What are the key priorities for inclusion in a ten year plan for the health service?*
- *What actions are needed to plan for, and take account of, future demographic pressures and their impact on the health system?*
- *In your experience, what are the key roadblocks you encounter in your particular area of health?*
- *The severe pressures on the Irish health service; and the poor outcomes relative to cost.*

While the challenges are considerable, there are also huge opportunities as medical innovation continues to advance and innovative companies, such as Celgene, continue to invest in and deliver innovative treatments for patients.

## Medicines Access

Our belief is that the optimal access to medicines should be a key strategic pillar of any health service plan over the next ten years. This necessity of access will be felt across the healthcare system including in the areas of cancer and immune-inflammatory diseases where population projections and poor lifestyle factors will see a significant growth in the number of patients needing care. For example, the total number of new invasive cancer cases is expected to rise by 84% and 107% for females and males respectively by 2040<sup>162</sup>. This will create a greater demand for access to new and innovative life-saving and life-extending medicines<sup>163</sup>.

This demand for access must be met by creating an environment which enfranchises patients, payers and industry so that timely access to new medicines can be delivered and Ireland becomes a desired destination for clinical trials, delivering the best outcomes that revolutionary new therapies can provide. For instance, medicines developed for Multiple Myeloma (cancer) – several of which have been developed by Celgene – have contributed to a significant improvement in overall survival in the last 10 years<sup>164,165,166,167</sup>.

New medicines are becoming increasingly specialised to cater for more specific and rarer conditions. These positive developments, however, create challenges for the governance of medicines. Patient access to new medicines, and the associated cost, will require significant consideration as to how Ireland develops a system in which patients have access to the best available medicines where those medicines offer value.

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<sup>162</sup> National Cancer Registry, Ireland (2014). Cancer projections for Ireland 2015-2040 . Available at:

<http://www.ncri.ie/sites/ncri/files/pubs/Cancer%20projections%20for%20Ireland%202015%20-%202040.pdf>. Date accessed: March 2016

<sup>163</sup> Parkin, D.M., L. Boyd, and L.C. Walker, 16. The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010. *Br J Cancer*, 2011. 105 Suppl 2: p. S77-81

<sup>164</sup> Facon T et al. Melphalan and prednisone plus thalidomide versus melphalan and prednisone alone or reduced-intensity autologous stem cell transplantation in elderly patients with multiple myeloma (IFM 99-06): a randomised trial. *Lancet*. 2007; 370: 1209–18

<sup>165</sup> Benboubker L et al. Lenalidomide and Dexamethasone in Transplant-Ineligible Patients with Myeloma. *N Engl J Med*. 2014;371:906-17.

<sup>166</sup> Dimopoulos MA. Long-term follow-up on overall survival from the MM-009 and MM-010 phase III trials of lenalidomide plus dexamethasone in patients with relapsed or refractory multiple myeloma. *Leukemia*. 2009; 23: 2147–2152

<sup>167</sup> San Miguel J. et al. Pomalidomide plus low-dose dexamethasone versus high-dose dexamethasone alone for patients with relapsed and refractory multiple myeloma (MM-003): a randomised, open-label, phase 3 trial. *Lancet Oncol*. 2013; 14: 1055–66

## Flexible Commercial Models

**Recommendation:** *The commercial pricing of medicines must be flexible*, allowing for emerging technologies, and accommodating both large and small patient groups. Mechanisms for flexible commercial models should be considered, to ensure patients' access to the best therapies.

Flexible commercial models for the pricing of prescription medicines are being examined and debated internationally to deliver access for patients that offer value for both the payer and industry. A failure to identify and implement suitable flexible commercial models for Ireland could lead to the exclusion of groups of patients from life prolonging and enhancing treatments.

Among those nations exploring flexible commercial models is the UK, where the National Institute for Health and Care Excellence (NICE) has recently carried out an exercise in the area of Health Technology Assessment for advanced cellular therapeutics, which demonstrated that medicines with the potential to achieve a step-change in patient outcomes will likely require collaboration with Industry and innovative payment models to manage the financial risk, while allowing patient access to these therapies.

Speaking about the need to support such innovative therapies, Programme Director for Scientific Affairs at NICE, Dr Nick Crabb said, *"Products with these, albeit hypothetical, characteristics would represent major advances in therapy, offering profound benefits to eligible patients compared with the current NHS standard of care. An additional 10 quality adjusted life years (QALYs), as in the example used in our exercise, represents a 10 year life extension at full health. Step-change improvements in patient outcomes from cancer treatments of this magnitude are rarely seen with conventional therapies. But the introduction of these products may also present financial challenges. Methods will need to be developed that allow healthcare systems to find ways of making them available to patients in a financially sustainable way."*

The willingness and ability of the health service to work with Industry to implement flexible commercial models will be critical to ensuring the maximum possible health benefits of future innovations are realised.

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## Patient and Clinician Involvement

**Recommendation:** There should be greater opportunity for *patient and clinician engagement* in the Irish medicines appraisal system to expand on the current evaluations of cost effectiveness.

Access to medicines could be improved through increasing patients' and clinicians' voice in the medicines' appraisals process, encouraging a broader discourse. This will create a more inclusive and transparent regime which will support patients' timely access to new innovative medicines.

A greater emphasis on their involvement can improve the conversation around medicines access, capturing information which would otherwise not be gathered within the current

framework, allowing for a more informed, patient-centric decision. This has proved very effective in Scotland where end of life and rare condition medicines are now reviewed within such a framework.

When a medicine is evaluated but not recommended, there is the opportunity for a further stage of review accounting for the value of the medicine to its key stakeholders (patients / clinicians). Their input can explain how a medicine will be used in clinical practice, which may be different to the clinical evidence supplied. In Scotland, evidence has shown an upward trajectory in approvals since the introduction of PACE (Patient & Clinician Engagement) groups, highlighting the importance of their contributions in ensuring the most effective treatments are available to patients.

The work of the PACE groups has been underpinned by the successful Scottish New Medicines Fund, established through the savings from the rebate to the Scottish Government made by the pharmaceutical industry under the UK-wide branded drug pricing scheme, the Pharmaceutical Price Regulation Scheme. The reinvestment of these savings into new medicines, coupled with the contributions of patient and clinician involvement in the review process has resulted in a significant increase in the number of drugs coming to market for patients.

As medicines become increasingly sophisticated and specific, and hence, harder to evaluate, value-based evaluations with a strong patient and clinical input will be important in maintaining appropriate and timely access to new medicines. By learning from the experiences of systems such as Scotland we would hope Ireland can continue to keep the patient at the heart of medicines access policy by developing processes with a similar objective.

#### **INTERNATIONAL EXPERIENCE**

**Case Study:** The Scottish Medicines Consortium (SMC), Patient and Clinician Engagement Group (PACE)

**Background:** The SMC is the body in Scotland which appraises medicines and makes decisions on their use. In May 2014, the SMC introduced the PACE process which gives patients and clinicians a stronger voice in SMC decision making. For certain medicines, a PACE meeting can now be convened to collect further evidence from patients and clinicians which can then be taken to the final SMC meeting and considered as part of the decision making process. It is generally regarded that this has been a very positive development in making sure that patients' voices are heard and clinical expertise is well represented. Assisted by a PACE group the SMC seek to establish:

- *How well the medicine works;*
- *Which patients would benefit from receiving the medicine;*
- *How safe the medicine is compared to currently used treatments;*
- *What effects the medicine has on the patient's life; and*
- *How much the medicine costs compared to the other treatments*

**Results:** Supported by the Scottish New Medicines Fund, PACE groups have had a constructive influence on the medicines approval process with acceptance rates up to 50%, from a prior five year average of 33%. PACE groups have proven to be a positive influence on the SMC's decision making process for accepting new medicines, particularly in cases when expanded definitions of cost-effectiveness are relevant<sup>168</sup>.

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## Making Medicines Work

**Medicines Optimisation:** Celgene calls for the development of an end-to-end strategy including pharmaceutical companies, clinicians, prescribers and patients to assist patients make the most of their medicines – *medicines optimisation*. The incorrect use of medicines has significant implications for both the effectiveness and safety of medicines as well as leading to significant wastage with an associated cost.

Recent evidence collated by the Royal Pharmaceutical Society (UK) indicate that in England only 16% of patients prescribed a new medicine take it as prescribed, experience no problems and receive as much information as they need.<sup>169</sup> The same study also suggests that just ten days after starting a medicine, almost a third of patients are already non-adherent, of these, 55% did not realise they were taking their medicines incorrectly. Furthermore, at least 6% of emergency re-admissions are caused by avoidable adverse reactions to medicines<sup>170</sup>. It is reasonable to expect a similar picture exists in Ireland, where patient safety could be improved and strain on public resources reduced by a medicines optimisation strategy.

As well as patients not taking medicines correctly there is also the issue of medication errors. Research by the Irish Medication Safety Network looking across eight hospitals found that from 1 January 2006 to 1 June 2007 there were 6179 medication safety incidents or near misses reported. Of these, 95% did not result in patient harm, however, eleven incidents may have contributed to or resulted in permanent or life-threatening harm or death and a further 315 incidents resulted in temporary harm<sup>171</sup>.

An inclusive strategy involving pharmaceutical companies, clinicians, pharmacists and patients will identify and address all potential sources of patient misunderstanding, raise user awareness of the need to take medicines, thereby removing unnecessary and avoidable demands on hospital resources.

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<sup>168</sup> Assessing Trends in SMC Advice Decisions (October 2009- September 2015) O'Neill, P. and Zamora, B. Consulting Report February 2016 P.9

<sup>169</sup> N Barber, J Parsons, S Clifford, R Darracott, R Horne. Patients' problems with new medication for chronic conditions. *Qual Saf Health Care* 2004; 13: 172-175. <http://qualitysafety.bmj.com/search?author1=R+Horne&sortspec=date&submit=Submit>

<sup>170</sup> York Health Economics Consortium and The School of Pharmacy, University of London. *Evaluation of the Scale, Causes and Costs of Waste Medicines. 2010* [http://php.york.ac.uk/inst/yhec/web/news/documents/Evaluation\\_of\\_NHS\\_Medicines\\_Waste\\_Nov\\_2010.pdf](http://php.york.ac.uk/inst/yhec/web/news/documents/Evaluation_of_NHS_Medicines_Waste_Nov_2010.pdf)

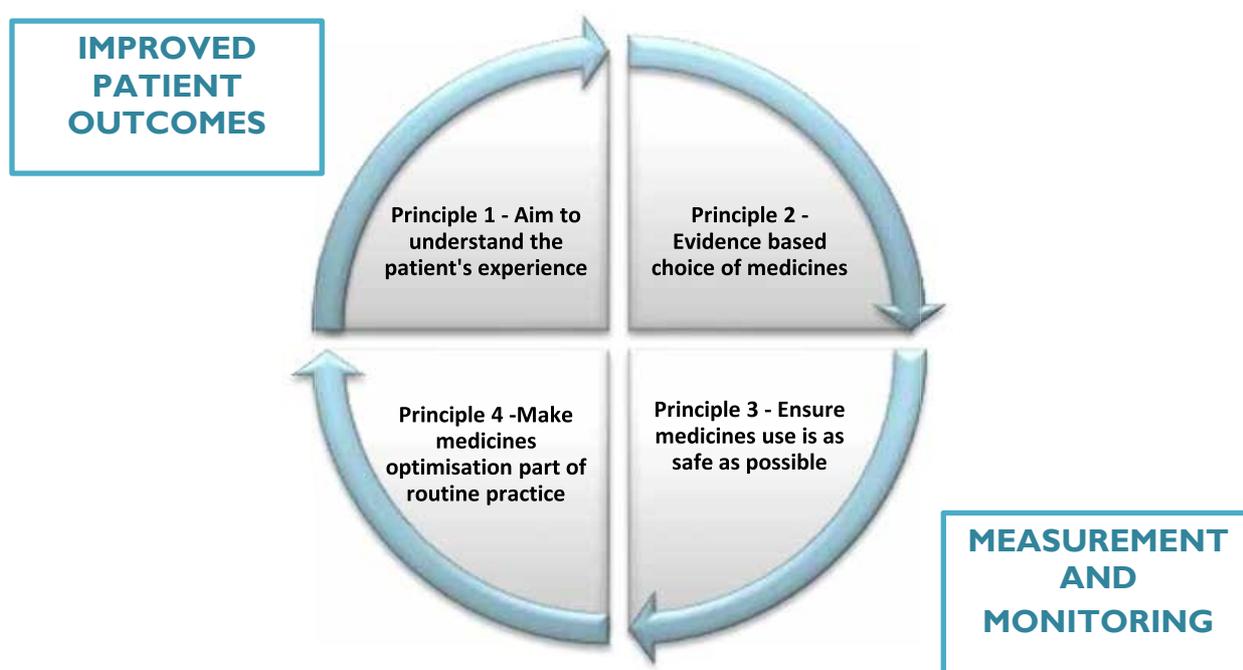
<sup>171</sup> Medication Safety in Ireland (review of data between 1/1/06 & 30/6/07) IMJ. - (Dec 2009) Available at <http://www.imsn.ie/images/publications/imsn-medication-safety-in-hospitals.pdf> Date accessed Aug 2016.

A Medicines Optimisation approach addresses four key areas of strategic importance for the development of the Irish Health Service.

- ❖ *Do patients take their medicine;*
- ❖ *How well are the medicines being used,*
- ❖ *Is the maximum value being derived from the medicines; and*
- ❖ *Are patients actually getting the right medicines?*

Medicines optimisation aims to confront the issues around optimal use of medicines by addressing four underlying principles:

### PRINCIPLES OF MEDICINES OPTIMISATION



There are currently various programmes and initiatives aimed at improving the use of medicines in Ireland. Bodies such as the National Medicines Information Centre are valuable resources to support the development of a fully aligned strategic approach to medicines optimisation including the need to develop a holistic cultural approach to the use of medicines. This approach should ensure all healthcare workers and patients understand their role in the safe and effective use of medicines.

As medicines use evolves over the next 10 years along with the health service it will be important that medicines optimisation is an integral part of the service developments and is resourced appropriately.

## The Collection and Use of Data

**Recommendation:** The development of a national IT system or systems with the ability to collect real world health outcomes data to support the adoption and optimal use of medicines as well as other health care interventions.

Real-time data has the power to inform the effective use and drive efficiencies in an optimal medicines strategy, benefitting patients, clinicians and the health system. This will be essential as the pressures of an aging population begin to impact the health system over the next ten years.

Currently medicines go through a rigorous assessment to determine whether they offer value to the health service. Once approved for use, there is limited follow up conducted to monitor the use of these medicines in terms of the value they are bringing to patients when being routinely used. In an ideal system, patient outcome data would be collected in real-time in order to give useful information on the ongoing use of medicines.

The collection of patient outcome data allows assessments to be made as to whether the expected benefit from a medicine is being realised within a particular service. Experience tells us that there can be significant variation in how medicines are used once they are approved and it is likely that this leads to significant variation in patient outcomes.<sup>172</sup>

The collection of outcomes data would support the optimisation of medicines use in order to achieve the maximum gain from any intervention. This is of particular importance now that medicines are becoming increasingly specialised and the use of innovative pricing mechanisms related to patient outcomes are frequently being explored as a route for ensuring value is being achieved through the use of medicines. The availability of data to support this will be critical.

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## Collaboration with Industry to Get the Most out of Medicines

**Recommendation:** Establish a *strategic engagement group* between the pharmaceutical industry and the health service to identify areas where we can improve patient outcomes drawing on best practice in medicines introduction and use.

The pharmaceutical industry has considerable expertise in the use of the medicines it develops and has a large and often underutilised understanding of those medicines and the opportunities they present for improvements in healthcare provision. Celgene has a genuine interest in ensuring the correct patients get the correct medicine at the correct time in a manner which delivers better patient outcomes, while driving efficiencies across the health system and, hence, alleviating pressure on acute care resources.

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<sup>172</sup> N Barber, J Parsons, S Clifford, R Darracott, R Horne. Patients' problems with new medication for chronic conditions. *Qual Saf Health Care* 2004; 13: 172-175. <http://qualitysafety.bmj.com/search?author1=R+Horne&sortspec=date&submit=Submit>

There is an opportunity for greater collaboration between industry and the health service to create partnerships based on a mutual desire to improve patient outcomes. This is particularly important in the context of medicines optimisation.

This principle has been in operation in Scotland for some time and is captured in the Scottish Government's guidance document "A Common Understanding 2012 – Working Together for Patients".<sup>173</sup> This document sets out a clear vision for collaboration with expectations around conduct of stakeholders and how joint working can take place in an appropriate way to the benefit of patients.

Director General Health and Social Care Derek Feeley said

*"Appropriate and constructive joint-working between NHS Scotland and the pharmaceutical industry has the potential to encourage the development of new products and services that are evidence-based, that better match the needs of patients and that make a greater contribution to sustainable, quality improvement in care."*<sup>174</sup>

We believe that creating a culture of collaboration between the health service and the organisations which research and develop the medicines that clinicians use could be a significant strategic step with many benefits for optimising medicines use and developing cutting edge services.

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<http://www.celgene.ie/>

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<sup>173</sup> Scottish Government Guidance. A Common Understanding 2012 – Working Together For Patients. Guidance on Joint-Working between NHSScotland and the Pharmaceutical Industry. Available at <http://www.gov.scot/Resource/0040/00407602.pdf> Accessed Aug 2016

<sup>174</sup> *Ibid*

## Centre for Medical Health (LSE)

Please find attached a hyperlink link to an economic evaluation of acute mental health services input to an general hospital (Liaison Psychiatry/Psychiatry of Old Age) which generated a saving of £4 for each £1 spend, due mainly to reduced bed care usage in elderly patients.

This evidence base for the RAID model has led to a large expansion of similar services within acute hospitals across England

[Report on Economic evaluation of a Liaison Psychiatry Service](#)

Dr Siobhán MacHale MPhil FRCPI FRCP (Edin) FRCPsych  
Chair of Faculty of Liaison Psychiatry  
College of Psychiatry of Ireland

Consultant Liaison Psychiatrist  
Dept of Psychiatry, Beaumont Hospital, Dublin 9  
& Senior Lecturer RCSI

MCRN: 12358

[siobhanmachale@beaumont.ie](mailto:siobhanmachale@beaumont.ie)

## Children in Hospital Ireland

Following consultation with members of Children in Hospital Ireland, three key areas were identified for specific attention in our submission: enhanced integration of care for children with complex health needs, further development of play for children in hospital, and enhanced mental health services for children and adolescents.

There are many challenges within the infrastructure of primary care that impacts on service delivery to children and their families, compounded by advances in technological innovation, and population demands. It is acknowledged that some initiatives are beginning in this area in the Irish context, however, there remain extensive challenges. The extent to which this requirement is met in practice by national health care systems, varies considerably among the countries of Europe, and is the core purpose of the Horizon 2020 funded project Models of Child Health Appraised (MOCHA), running from 2015 to 2018 (MOCHA Project 2016). In the meantime there is a need for: development of specialist community posts, enhanced clinical governance, increased equity of access and a comprehensive digital clinical information system.

For the child in hospital the absence of an appropriate means to process and cope with care delivery can lead to initial mild stressors progressing to a toxic level, which have been shown to have adverse effects on a child's health, well-being, growth and development. This has the potential to lead to negative long-term consequences ranging from psychological discomfort and distress to the child's failure to achieve developmental milestones. To date the need to assess and facilitate play in hospital has not received any particular attention of note in Irish Government policy. Given the firm evidence of the value of play in hospital it is important to recognize the skills and value of Hospital Play Specialists and play volunteers, to ensure funding for the enhanced delivery of this service and to provide a funded play service in every children's unit throughout the country.

Ireland's poor track record in addressing the mental health needs of children and adolescents was highlighted again in the recent UN Committee on the Rights of the Child (2016) which identified significant deficits in the State response to mental health issues in

children. It is estimated by Cannon *et al.* (2013) that by the age of 13 years almost 30% of young Irish people will have experienced some form of mental disorder and by the age of 24 years, over 50% of young Irish people will have experienced a mental disorder. The gravity of the current situation requires immediate action on what is already known, and promises already made, including: reducing access time to mental health support, enhanced early diagnosis and intervention programmes for children with behavioural /mental health problems and an increase in dedicated mental health care facilities for children and adolescents to ensure they are provided with expert care by staff who are appropriately qualified to care for them.

## **List of Recommendations**

### **Improving Integrated Care**

- Specialist community based posts, including care coordinators and nurses with specialist training to support the transition of these children from acute setting to home, and to support their ongoing care in the community.
- Agreement and direction at policy level on the criteria for competent care delivery and clarity in the responsibility and regulation of training and education of nurses and healthcare staff caring for these children.
- A clinical information system that will transcend organisations to enhance information flow and integration of care delivery for children with complex care needs and their families.
- Address any inequity of access to care provision in the home to ensure care provision is not influenced by post code.
- An initial funded pilot project of a defined model of integrated care for children with complex care needs, prior to national implementation.

### **Enhancing the Provision of Play**

- Recognition of the skills and value of Hospital Play Specialists (HPSs) and play volunteers for children in hospital.
- Further education and training of HSPs and the provision of a funded therapeutic play service in every children's unit throughout the country as an essential member of the multi-disciplinary team.
- Funding of CHI to continue to recruit, train and support volunteer teams and around the country.

- Action recommendations from *Ready, Steady, Play!* (National Children's Office 2004), with a dedicated budget line for the provision of ongoing development in this area.
- Establish community play specialist roles to enhance the care of children with chronic illness across the acute – community care interface.
- Establish developmentally appropriate programmes of play and distraction for children with special healthcare needs in hospital.

### **Enhancing Mental Health Services for Children and Adolescents**

- Reduce access time to mental health support as a priority.
- Early diagnosis and intervention programmes for children with behavioural /mental health problems.
- Increase awareness of supports available, and how to access them, for children, adolescents and their parents / guardians.
- Increase psychological support for children and families in acute settings following traumatic injury.
- Increase dedicated mental health care facilities for children and adolescents to ensure they are provided with expert care by staff who are appropriately qualified to care for them.

### **INTRODUCTION**

CHI is a voluntary organisation committed to promoting and ensuring the welfare of all children in hospital and their families, and functions as part of a wider European network. For 41 years the organisation has been directly working with sick children to bring them fun and support and it uses its expertise to deliver unique daily and weekly play sessions that support child patients, parents and staff in 20 hospital wards and playrooms nationwide. CHI has a strong profile in child advocacy in Ireland and internationally, demonstrated through: experience in supporting parents/guardians and children; input in to key hospital and paediatric unit developments; and a record of delivering, and contributing to the development of play and therapeutic services for children in hospital through a variety of salient activities. Following consultation with members three key areas were identified for specific attention in our submission: enhanced integration of care for children with complex health needs, enhanced mental health services for children and adolescents and further development of play for children in hospital.

## IMPROVING INTEGRATED CARE

There are many challenges within the infrastructure of primary care that impacts on service delivery to children and their families, compounded by advances in technological innovation, and population demands. This challenge is particularly noteworthy for children with complex healthcare needs, children who have substantial healthcare needs as a result of one or more chronic conditions, with functional limitations that often require technology assistance and need to access multiple health support services (Elias & Murphy 2012). Population prevalence estimates by the World Health Organisation (WHO) suggest that one in every 33 infants is born with a congenital malformation (WHO 2012). While a relatively small proportion of the population, the cost of healthcare for this group is very high; figures from the United States show that children with complex health needs account for as much as one-third of healthcare spending for all children (Berry *et al.* 2014). Although the provision of care closer to home for such children is a policy objective internationally (Peter *et al.* 2011), integration of health services is insufficient with wide variation in systems of care for these children. Progress towards achievement of this goal has been slow despite growing evidence that homecare: provides a means of mitigating the barriers and isolation children and their families experience during the transition from hospital to home, can significantly reduce hospital utilisation, and reduces the cost of care for children with complex care needs (Long *et al.* 2013, Parker *et al.* 2013).

Key constituents for a successful transition to home for such children were identified by Noyes *et al.* (2014). It is acknowledged that some initiatives are beginning in this area in the Irish context, however, there remain extensive challenges. These include communication of a child and family's needs at the acute-community interface, lack of clarity regarding the roles, scope of practice, responsibilities, supervision and monitoring of nurses, trained carers and parents; confusion over eligibility for services and the process for seeking funding for home care packages; and no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multi-disciplinary team (Brenner *et al.* 2015). Furthermore, there is inequity of access depending on geographical location and the governance of care for children with complex care needs in the community in Ireland is often unclear and is compounded by the fragmented nature of health service delivery to this population. This approach requires direction and support at the level of

health service policy and is compounded by the absence of nationally-agreed standards for the care of children with healthcare needs in hospital or in the community in Ireland. This problem is not unique to the Irish setting. It is consistent with the diverse approach to the education preparation of nurses and healthcare professionals who care for these children and their families across Europe.

Many children with complex health issues are also living well into adulthood. For example, children with diseases such as cystic fibrosis and sickle cell, who would not have been expected to reach adulthood in the 1970s, are now living into their 40s and 50s (Bourke *et al.* 2009, DeBaun & Telfair 2012). Despite advances in life expectancy, maintaining their quality of life during the transition period remains problematic and coincides with the period in their life where there is a reduction in parental responsibility and a peak in the influence of peer risk-taking behaviour (Holtslander *et al.* 2012, Helgeson *et al.* 2014). The challenge then is to identify a suitable programme for this time in a young adult's life that will accommodate care continuity, support for greater responsibility and compliance with treatment. One example of such a support is the Stepping Up programme launched in 2013 ([www.SteppingUp.ie](http://www.SteppingUp.ie)).

Models of care in some European countries appear to be more facilitative of these healthcare demands than others, such as the multi-professional primary care teams in Sweden and the Netherlands. However, little is understood about the specific processes and procedures that contribute to the success or failure of such models for this group, which varies considerably among the countries of Europe, and is the core purpose of the Horizon 2020 funded project Models of Child Health Appraised (MOCHA), running from 2015 to 2018 (MOCHA Project 2016). This study is embedded in the various peculiarities of national healthcare systems and the ethical and legal concerns bound to the linkage of child health data. One aspect of the MOCHA project, led by Dr Maria Brenner, is to provide an updated comprehensive analysis of the current approach in each EU and EEA Member State to managing the care of children with complex care needs, with particular regard to the integration of care at the acute/community/primary interface. The outcome of the study therefore has the potential to make a wide contribution to individual countries of the EU/EEA to understand their own level of integration of services mapped against responses

from other member states. Further work, using the same surveys will be used within the project to map the EU/EAA picture against that in the United States for children on long-term ventilation and against that in Australia for children with enduring mental health conditions. Early results are expected towards the end of 2016.

### **ENHANCING THE PROVISION OF PLAY**

It is suggested that healthcare-related stress and anxiety in children ranges from positive, to tolerable, to toxic (Middlebrooks & Audage 2008). Positive and tolerable stress may produce minor short lived physiological and psychological discomfort which the child can tolerate and overcome if appropriate support is provided by an adult carer or a healthcare professional. However, if support is not provided or if there is long-term multiple exposure, these mild stressors can progress to a toxic level, which have been shown to have adverse effects on a child's health, well-being, growth and development with potentially negative long-term consequences (National Child Traumatic Stress Network 2014). Consequences range from unnecessary psychological discomfort and distress to the child's failure to achieve developmental milestones. Children with chronic illnesses may be particularly at risk of adverse outcomes where ongoing intrusive and painful interventions are required (Schumacher & Meleis 2010, Ekra & Gjengedal 2012). Strategies such as the use of therapeutic play, toys, video games, painting and music, among others, have been reported in the literature to achieve a lower level of anxiety and stress both in hospital settings and in general (Guo *et al.* 2012, Ladouceur *et al.* 2013, Rosen *et al.* 2013). Behavioural and distraction methods have also been identified as an efficient way of reducing paediatric anxiety compared to medications (Golan *et al.* 2009, Ni *et al.* 2012).

It is widely acknowledged that these benefits go beyond reducing stress and fear during a clinical procedure; specifically these benefits include boosting a child's confidence and self-esteem, providing an outlet for emotions, facilitating communication, and assisting in diverting a child's thoughts from aspects of their clinical care (Jun-Tai 2008, Kline *et al.* 2010, Weiss *et al.* 2011). Research on therapeutic play for the child in hospital has focused on identifying and understanding the optimum delivery of therapeutic and specialised play to help a child cope with being in hospital. This includes studies on the impact of play prior to clinical procedures and the benefit of play during clinical procedures (Kline *et al.* 2010,

Weiss *et al.* 2011). For example, Jun-Tai (2008) focused on the impact of play on children prior to wound dressings, in which children of varying ages were afforded the opportunity to relax in a tranquil environment to instill a sense of calm prior to having a change of wound dressing. The intervention resulted in children being more relaxed at the start of the procedure, and being more co-operative during the procedure. This was beneficial in decreasing the length of time required to perform the procedure and improved the child's experience of having a clinical procedure in hospital.

Play constitutes an important parameter of a child's normal development and collectively these studies support the value of play in increasing the child's ability to cope with the demands of hospital. Though the use of play, children have the chance to gain control in many situations, thus supporting the child's interaction with healthcare into a more positive experience, enhancing their potential to continue engaging with their healthcare providers (an exceptionally important issue during adolescent transitions to self-management). To date the need to assess and facilitate play in hospital has not received any particular attention of note in Irish Government policy. Instead the value of play for children has focused on the provision of play facilities in communities (National Children's Office 2004). In contrast, the work of Hospital Play Specialists (HPSs) and the voluntary play service largely goes unrecognised, and they are not referred to in the National Clinical Programme for Paediatrics and Neonatology (2016).

HSPs are skilled in the use of play in a variety of therapeutic and specialised ways, across all clinical settings, to minimise stresses on children in hospital. They use play as a distraction, for education and preparation about procedures that the child might have to experience, and they also use play post-procedurally to support a child to understand what has happened to them. Due to the limited professional play service available much of the play support in Ireland is provided by voluntary recruits who are trained by CHI. Volunteers provide familiar and normalising play, the everyday activities children would experience in their everyday lives. This in itself is therapeutic for the children but the intention is to give them the opportunity to engage, socialise, play and above all, have a bit of fun. The volunteers work under the direction of the HPS, where there is a HPS on staff. Given the firm evidence of the value of play in hospital it is important that the skills and value of HPSs,

and play volunteers, are recognised and supported in future health service planning for children's health services throughout the country.

## **ENHANCING MENTAL HEALTH SERVICES FOR CHILDREN AND ADOLESCENTS**

In Ireland, the current government health strategy has made many recommendations in response to the UN Convention (United Nations 1989) including the establishment of out-of-hours social services as a priority, early intervention programmes for children with behavioural or intellectual disabilities, the expansion of mental health services for children and adolescents, and a national integrated programme for child health. However, to date little progress has been made on most of these recommendations. For example, out of hours access to social services continues to be a considerable problem and intervention programmes for children with disabilities is insufficient in meeting the demand. In recent years, despite the publication of a Vision for Change (Department of Health & Children 2006), mental health services for children have not shown any notable improvement. The most recent epidemiological study (Cannon *et al.* 2013) surveyed 1,131 young people and conducted 453 diagnostic clinical interviews with young people to assess them for the presence of mental disorders and to examine their overall level of functioning. The study found that young Irish adolescents in the 11-13 year age range have higher current rates of disorder (15.4%) than similarly-aged young adolescents in both the USA (11.2%) and the UK (9.6%). The study estimates that by the age of 13 years almost 30% of young Irish people will have experienced some form of mental disorder and by the age of 24 years, over 50% of young Irish people will have experienced a mental disorder.

The Children's Mental Health Coalition (2015) make a number of salient recommendations, based on a thorough review of the literature on child and adolescent health needs, which we support. These include the need to: build capacity in primary care services to effectively prevent, detect and appropriately treat child and adolescent mental health difficulties and disorders; ensure accessible, community based, evidence-informed and outcomes-monitored child and adolescent mental health services; develop accessible, inclusive, developmentally appropriate specialist inpatient care for children and young people with complex mental health needs, along with local, evidence-informed services. In addition it is important to highlight that care of children with mental health issues in acute adult medical

facilities continues to occur due to the absence of appropriate care facilities. This repeatedly goes against best practices internationally, with staff not qualified or equipped to address the specific needs of such children and their families. All of these concerns were again brought to the fore internationally in the UN Committee on the Rights of the Child (2016) which identified significant deficits in the State response to mental health issues in children. While the recent initiative by Helen McEntee TD, Minister of State for Mental Health and Older People, regarding the National Taskforce on Youth Mental Health is welcomed, the gravity of the current of deficits in mental health services for children requires immediate action on what is already known and promises already made.

<http://www.childreninhospital.ie/>

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## College of Psychiatrists of Ireland

The College of Psychiatrists of Ireland is the professional body for psychiatrists in Ireland and the sole body recognised by the Medical Council and the HSE for Training of doctors to become specialists in Psychiatry and the supervision and assessment of the career long competence assurance of trained specialists in Psychiatry.

The College of Psychiatrist of Ireland in making this submission would like to emphasise these main themes:

**Parity of funding for mental healthcare with physical healthcare.**

**Funding that promotes community care.**

**Funding that ensures the proper functioning of primary care and frees out secondary and tertiary care for those who need it.**

**Staff recruitment, training and retention.**

**Simplification of administrative systems.**

**Access on the basis of need not income or geography.**

### Strategy

#### **1. *What are the key priorities for inclusion in a ten year plan for the health service?***

- Mental Health must have parity of investment with physical health in acknowledgment of the level of damage that mental health problems cause to individual, their families and the state.
- Increased budget for mental health services. Budget should be at least 12.5% of GDP similar to other European countries.
- Financing must support a community based model of service delivery in line with the national policy 'A Vision for Change'.
- People with mental health support needs must have access to appropriate interventions regardless of income or geographical position.
- Urgently plan to correct the critically low level of medical and allied professional staff in the Mental Health Services.
- Develop a long term plan for staff retention and recruitment.
- Information must be readily available to clinicians, service users/patients and carers to facilitate access and use of resources to the maximum benefit of the patient.
- Administrative systems in healthcare must all should be co-terminus to allow for better co-ordination and information sharing.
- There should also be national patient records system.

- All clinicians should have ready access to IT systems that allow information gathering.
- Frontline Clinicians and other healthcare workers must be freed from local administrative work (e.g. answering phones, collating files, making appointments) to concentrate on patient interventions.
- Acute hospitals should be for acute illnesses that cannot be treated in the community. Resource initiatives should be community focused to ensure this.

***What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?***

- Financial resources nationally following the major financial downturn that occurred from 2008 onward.
- Lack of transparency on true financial resources.
- Simplifying confused and complex administrative systems.
- Critically low level of medical and allied clinical staff.
- Inability to recruit at Consultant level.
- Lack of control of funding at local levels.
- Lack of transparency on allocation of funding.
- The complexity, lack of flexibility and lack of speed and imagination of the recruitment process: there is no clarity on whether its local or central recruitment; there is no flexibility if local candidates are available who will undertake training to be able to fill a vacant post; there is no flexibility in the system if the particular post in a discipline cannot be filled and another suitable person in another discipline is available.
- Resource planning does not include private sector as well as public sector mental health support and illness intervention resources.

***What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?***

- Use of regression analysis to predict the ten year demographic picture and then use medical morbidity trends to predict the breakdown of need so that planned resourcing, including capital funding and staff training, can be predicated on this information.
- A progressive incremental plan to increase the budget for mental health services. Currently the budget is only at 6.5% GDP and it should be at least 12.5% similar to European sister countries.

- Scoping of available resources in public and private sectors to facilitate the maximum appropriate use of financial resources.
- Ensure training of sufficient clinicians to meet the need predicted.
- Proper resourcing of primary care services in the community, including primary care psychology, speech and language therapy, occupational therapy. This will have the effect of amelioration of conditions that currently add to secondary and tertiary mental health assessment and intervention waiting lists and delay those meeting criteria for secondary care services receiving them. An example is the many children with developmental delay currently on Child and Adolescent Psychiatry waiting lists when educational assessments and plans may suffice.
- Ensure modern theories on patient support inform the training and employment of staff (including the training of patient experts and the use of peer support workers, non-specialist therapists such as counsellors and behaviour therapists and specialist clinicians such as Psychiatrists).

### **Integrated Primary and Community Care**

***What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?***

- Allocation of resources based on the philosophy of care in the community not hospital bed requirements.
- Integrate health administration systems to include primary, secondary and tertiary mental and physical healthcare rather than the current diffuse models.
- Imaginative uses of personnel in the frontline to ensure that Specialists are available to those who need specialist assessment and intervention. An example is a pilot project in Roscommon using assistant psychologists under supervision by clinical psychologists to address long waiting lists in primary care.
- What are the key barriers to achieving this, and how might they be addressed?

***In your experience, what are the key roadblocks you encounter in your particular area of the health service?***

- Lack of appropriately trained staff in every part of the Mental Health Services.
- Focus on funding of hospital care rather than the community based model.
- Conflicting administrative systems and geography.
- Focus on physical health not mental health.
- Too many tiers of administration.

- Deficits in communication and information availability at a local level. This includes both lack of access to information search tools and lack of access to information on individual patients especially when they present in crisis.

***How would you ensure buy-in from health care professionals to progress towards an integrated health care model?***

- The College of Psychiatrists of Ireland’s membership are trained in and fully supportive of an integrated care model in Psychiatric care.
- All trainees of the College of Psychiatrists of Ireland are trained in an integrated care model and training sites are those that practice such a model where available.

***Are there any examples of best practice that the Committee should consider? Please refer to any evidence you have to support this.***

- There are examples of best practice in Psychiatric Care delivery in Ireland (e.g. Building Blocks: Evaluation of a Home Based Service for Patients with Acute Mental Illness in North Kildare. HSE 2006). They have not generalised for various reasons. The College of Psychiatrists would be happy to facilitate presentations to the Committee on the models in practice if asked.
- The College of Psychiatrists of Ireland Workforce Planning Report 2013 – 2023 (December 2013) delineates with supporting arguments and data the requirements for training and staffing to ensure Consultant led acute and continuing care Mental Health Services in the future  
[http://www.irishpsychiatry.ie/Libraries/PGT\\_Documents/CPsychI\\_Workforce\\_Planning\\_Report\\_2013-2023\\_Dec\\_2013.sflb.ashx](http://www.irishpsychiatry.ie/Libraries/PGT_Documents/CPsychI_Workforce_Planning_Report_2013-2023_Dec_2013.sflb.ashx)

## **Funding Model**

***Do you have any views on which health service funding model would be best suited to Ireland?***

- The College of Psychiatrists of Ireland has already addressed the idea of Universal Health Insurance in a prior submission. The College stated then, and still holds that: “In theory Universal Health Insurance and a ‘Money Follows the Patient’ funding policy should allow a person with mental health problems to plan, with professional assistance, a personal road to recovery accessing the appropriate assessments and interventions wherever they are available.”

***Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating***

- This is not an area that the College is currently in a position to comment on.

**What are the main entitlements that patients will be provided under your funding model?**

- Access to the range of therapies and supports that facilitate wellness in line with the individualised Recovery Model of mental health supports. This would include acute treatment packages when needed and individual Recovery planning and resourcing. The latter may include clinical inputs and medication at both primary and secondary care level but may instead focus on alternative supports such as Peer Support and socialisation.

Examples of best practice, or estimated costs of such models if available.

- We refer to models such as cited in point 7 above.

<http://www.irishpsychiatry.ie/Home.aspx>

## Connected Care for 22q11.2 Deletion Syndrome

In communicating this message for consideration to the Oireachtas on the development of a 10 year plan for the Irish Health Service this submission will

- place a proposed model for connected care for 22q11.2 deletion syndrome into the context of developing care-pathways suiting the population health needs of those affected by rare diseases in Ireland and to incorporate these changes into the adoption of a 10 year plan for our health services.
- propose that the best health outcomes and value for money can be achieved by first developing a care-pathway model-of-care for rare diseases and secondly by re-orientating existing models of care towards primary and community care where the health needs of the majority of people affected by rare diseases can be met locally.

### 22q11.2 deletion syndrome:

- 22q11.2 deletion syndrome is a multi-system complex disorder with multiple associated medical, psychiatric, educational and social anomalies.
- 22qDS is caused by a micro-deletion of genetic material on the long (q) arm of chromosome 22. It is the most common chromosomal micro-deletion and one of several chromosome conditions that cause abnormalities.
- Individuals with 22q attend multiple specialists over the life-span of the condition thus requiring a life-span approach with attention needed at transition from paediatric to adult care and a particular focus on mental health well-being at this crucial period.
- Evidence based research shows that there are significant shortfalls in current service provision which is ad-hoc with poor communication between health care professionals, limits opportunities for early interventions and causes a significant burden of care on families.
- 22qDS is considered as a rare disease. Rare diseases are 'individually rare but collectively common'. Ireland has an under-resourced genetic service and with no rare disease registries which makes it impossible to calculate the true prevalence of rare diseases here. The Irish rare disease population is conservatively estimated to be in the region of 300,000.
- Rare diseases are a 'significant cause of physical, intellectual and sensory disabilities'. (National Rare Disease Plan for Ireland Chapter 1, page 7)

### Section 2. Recommendations

#### *I would like the committee to recognise that rare diseases are*

- individually rare yet collectively common
- a significant cause of physical, intellectual, mental health, learning and sensory disabilities and that
- the lack of awareness between various disability organisations, along with health, education and social protection departments and the general population of the link between disability and rare diseases with a parallel needs to be addressed.
- during consultation phases the National Rare Disease Plan for Ireland acknowledges **“awareness of rare diseases was a cross-cutting issue – this lack of awareness was evident at all levels of the health-care system, as well as in respect to**

***access to public and private services and entitlements both within the clinical setting and beyond***”(Chapter 4; page 23)

***I would like the Committee to consider that***

- - all rare diseases are not life-limiting and not all require expensive ‘orphan’ drugs. Given the right supports many people with rare conditions live well with adequate treatment and management of their condition.
- - currently in many cases it is the parent /caregiver of a child with a rare disease who co-ordinates their health care.
- - parents and patient organisation have developed considerable expertise in their individual conditions and are a rich, under-utilised resource.
- - many health related charities/voluntary organisations are set up by parents of children affected by a rare/genetic condition who felt isolated and despairing at the lack of information, ready access to services.
- - apart from health related issues these parents are generally deeply concerned about educational opportunities, independent living and fears for their children’s futures.
- - parents and patient organisation have developed considerable expertise in their individual conditions and are a rich, under-utilised resource.
- - recommendations from the National Rare Disease Plan for Ireland

***In particular I would like the committee to***

Actively advocate for implementation all 48 recommendations of the National Rare Disease Plan for Ireland 2014 -2018 taking cognisance in particular of recommendation 46 stating that The National Rare Disease Plan for Ireland encompasses **a holistic and person centred** view of rare disease patients and their families, one that goes beyond health care issues.

(40 – 48 Chapter 6 **Empowering, protecting and supporting rare disease patients and carers.**)

**Section 3. Information and Study Cases.**

**22q11 Ireland Support Group:** Who we are and what we do.

***In 22q11 Ireland we believe in our children’s gifts, capacities and strengths. We also believe that health and social care delivered in a timely, accessible and coordinated manner will result in better outcomes and greatly assist our children to achieve their full potential.***

The Irish Support group with the help of Prof Kieran Murphy (Consultant Psychiatrist) was set up in 2007 with 3 families. Current membership stands at over 150 families. At this point in time the organisation is self-funding and wholly voluntary.

22q11 Ireland provides help and support for individuals and families in Ireland affected by 22q11.2 Deletion Syndrome Through education, research, outreach and advocacy the organisation seeks to raise awareness of this little known condition. 22q11 Ireland are committed to giving parents and families up-to-date accurate information enabling them to

know what they need to know in terms of treating and managing the condition. Although levels of awareness of 22q11.2 deletion syndrome amongst doctor's, clinicians, therapists and educators is quite low in Ireland it has risen in accordance with the rise of parental knowledge and expertise.

Our fundraising efforts focus in the main on our annual conferences and our family days. We also disseminate printed information in the form of leaflets and the UK's Consensus Document for treatment/management of 22qDS.

To ensure that the voices of young people with 22q11.2DS and that of their families are heard regarding their lived experience, needs and the development of services, 22q11 Ireland have secured Irish Research Council funding to conduct participatory research in collaboration with Professor Fiona McNicholas, Child & Adolescent Psychiatry UCD and Lorna Kerin of Love Knowledge Consultancy.

22q11 Ireland are a highly-engaged, pro-active group who have forged an extensive network with families here in Ireland and abroad. We have also developed good working relationships with internationally renowned clinicians and researchers who are experts in the condition. We regularly pay for 22q experts to attend and present at our national conferences. 22q11 Ireland has co-hosted an International conference here in Ireland in 2013 and will host a European conference in 2017.

In an Irish context and as far back as 2009 this recommendation was made for individuals born with 22q11.2 deletion syndrome in Ireland.

***“The management of individuals with this disorder [22q11.2 deletion syndrome] is optimised through an integrated and co-ordinated multi-disciplinary approach where the needs of affected individuals can be identified at an early stage. Individuals require a comprehensive and regular assessment to identify their medical, psychiatric, speech, educational and social needs across the life-span. In Ireland, guidelines should be developed for the comprehensive management of multisystem disorders such as 22q11.2DS”***

Professor Kieran Murphy and Dr. Sarah Prasad 2009

**Our vision for a 22q clinic/coordinated care** is based on the research literature supporting the premise that early diagnosis provides the best opportunity for affecting the course of the condition and optimizing outcomes. This includes screening for and co-ordinated management of associated conditions. Because of the complexity and range of complications often found in children with 22q11 DS affected children attend multiple specialists. These children require comprehensive management given their multiple medical and therapeutic needs and their complex care needs outside of any medical environment.

The skilled specialists are available in Ireland and some are already regularly seeing these children. For example approx. 80 children with 22q11 DS have been assessed in the immunology department in OLHC. Currently the overall care of those with 22q11Ds is coordinated in ad-hoc fashion with suboptimal communication between different specialties treating the same child.

## **This vision translates to recognition that**

- The individual with 22q and best outcomes for the individual are always placed center first.
- Care is based on internationally evidenced-based best-practice guidelines and utilises 'syndrome specific expertise' outside Ireland (see references)
- In an Irish context care follows recommendations made in the National Rare Disease Plan for Ireland 2014-2018.
- Optimal use of IT including use of EHR's (electronic health records) and 'virtual' consulting for clinical support.
- There is high-value placed on comprehensive, multi-disciplinary treatment and teamwork.
- Consultant paediatrician led with a clinical care-coordinator as pivotal to its success.
- The clinic is well linked to other medical, professional, educational and social-care resources to advocate for and provide optimal services.
- Audit and research integral to overall care - health and social outcomes evaluated and monitored longitudinally.
- Mutual respect for the partnership between parents, individuals with 22q DS, health care professionals and other service providers. Parents and professionals will jointly learn and share their expertise and experience.
- Development of a close working relationship between members of the MDT and the 22q11 Ireland Support Group utilising collective wisdom, expertise and experience.
- Place particular attention on transition to adult care and overarching need for timely access to mental health services.
- Seek to educate a range of professionals about 22qDS.
- Provide advice as needed to families needing clinical information to support applications for social care and educational resources
- **Be seen as a model for provision of care for other rare chromosomal disorders.**

## **eHealth Ireland**

### Background

"A national Electronic Health Record (EHR) has been identified by HSE National Directors and clinical leaders as a key capability requirement for the future delivery of healthcare. While technology solutions are a key component, there will be a primary focus on how clinicians and administrative staff work with this technology in a way that closely aligns with and underpins the ambition for Integrated Care and other national healthcare reform priorities. The national EHR programme represents a significant transformation in the use of technology and data to underpin effective and efficient care. This document acts as a foundation document for the definition of the national EHR Programme and for subsequent strategies, plans and business cases once the overall roadmap is defined".  
<http://www.ehealthireland.ie/Strategic-Programmes/Electronic-Health-Record-EHR/>

Individuals with 22q11.2 deletion syndrome will see multiple specialists; have repeated hospital admissions and ongoing physical, mental and social care needs over the life-span. The type of integrated care that electronic health records provide makes 22qDS an ideal candidate for inclusion to the Lighthouse Project list. The use of EHR's as described by the

Irish Medical Organisation fits perfectly with the vision for integrated care for 22qDS patients as outlined in the 22q business plan. The IMO in a submission to the HSE stated

***“Such a system would enable an integrated approach to the care of individual patients. The potential benefits of a national system of EHRs are numerous - electronic health records can enhance patient safety and quality of care, reduce repetition and errors in diagnostics and treatments and lead to administrative efficiencies. Electronic health records can support integrated care and the smooth transfer of patients between settings. The collection of data also allows for the advance of medical knowledge, management of disease and health service planning.”***  
<https://www.imo.ie/news-media/publications/IMO-Submission-to-the-HSE-on-Electronic-Health-Records-Final.pdf>

As cited in the National Rare Disease Plan for Ireland (p.32) the Irish EUROPLAN Conference 20011 recommended that “a national electronic healthcare record be developed for rare disease patients because it was seen by patients as a key need in their interaction with services” (EUROPLAN,2011)

### **Placing a model for coordinated care of 22q11.2 deletion syndrome in the broader context of healthcare for other rare and genetic conditions.**

Individually chromosome disorders are rare - collectively they are common. Unique (Rare Chromosome Group UK) to date have produced over 70 information leaflets on different chromosomal conditions. A specific model of care (as per recommendations contained in the National Rare Disease Plan for Ireland) for 22q11.2 deletion syndrome has the potential for development of ‘gold-standard’ treatment and management of rare chromosomal disorders.

### **National Rare disease Plan for Ireland 2014-2018:**

EU developments in the area of rare diseases accompanied by wider developments in the Irish healthcare system call for the development of CoE’s (Centers of Excellence). “CoE’s are care centers that bring together a group of multidisciplinary, specialised competencies, from offering consultations, medical examinations, genetic testing and counselling and social services to facilitating inclusion in research protocols and clinical trials as a patient-centered service, ensuring timely diagnosis and appropriate follow-up care”. (National Rare Disease Plan for Ireland, 4.4.2. Centres of Expertise, page 36).

EUCERD (European Union Committee of Experts on Rare Diseases) recommends ‘provision of management and multidisciplinary care of rare disease patients at designated Centers of Expertise, including the provision of psychosocial care and the development of healthcare pathways for patients (applicable to specific genetic rare diseases, e.g. Marfan Syndrome, Tuberous sclerosis, William syndrome DiGeorge Syndrome [aka 22q11.2 deletion syndrome]’.

Empowering, protecting and supporting rare disease patients and carers: The European Council (EC) Recommendation of 8th June 2009 on an ‘Action in the field of rare diseases’ (2009/C 15/02) advises that ‘Member States should aim to involve patients and patient organisations in the policy process and seek to promote the activities of patient groups.’

A theme arising during consultation for the National Rare Disease Plan for Ireland on patient empowerment suggested a 're-orientation of the health system to become more user-friendly, patient-centered and family centered'.

As the national support group for families in Ireland affected by 22q11.2 deletion syndrome, 22q11 Ireland would like to see a family support worker as an integral part of care-coordination for families affected by rare / genetic conditions. The National Rare Disease Plan for Ireland during consultation acknowledged the diverse functions of patient organisations in '**providing support, information, advocacy, advice, research and fundraising**'. (p.63)

Research: The National Rare Disease Plan for Ireland steering group recommendations include designated Centers of Expertise incorporating relevant research to rare diseases in their remit, in particular with regard to registries, health service and translational research.

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N.B Prior to publication of the Irish rare disease plan a Rehab 2008 report cited recommendations for social support needs of families in Ireland affected by rare disorders (see references)

**Case Study 1:** Donegal. 22 year old male living with 22q11.2 Deletion Syndrome.

Diagnosed at 10 years of age through cleft palate team. Earlier symptoms include speech, language and communication difficulties, palate, frequent ENT and chest infections. Social anxiety and learning difficulties.

Currently under the care of;

- GP Dungloe
- ENT, Letterkenny Hospital ( 90 mile round trip )
- Orthopaedics, Mater Hospital ( 400 mile round trip) Dublin
- Orthopaedics , Cappagh Hospital, Dublin
- Cappagh do NOT have access to file in the Mater
- Ophthalmology, Sligo Hospital
- Immunologist , Beaumont Hospital, Dublin
- Endocrinology, Mater Hospital Dublin
- Infectious Disease, Mater Hospital, Dublin
  - 2010 Spinal fusion (rods inserted)
  - 2011 Spinal fusion failure- extension fitted
  - 2015 All hardware removed due to infection.

**January 2015** developed eye infection. Referred to Sligo, diagnosis of uveitis – accompanied by considerable and frequent headaches. Treatment began with eye-drops, 3

– 4 weeks. A further infection appeared on the patient's back and antibiotic treatment began and continued until July 2016 (with an odd break in-between). Referred to orthopaedics and all hardware removed in March 2015 (MSSA Infection).

This infection caused a cavity on the back, has never fully cleared and the patient is now scheduled for a further procedure to attempt to clean and heal tissue internally.

### **From January 2015 to date**

- Approx forty 400 mile round-trips to Dublin during this period at considerable financial expense and substantial stress to the individual and his care-giver. (roughly 3 of these happened twice in the one week)
- Minimal communication between specialists during this period.
- Parent asked to see immunology (outcome of activities / information of the 22q11 Ireland Support) No prior contact with Immunology
- Infectious disease liaising with parent (not GP, if issue calling parent). Immunology liaising with GP (cc'ing test results – not happening with ID)
- Significant difficulty with non-returning of calls by the parent to the Mater during this period. Overall stress considerable on individual and caregiver.

### **Case Study 2: Limerick**

- In 2009 at 20 weeks pregnant a heart abnormality detected. Tested for 4 chromosome abnormalities. Tests negative.
- Referral to Holles Street diagnosed tetralogy of fallot, and double outlet right ventricle. Recommendation for a FISH test for 22q11.2 deletion syndrome made. Tested positive.
- Baby was born at 39 weeks with Tetralogy of Fallot and complications to his left ventricle and his mitral valve - transferred to Crumlin. Mother reports this time as being an 'emotional blur' with tests, scans and x-rays being taken but little explanations given as to what they were for. Healthcare professionals knew nothing or very little about 22q11DS.
- Mother also reports great difficulties with drawing bloods and that this was quite distressing.
- Because of ante-natal diagnosis parents informed themselves with maxappeal booklet (sent by 22q11 Ireland) and various other websites so they knew what teams to ask for ...ENT, plastics etc.
- Allowed home after 10 days with some referrals made.
- Follow-up with paediatrician in Limerick revealed 'mild' hypotonia, hernia, stridor when crying, and a bifid uvula.
- A referral for plastics came the day after an appointment with cardiologist. Parents tried to change outpatients appointment so they would not have to go up to Dublin 2 days in a row - unsuccessful getting through to outpatient phone line.
- Parents report plastics appointment very 'thorough'. Attended cardiology every 6 weeks.

Quote from mother at the time: ***"I think if there was one person in specific we could have shown the care plan to and they could have put in requests for various teams to***

*get involved baby's care. But, it was a case of if a geneticist came, I'd ask him about immunology and when neonatologist came I'd ask her about his cleft palate and she would send request in for ENT and plastics etc. Even now, I am still ringing different people asking for my referral to plastics to look at his soft palate".*

### **Case Study 3: Dublin**

Born in 2009.

- Symptoms early on (as reported by parents). Milk down nose. Would 'choke' when feeding. Parents made many visits to A & E (two separate hospitals) and were told that it was reflux 'she would grow out of it by the time she could sit up'. Sent home with baby Galviscon. Palate examinations made at the time did not pick up anything.
- Parents describe these episodes as 'incredibly stressful'.
- Sacral dimple (was told normal and would close)
- Sleep disturbances (improved today but ongoing)

#### **Developmental delays.**

- Slow as in crawling (she never did, just bum shuffled), walking, talking and then doing tasks like puzzles and bricks.
- Babbling at 18 months – no clear speech. PHN referred to local S&L and put on waiting list. No speech improvement after a year of speech therapy. Further referral made, this time to consultant.
- Sub-mucous cleft diagnosed and had first palate operation at 4yrs age. Parents report no dramatic improvement in speech.
- Also had 12 teeth out at aged 4. (rapid decay)

**Child started school** and teacher flagged some 'behavioural' issues, mentioned dyspraxia.

- Parents at this time informed cleft team of school reports and concerns about behaviour, never sitting still, constant talking, anxious behaviour and co-ordination issues.
- Referral made to paediatric consultant who took medical history and bloods and sent to test for 22q11DS. Diagnosed at 5yrs old in October 2013.
- Parents given a 'printed off sheet' of 22q information at told that appointments would be made to 'check her major organs'. (Parents speak of the 'invaluable' support from 22q Ireland after diagnosis, found on Internet)
- November 2013 confirmation there was still a gap in palate and re- assessment in 6 months' time would be needed before consideration of further surgery.
- 2nd palate operation in 2014. Parents report a 'significant' improvement in speech after this and child was 'signed off' with the local S & L team.

**Current status:** Child sees GP, Paediatric consultant and MH team. Parents report ongoing and worsening behavioural and anxiety issues and currently have an appointment to see a psychologist. Child struggles socially and academically in school. Parents are 'fearful' of what the future might hold.

## **Recommendations for action by Government or other actors.**

**Strong recommendation** for action by Government to fully implement the National Rare Disease Plan for Ireland in collaboration with the Rare Disease Office and patient organisations.

**Consider** incorporating into a 10 year health-care plan

- a robust, well-resourced genetic and genomic network
- cross-ministerial consultations involving health, disability, social protection, education, mental health, children, justice and equality.
- In addition appointing a designated person/team to liaise with the CRA (Charity Regulatory Authority) to evaluate how many charitable organisations are specific to health and set up to deal with perceived unmet healthcare needs.

### **References:**

Consensus Document on 22q11 Deletion Syndrome (22q11DS) MaxAppeal Dec 2012

[http://www.maxappeal.org.uk/downloads/Consensus\\_Document\\_on\\_22q11\\_Deletion\\_Syndrome.pdf](http://www.maxappeal.org.uk/downloads/Consensus_Document_on_22q11_Deletion_Syndrome.pdf)

Practical Guidelines for Managing Patients with 22q11.2 Deletion Syndrome. 2011 Journal of Pediatrics <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3197829/>

Practical guidelines for managing adults with 22q11.2 deletion syndrome. Genetics in Medicine (2015) 17, 599–609 <http://www.nature.com/gim/journal/v17/n8/full/gim2014175a.html>

Towards a safety net for management of 22q11.2 deletion syndrome: guidelines for our times. 2014 European Journal of Pediatrics <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4032642/>

EUROPLAN National Conferences CONFERENCE FINAL REPORT - IRELAND 2011

[http://download.eurodis.org/europlan/2\\_EUROPLAN\\_Guidance\\_Documents\\_for\\_the\\_National\\_Conference/final\\_report\\_ireland.pdf](http://download.eurodis.org/europlan/2_EUROPLAN_Guidance_Documents_for_the_National_Conference/final_report_ireland.pdf)

Commission expert group on rare diseases (Formerly EUCERD)

[http://ec.europa.eu/health/rare\\_diseases/expert\\_group/index\\_en.htm](http://ec.europa.eu/health/rare_diseases/expert_group/index_en.htm)

EUROPLAN: European Project for Rare Diseases National Plans Development

<http://www.europlanproject.eu/>

National Rare Disease Plan for Ireland 2014-2018 3.7.2014

<http://health.gov.ie/blog/publications/national-rare-disease-plan-for-ireland-2014-2018/>

An investigation into the social support needs of families who experience rare disorders on the island of Ireland 2008 [http://www.rehab.ie/about/PDFS/July2008/RehabCare\\_RD\\_Report.pdf](http://www.rehab.ie/about/PDFS/July2008/RehabCare_RD_Report.pdf)

**NB: The Business Plan for a co-ordinated care model for 22q11 Deletion syndrome is at first draft stage and will be available upon request when available.**

Anne Lawlor,

Chairperson of 22q11 Ireland Support Group

Ph: 087 7412856

email: [alawlor4@gmail.com](mailto:alawlor4@gmail.com)

<https://www.22q11ireland.org/>

## Community Law & Mediation

CLM is an independent, community-based organisation that works to empower individuals experiencing disadvantage by providing free legal, mediation and information services. At a national level, we seek to have a wider impact through our campaigns for law reform and by acting as a resource for other advocacy organisations.

### Executive Summary

CLM welcomes the approach taken by the Oireachtas Committee on the Future of Healthcare in recognising the need for a cross-party approach on a long –term health strategy.

This submission to the committee looks at the current framework for home care packages. The current framework is non statutory and the provision of services varies throughout the country.

Failure to give appropriate consideration to a person's right to receive care in their home may lead to the HSE and/or the State being in breach of their obligations pursuant to Article 8 of the European Convention on Human Rights as enacted by the European Convention on Human Rights Act 2003.

In light of increasing life expectancy and in order to ensure equitable service provision throughout the State, CLM recommends that the ten year plan for healthcare provision in Ireland provide:

1. A statutory framework for the provision of care in the home;
2. Adequate resources for home care packages; and
3. Adequate resources and supports for family carers.

### Background

Currently in Ireland, a large proportion of older people requiring care and support receive that from their family members. For those who do not have sufficient levels of family support,

there are two principal options: care in a nursing home or remaining at home with the support of a home care package.

## **Current Position**

### ***Current Statutory Framework***

#### ***Obligation to Provide Nursing Home Care***

There is a statutory scheme for the provision of nursing home care, set out in the Nursing Home Support Scheme Act 2009, the *Fair Deal Scheme*. This provides a means for those who require long term inpatient care to access same. It is arguable that the State is responsible for the provision of long term inpatient care<sup>175</sup> but according to a report of the Ombudsman in 2010, the HSE has adopted the position that it is not obliged to provide such care<sup>176</sup>.

#### ***Obligation to Provide Care in the Home / Home Care Packages***

There is a HSE funded scheme of Home Care Packages which is non-statutory. This means that there is no statutory obligation to provide care to people who wish to remain in their home. As there is no statutory obligation, there is no express statutory right for a person to be provided with care in their home.

#### ***The Provision of Home Care Packages in Practice***

A very recent report, *Meeting Older People's Preference for Care: Policy, But What About Practice*,<sup>177</sup> demonstrates that people applying for Home Care Packages will experience different levels of intervention and variation in services depending on where they reside.

The report notes the following issues in relation to the provision of Home Help:

- Long waiting times;
- Red tape and lack of flexibility;
- Time-to-task approach;
- Move away from domestic support;
- Lack of recognition of psycho-social needs<sup>178</sup>.

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<sup>175</sup> Section 52 (1) Health Act 1970

<sup>176</sup> Who Cares: An Investigation into the Right to Nursing Home Care in Ireland: A Report to the Dáil and Seanad in accordance with section 6(7) of the Ombudsman Act 1980, November 2010, pp.51-53

<sup>177</sup> Irish Association of Social Workers, Age Action, The Alzheimer Society of Ireland, UCD, 2016

<sup>178</sup> Ibid. p. 25

The report also states that there were discrepancies in the provision of Home Help based on geographical location<sup>179</sup>. Similarly, for those requiring 'home care attendants', the report identifies that home care attendants were available in some community health care organisation areas but in others, they no longer had home care attendants<sup>180</sup>. The report also comments on how day care and meals on wheels varied depending on geographical location. Furthermore, access to day care also depended on the availability of transport.

The report mentions that staff working within the community healthcare setting said that there are no intensive health care packages available and the only report of the provision of same were two separate reports made by hospital social workers<sup>181</sup>.

The aforementioned report goes into further detail about the assessed need of the person and the actual number of hours provided and notes that medical social workers reported that of the total number of older people receiving home care, 40% were not receiving the number of hours recommended in their assessment. The number of hours provided were based on the availability of funding<sup>182</sup>.

In short, this report detailed wide ranging variation in terms of the nature of supports available and the level of service provided. The report also detailed the difficulty in accessing services, complicated by red tape, delays and funding.

### ***Emerging caselaw***

It is the view of CLM that whilst the failure to put in place a statutory obligation on the State to provide care in the home is not itself a breach of a person's human rights, in certain instances, the failure to offer an appropriate package of care in the home in lieu of nursing home care may result in the HSE being in breach of the person's fundamental rights. There is a commonly understood legal principle in Irish case law known as 'separation of powers', i.e. courts should not infringe on the role of government, including government expenditure, however, in the recent High Court case of CA and TA v. Minister for Justice and Equality [2014] IEHC 532, Mac Eochaidh J stated in this judgment

*"In my view in a situation where an applicant claims that 'direct provision' is having such adverse effects on her life as to cause harm and where such circumstances are backed up by appropriate medical and other independent evidence, a Court would be*

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<sup>179</sup> Ibid. p.25

<sup>180</sup> Ibid. p. 27

<sup>181</sup> Ibid. p. 28

<sup>182</sup> Ibid. p. 29

*entitled to grant appropriate relief, even if the only remedy for the wrong involved the expenditure of additional resources by the State.*<sup>183</sup>

The court in this case (which related to direct provision) suggests that there may be a time that the courts would feel it appropriate to breach the separation of powers. The Judge was relying upon the potential impact on the health and welfare of a person and, as such, the principle could be applicable if the medical opinion were that health and welfare of a cared for person would be adversely affected by not considering their need to be provided medically recommended supports in their home.

Ireland ratified the European Convention on Human Rights by enacting the European Convention on Human Rights Act 2003. Article 8 of the European Convention on Human Rights deals with a person's right to respect for private and family life, home, and correspondence. It states:

*"1. Everyone has the right to respect for his private and family life, his home and his correspondence.*

*2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others".*

In a number of decisions in the United Kingdom, the courts have decided that in assessing the appropriate care for a person, they must consider their Article 8 rights (i.e. their right to respect for private and family life and their home)<sup>184</sup>. Arguably, a court in Ireland could find that the HSE has breached a person's Article 8 rights by not giving any or any adequate consideration to a person's right to remain in their home when recommending the care which should be provided. The aforementioned report, *Meeting Older People's Preference for Care: Policy, But What About Practice*, refers to a number of quotes made during their qualitative analysis which suggest that older people and people with dementia are going into long term care due to the lack of appropriate supports, including supervisory hours<sup>185</sup>.

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<sup>183</sup> Paragraph 12.6

<sup>184</sup> Connor, *Re An Application for Judicial Review* [2004] NICA 45 (14 December 2004); and *Gunter v. South Western Staffordshire Primary Care Trust* [2005] EWHC 1894

<sup>185</sup> *Ibid.* p.34

### ***Varying provision throughout the country***

A major concern, already noted, is the variation in service provision throughout the country. Simply increasing funding levels will not address this issue, however, a statutory obligation would ensure that a person's provision of care is based on need rather than on location.

### ***The Importance of Choice***

CLM advocates policies and practices which allow cared for people to have reasonable control and choice around the type of longer term care which is most appropriate for them. A person should be supported to remain at home for as long as reasonably possible, if that is their wish.

### ***Economic Argument***

The cost of care varies considerably relative to the need of the person and their location. Family Carers Ireland, in their submission to the Oireachtas Committee<sup>186</sup>, have approximated the average daily cost of:

- a) Hospital care;
- b) Nursing home (based on an average);<sup>187</sup> and
- c) Home care<sup>188</sup>.

The figures suggest that the daily cost for hospital care is €909; nursing home care is €128; and home care €76.

In the context of the ever growing ageing population, there is a strong economic impetus for establishing a sustainable framework for home care packages.

Family carers provide a significant level of care in Ireland. Family Carers Ireland estimate that there are approximately 200,000 family carers in Ireland<sup>189</sup>. Their ongoing commitment and involvement should not be underestimated in terms of the importance of the cared for person's identity and social identifier. Family carers significantly reduce the financial cost of nursing home and home care packages on the State whilst often leaving themselves under serious financial and other strains such as health.

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<sup>186</sup> 'There's no Place Like Home' Family Carer's Ireland Submission to the Oireachtas Committee on the Future of Healthcare

<sup>187</sup> These figures are based on HSE National Casemix Reports

<sup>188</sup> Based on payment of Carer's Allowance (€204 p.w.), Carer's Support Grant and Home Help for 2 hours per day at €21 p/h.

<sup>189</sup> <http://familycarers.ie/about-us/merger-story/>

CLM recommends that for older people who choose to live at home, the choice, in so far as reasonable, should be facilitated with adequate resources for care for both the cared for person and the carer.

### ***Summary and Conclusions***

Looking specifically at the questions posed by the Oireachtas Committee on the Future of Healthcare and the subheading 'strategy', the ageing population must be of paramount concern in any future plan for the provision of services. Adequately facilitating a person to remain at home not only respects a person's right to private and family life but also makes economic sense. The failure to provide an express statutory obligation for a home care package facilitates the variation in provision of services and the lack of transparency. Furthermore, where no adequate consideration is given to all forms of care options, including the right of the person to remain in their home, there is a breach of human rights, namely a breach of Article 8 and the protection afforded to family, private and home life. There is strong legal argument for legislating for provision of home care packages.

### ***Recommendations***

- Provide a clear, transparent process set out in statute. There is a great discrepancy between the level of services provided nationwide. A sufficient statutory framework would go some way to removing the discrepancies between the processes and services according to location. There would also be an express obligation on the
- HSE to consider the option of a person's right to remain at home, with sufficient resources to meet their needs.
- In providing a statutory framework, provide sufficient resources to meet the recommendations contained in the cared for person's care plan

Provide adequate resources to support the family carer.

<http://www.communitylawandmediation.ie/>

## Connolly for Kids Hospital Group

This submission is made by the Connolly for Kids Hospital Group (C4KH).

The Committee, in its request for submissions, under the “Strategy” heading, asks interested representatives to examine key priorities for inclusion in a ten-year plan for the health service. Furthermore, the request calls for “relevant factual information, data or case studies from which the Committee could draw conclusions, or which could be put to other parties for their reactions”. As a group of experts it is our aim to set out such information in relation to the National Paediatric Hospital (NPH), a key priority of the future health service plan, and in particular to highlight how critical its location is to the effective discharge of its function.

In this submission the importance of the NPH as the strategic ‘HUB’ of a network for delivery of tertiary, secondary, primary and community care to the children of Ireland is emphasised. The major shortcomings of the proposed St James’s site for the NPH touching on aspects of clinical outcomes, the primacy of maternity co-location, the demographics of the paediatric population countrywide and in the GDA are examined. Access and parking issues for both patients and staff, the needs of a Major Trauma Centre and value for money are highlighted.

### Main Submission

On 23<sup>rd</sup> May 2007 the National Paediatric Hospital Development Board (NPHDB) was established by statutory instrument (SI 246), by the Minister for Health and Children, Mary Harney, on the eve of a general election<sup>190</sup>. Its job was to “design, plan, build, equip and furnish” a national paediatric hospital (NPH).

In 2013, a non-statutory Children’s Hospital Group Board was established. The Government altered the membership and brief of the NPHDB which became “The Builders’ Board”. However, no amendment was ever made to SI 246.

### **The National Paediatric Hospital (NPH) - the strategic ‘HUB’ Hospital**

The forward-looking, though incomplete, National Model of Care for Paediatric Healthcare Services in Ireland Executive Summary (RCPI/HSE, Dec 2015)<sup>191</sup> states that the new NPH will be the ‘HUB’ and the regional and local paediatric units the ‘spokes’ of an integrated National Network for Paediatric Services reaching out into primary and community services for children throughout Ireland.

The Function of the HUB hospital –

- To deliver multi professional, multi-disciplinary Tertiary (highly complex) care, inpatient and outpatient, to Ireland’s sickest or seriously injured children.
- To deliver all inpatient Secondary (less complex) care for children in the Greater Dublin Area (GDA).
- To deliver all anaesthesia required by children in the GDA - for diagnostic procedures, day surgery and inpatient procedures.

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<sup>190</sup>The National Paediatric Hospital Development Board (Establishment) Order, 2007, S.I.246 available at <http://www.irishstatutebook.ie/eli/2007/si/246/made/en/print>

<sup>191</sup>National Model of Care for Paediatric Healthcare Services in Ireland Executive Summary December 2015 available at <https://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatology/modelsofcare/ExecutiveSummaryfinaldraft.pdf>

- To be the sole Emergency Department for children in the GDA (ambulances bypass the Satellite centres at Tallaght and Blanchardstown).
- To deliver and facilitate Educational , Research and outreach service co-ordination to the Urgent Care/Outpatient Clinic Satellites in the GDA, and to the 'spokes' in the Model of Care, to Maternity hospitals and Third Level Education Institutions<sup>192</sup>.

### **Choice of Site**

CHILDREN FIRST –Their HUB hospital - Where should it be?

C4KH supportstrilocation of the HUBPaediatric Hospital witha Maternity Hospital and with an Adult Hospital on an academic campus. However, C4KH strongly opposes the location of the hospital in Dublin's inner city on the St James's hospital campus.Why?

A little background- No report ever recommended St. James's. The only group ever tasked with choosing a site for the new NPH was "The Joint Health Service Executive / Department of Health and Children Task Group to advise on the optimum location of the new National Paediatric Hospital". No children's healthcare professional or service-user representative was on that group. In June 2006 it reported, recommending the Mater hospital site<sup>193</sup>.As a Strategic Infrastructural Development,Planning application was submitted to An BordPleanála (ABP) in July 2011. The site wasrejected<sup>194</sup>.

On 6<sup>th</sup>November 2012, the Cabinet chose the St. James's hospital campus as the site on the recommendation of the then Minister for Health, now senator, James Reilly. The Department of Health press release of that datestates "The decision has been led by clinical considerations". What clinical considerationsled to this choice of site by the Minister?

The following transcript from 23 June 2016 is, to the C4KH group's knowledge, the first public record of the reasons Minister Reilly had presented St. James's for endorsement by Cabinet,on the 6<sup>th</sup> Nov 2012.

Transcript Radio Interview:

Newstalk Programme:Moncrieff<sup>195</sup>

Date: Thursday 23rd June 2016 . Time: 13:50hrs Duration: 03:00mins

### **St James's Children's Hospital Site.Senator James Reilly on Why He Chose the Correct Site to Build the new National Paediatric Hospital**

**Sean Moncrieff:**Senator James Reilly is still with us, we have been talking obviously about the Health Service. And we've had a few texts in here on a kind of similar theme. Please ask Senator Reilly why he chose the Wrong Site at St James's for the Children's Hospital? Blanchardstown is more accessible, faster, cheaper and has the Rotunda going there. No one can explain this Medical Specialty Reason either. Can he?

**Senator James Reilly (Fine Gael):**First of all I didn't choose the Wrong Site. I chose the Right Site. As advised by an Expert Group of both National and International People.

<sup>192</sup>The clinical case for the new children's hospital, its satellite centres and tri-location . Children's Hospital Group. available at <http://www.nchplanning.ie/wp-content/uploads/2015/07/3-Clinical-Case-for-New-Childrens-Hospital.pdf>

<sup>193</sup>Report of the Joint Health Service Executive/Department of Health and Children Task Group to advise on the optimum location of the new national paediatric hospital May 2006 available at [https://www.hse.ie/eng/services/publications/hospitals/Report\\_of\\_the\\_joint\\_HSE\\_Dept\\_of\\_Health\\_task\\_group\\_to\\_advise\\_on\\_the\\_location\\_of\\_the\\_new\\_paediatric\\_hospitals.pdf](https://www.hse.ie/eng/services/publications/hospitals/Report_of_the_joint_HSE_Dept_of_Health_task_group_to_advise_on_the_location_of_the_new_paediatric_hospitals.pdf)

<sup>194</sup>An BordPleanála reference Ref 29N.PA0024

<sup>195</sup>[Seán Moncrieff interviews Senator James Reilly](#). Newstalk106 -108, [NPH comments starts at 13 min into the interview] 23.06.2016

I will actually explain what the primary concern here was. We have a small population, North and South, for some of the more rare conditions. What we wanted to achieve was an economy of scale here, where we would have sufficient numbers to deal with some of the rarest of problems, which currently require our children to go abroad for treatment. Now if you're ill with a condition as an Adult, it's distressing. But when you're a Child, it's particularly distressing, and you want your family around you. So the more people, more children we can treat in this country, that was the goal. So the, being able to bring the Experts, the Super Specialists, who deal with Adults and Children, for these very rare conditions, was a primary concern, and the Primary Clinical Driver.

...certainly, you know, the arguments made around access, and at a Greenfield Site.

I mean you might as well go to a Greenfield Site, no disrespect to James Connolly. Because you know, James Connolly it's an excellent Hospital, but it's a Model 3 Hospital, it doesn't have the Super Specialists in there. The bulk of them are in St James's. The site is plenty big enough, plenty big enough. And it has excellent transport connectivity. Now people talk about a sick child, you're not going to use public transport. That is never the case anyway, because a sick child is always brought in by an Ambulance or parents in a hurry. But the main traffic in any large Hospital like that, is Staff. And the fact that Staff can get in and out in a way that doesn't cause all sorts of traffic problems, because the infrastructure is there, is a huge consideration.

We went through this back and forth and back and forth. And at the end of the day, I am from Fingal, and Blanchardstown is in Fingal, so I mean you know Fingal would have been attractive to me. The Mater was attractive to me. But at the end of the day, the best, the best decision, on the best of advice was St James's. And I believe now what we have to do is, and I know there's a petition out there with 60,000 people saying, you know, move it. Let's please not revisit this. There are children who are in trouble today. This hospital needs to be built as quickly as possible, not delayed by another two years of wrangling. The decision is made. The money is there. Let's build it as quick as we can. So that we can truly say that those dark days, and how we treated children in the past, and God knows they were dark, are done. \\

C4KH completely rejects this utterly ridiculous claim which has no evidence base. There are no rare diseases that can be treated by adult hospital 'super specialists' from an adjacent hospital. Children with rare diseases which cannot be treated in the NPH will continue to be referred to paediatric centres abroad which have global referrals and expertise in particular diseases. No medical literature supports the claim of clinical advantage from adult hospital co-location. There is no clinical advantage to such children of being beside St James' hospital. *Relevant* clinical priorities were set out by the DoH/HSE location Task Group<sup>196</sup>.

Improved clinical outcomes will result first and foremost from the Dublin children's hospitals coming together to form the NPH. The breadth and depth of specialisation (>39 specialities including diagnostic services) will be concentrated *within* the NPH. It is not dependent on adult expertise or equipment in an adjacent hospital.

Where consultants are trained in both adult and paediatric specialist care eg Orthopaedic specialists treating patients with scoliosis, such patients will continue to transition to the various adult hospitals where their consultants do their adult patient work. St James's hospital does not have the capacity (theatres, beds, outpatient clinic availability) to absorb these patients or NPH consultants into its adult services.

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<sup>196</sup> A prioritisation exercise for the collocation of adult hospital specialities with a tertiary paediatric hospital in Dublin, received under FOI, available at <http://thenewchildrenshospital.ie/wp-content/uploads/2011/08/Priorities-co-location-Task-Group-2006.pdf>

### **Maternity- the Essential and Primary Co-location Hospital**

Co-location of the NPH with a full-service maternity hospital is essential, and for children is much more important than co-location with an adult hospital. Obviously sick mothers require co-location with an adult hospital, therefore tri-location of hospitals is best.

Neonates make up a significant proportion of paediatric ICU admissions. Thirty per cent of all paediatric ICU (PICU) admissions to Crumlin and Temple St. Hospital ICUs are newborn babies and 50% of emergency PICU admissions are newborns. Of newborn babies admitted to PICU 50% are from Dublin maternity hospitals and 50% are from other maternity hospitals. 530 critically newborn infants are transferred per annum by the Neonatal Retrieval ambulance service from maternity services nationwide to tertiary paediatric hospitals in Dublin<sup>197</sup>.

As part of its planning application the NPHDB submitted a Draft Site Capacity Study, (no Masterplan was submitted), to ABP, August 2015. It states that building a maternity hospital on the St James's site linked to the children's hospital would require the adult Outpatient building (18 year old) to be demolished and its services relocated, and a new adult Emergency Department, a new ICU and a new Facilities Management hub for the adult hospital to be built<sup>198</sup>.

C4KH holds that such an undertaking defies common sense, would be prohibitively expensive and unlikely to be deliverable within any reasonable timeframe. Meanwhile avoidable deaths in children will continue. The advantages of Maternity and Paediatric hospital co-location are extensively referenced in medical literature<sup>199</sup>.

The following are just some of the many examples of experts stating the primary need for co-location with a maternity hospital:

#### **A submission from the Board of Directors of Our Lady's Children's Hospital Crumlin (Sept. 2006) to the DoHC/HSE 'Transition Group' emphasised the paramount importance of co-location -**

"The new Children's Hospital *must* be co-located with a full-service maternity hospital" including high risk/tertiary neonates. Co-location in this context means an intimate physical adjacency – no more than the width of a corridor – between maternity and paediatric services with neonatal intensive care forming the service bridge between the two. Such a co-location will eliminate the transfer of very sick neonates between hospital sites and speed intervention by the multi-disciplinary paediatric team. *It will effect a lasting improvement in neonatal morbidity and mortality*, benefits which have been demonstrated in well-researched submissions by many obstetric and neonatal consultants. *They are of such a magnitude that the Board believes the maternity component of development should proceed simultaneously with the new Children's Hospital.*"<sup>200</sup>

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<sup>197</sup> From Coombe Women and Infants University Hospital submission to the Dolphin Group (p4), April 2012, (received by the New Children's Hospital Alliance, a C4KH member, under FOI)

<sup>198</sup> NPHDB St James's Campus- Draft site capacity study available at <http://www.nchplanning.ie/wp-content/uploads/2015/07/3a-St-James-Campus-Draft-Site-Capacity-Study.pdf>

<sup>199</sup> References listed in Submission to An Bord Pleanála PA0043 October 2015 accessible through <https://mega.nz/#!KxAjhRgZ!B5-ZE74ENrZAUUsWm6fhXgJH14SdM8dWmWe446WOpK44>

<sup>200</sup> "A world class tertiary Children's Hospital for Ireland" Submission to Transition Group by Board of Management of Our Lady's Children's Hospital Crumlin, September 2006, available at <http://thenewchildrenshospital.ie/wp-content/uploads/2011/08/A-world-class-Tertiary-Childrens-Hospital-for-Ireland.pdf> Our italics

The DoHC/HSE Transition Group 'disappeared' without producing any reports when Minister Harney signed the National Paediatric Hospital Development Board into law in SI 246 in May 2007 on the eve of the General Election.

2. A submission to ABP (Sept 2015) signed by fifteen senior consultants working in Critical Care in Temple St and Crumlin Children's hospitals stated:

"We, whose daily practice involves caring for critically ill neonates, unreservedly support the need for a single, national children's hospital, and are willing to compromise on many fronts to achieve this goal, acknowledging that no site is ideal.

Co-location with a physically linked maternity hospital is, in our expert opinion, non-negotiable. We are unwilling to endorse a national children's hospital on a site that cannot accommodate this truly critical adjacency. To do so would be to fail those infants whom we are entrusted to protect. *To proceed with such a project will result in the avoidable death or disability of many new-born babies for years to come.*"<sup>201</sup>

### **Demographics**

Under the "Strategy" heading the Committee asks what actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population) and their impact on the health system.

The government-commissioned Dolphin Group report<sup>202</sup>, states:

**"The NPH site investigation should take into account the location of the children if the focus is to be on the best service for children"**

### **Ireland's Child Population**

There were just over one million children living in Ireland in 2011 according to the CSO. The number of children in Ireland increased by 10.9% between 2006 and 2011, with the number of 0-4 year olds showing a larger increase (17.9%). This compares to an increase of 8.2% in the general population during this period. Within the European Union (EU), Ireland has the highest proportion of its population who are children, 25% compared to an EU average of 19%. There were 69,267 births in Ireland in 2013...Irish birth numbers and rates peaked between 2008-2009 and a reducing trend has been evident since then.

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<sup>201</sup>*The Department of Cardiothoracic Surgery, Our Lady's Children's Hospital, Crumlin*

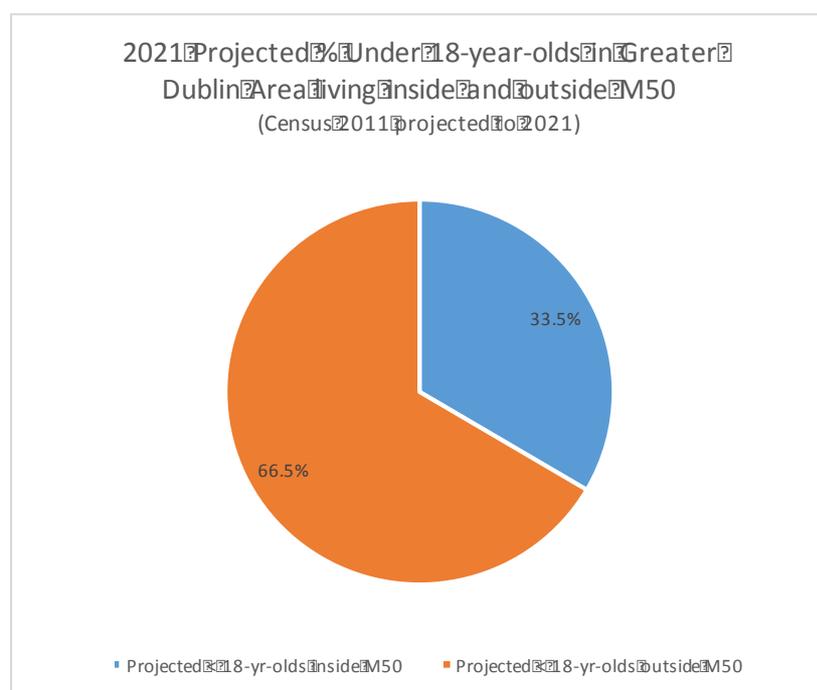
Professor Mark Redmond, Mr Lars Nolke, Mr Jonathon McGuinness; *Department of Cardiology, Our Lady's Children's Hospital, Crumlin* Dr Colin McMahon, Dr Orla Franklin, Dr Paul Oslizlok, Dr Kevin Walsh, Dr Damien Kenny, Dr Terry Prendiville; *The Joint Department of Paediatric Intensive Care Medicine Our Lady's Children's Hospital, Crumlin and The Children's University Hospital, Temple Street*; Dr Martina Healy, Dr. Kevin Carson, Dr Cathy McMahon, Dr Dermot Doherty, Dr Suzanne Crowe, Dr Cormac Breatnach. Our italics

<sup>202</sup>Review group on the National Children's Hospital, Dolphin Report June 2012, appendix 5 A note on Planning Context available at [http://health.gov.ie/wp-content/uploads/2014/08/Dolphin\\_Full-Appendices-1-5.pdf](http://health.gov.ie/wp-content/uploads/2014/08/Dolphin_Full-Appendices-1-5.pdf)

## Ireland's Child Population in the Greater Dublin Area(GDA)

### Child Population in the Greater Dublin Area relative to the M50 (Census 2011)

<18 years old			
County	Pop Inside M50	Pop Outside M50	Total Pop
Dublin City	95,295	0	95,295
Dún Laoghaire-Rathdown	36,297	8,664	44,960
Fingal	0	75,795	75,795
South Dublin	16,135	55,074	71,208
Kildare	0	59,449	59,449
Meath	0	53,400	53,400
Wicklow	0	36,444	36,444
<b>Total</b>	<b>147,726</b>	<b>288,825</b>	<b>436,551</b>
<b>Total %</b>	<b>33.8%</b>	<b>66.2%</b>	



These figures demonstrate the current and projected major paediatric GDA population requiring inpatient secondary and tertiary care resides outside the M50.

### Demographics: Satellite Units for GDA patients

The Emergency Department at the NPH will serve both urgent care and emergency patients. Satellite units deliver urgent care (not emergency) and certain outpatient clinics during restricted hours, will have 6-8 observation beds and will not receive ambulances.

The NPHDB in its planning application August 2015<sup>203</sup> states:

#### **“Northside Satellite Location**

Connolly Hospital, Blanchardstown offered advantages over Beaumont Hospital in relation to the development of the Satellite Centre including less need for enabling work; shorter programme; lower capital cost; lower risk; and less impact on future development potential. Locating at Connolly would result in a Paediatric Population of

<sup>203</sup>NPHBD Planning Application, EIS, Chapter 4 Examination of Alternatives, section 4.3.10 “Satellite Centres Review of a Plan for the Ambulatory and Urgent Care Centres”

99,401 within a 30 minute travel time zone, with 43.6% classified as experiencing deprivation and 22.1% experiencing moderate to high deprivation.”

**“Southside Satellite Location**

A southside Satellite Centre, based at **Tallaght Hospital** would have a catchment of 99,481 children of whom 38.5% are classified as experiencing deprivation and 19.4% as moderate to high deprivation."

**“St. James’s Location**

The corresponding main hospital catchment zone would take in a paediatric population of 75,157." [Deprivation level not stated]

The NPHDB application to ABP quotes the <16 year olds population for the catchment area of the two satellites and the NPH as 274,039. The total population of <16 year olds of Dublin City and County is 259, 227 and of Kildare, Meath and Wicklow is 136,104. Most of the paediatric population of Kildare, Meath and Wicklow therefore seems unaccounted for in the application. It is unclear where these children are expected to attend. C4KH fails to understand why the NPH should be built in the area of lowest paediatric population. C4KH further notes that the Satellite Centres will be closed at night and have no inpatient beds.

< 18 years old			
County	Pop Inside M50	Pop Outside M50	Total Pop
Dublin City & County	147,726	139,532	287,258
Mid-East Counties	0	149,293	149,293
<b>Total in GDA</b>	<b>147,726</b>	<b>288,825</b>	<b>436,551</b>

< 16 years old			
County	Pop Inside M50	Pop Outside M50	Total Pop
Dublin City & County	131,618	127,609	259,227
Mid-East Counties	0	136,104	136,104
<b>Total</b>	<b>131,618</b>	<b>263,713</b>	<b>395,331</b>

<sup>204</sup>

Demographics and Tertiary patients

Tertiary patients are heavy users of hospital care. They have more frequent and longer admissions than secondary care patients. They travel by car – 75% of them from outside the M50. They wish to stop at the M50. Also, many children living inside the M50 live in suburbs close to the ring road and can more easily access the M50 than the city centre.

The following profile of patients attending Our Lady’s Children’s Hospital Crumlin illustrates this point -

- 75% of Tertiary care patients live outside the M50.
- Tertiary care patients account for >50% of all day case admissions.
- Day case admissions account for 60% of all admissions.

The reason that C4KH has had over 60,000 signatures and that 19 county councils around the country support our call for the M50 site is particularly due to concern for these children. These citizens understand the needs of these children and their families. Tertiary care children are our most vulnerable children, they and their families require our special respect, support and care.

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<sup>204</sup>Figures from CSO Census 2011

**Access to and Parking at St James’s**

Ambulances–the National Ambulance Service(NAS) informed the Dolphin group(F.O.I.data) that “exemptions provided to ambulances do not increase their speed in high-traffic areas....[and]...an important factor in relation to location is good access to a major thoroughfare such as the M50.<sup>205</sup>

C4KH wishes to emphasise the NPH will be the *only* facility receiving ambulances from the whole of the GDA(ambulances will bypass the satellite centres). C4KH is dismayed by the single lane access roads,the limited entry points to the James’s campus, the single narrow congested through-road in the narrow campus and GDA’s only paediatric Emergency Department being buried at the back of a new National Hospital.

**Car Parking**

Understandably Dublin City Council doesn’t want more cars on the narrow roads of the inner city.However, sick children travel by car. Therefore, the NPH, a new 21<sup>st</sup> century children’s hospital, should not be in the city.

Parking Spaces per bed in Children’s Hospitals Worldwide



Children’s Hospitals worldwide	Spaces per bed
Colorado, USA	14
Boston, USA	8.8
Melbourne, Australia	6.4
Toronto, Canada	4.4
NPH at St James’s, Ireland	1.3

Dublin city council restricts on-site parking to 2000 spaces, now and in the future, in the context of a staff complement of 8,300 (St James, NPH, maternity) and a total of 1733 bed numbers<sup>206</sup>. This is woefully inadequate.

<sup>205</sup> Minutes of Dolphin Group Meeting 2 May 2012, received under FOI

<sup>206</sup> 1020 St James, 473 NPH, 240 maternity

ABP's inspector's report on the NPH at the Mater stated "that the parking provision which is considered to be sustainable within a city centre location would be inadequate to facilitate the effective operation of the proposed development"<sup>207</sup>.

C4KH believes that this applies even more so to St. James's. Children first?

### Helipad

It is unacceptable that as the major referral centre for children thenew 'HUB' hospital for the children of Ireland cannot accommodate a ground helipad required for Coastguard Sikorsky helicopters, contrary to a recentDoH recommendation. "It is recommended that all future acute hospital developments in the State take into consideration the need for inclusion of a ground helipad, to facilitate the arrival of patients via the EAS and SAR, inter-hospital transfers and the transport of organ transplant patients and teams".<sup>208</sup>

### Major Trauma Centre

The NPH will be the country's Major Trauma Centre for children. As the NPH is the only hospital with a Children's Emergency Department and inpatient beds for children in the whole of the GDA, it is essential that it is accessible by ambulances and helicopters at all times. An emergency Major Incident event in Dublin city might easily challenge the accessibility of a NPH at St James's, an area already susceptible to gridlock. The M50 and its hard shoulder, and a ground helipad at Connolly Hospital would appear to be the correct choice.

Co-location of adult and paediatric Major Trauma Centres offers advantages for Major Incident planning (for example a ground level helipad). However, the distribution of tertiary adult services across the metropolitan Dublin area is fragmented<sup>209</sup> so there is no obvious co-location partner for the children's hospital. The development of the campus at Connolly is the logical choice for such a facility in the 21<sup>st</sup> century.

### Value-for-Money

Both the NPH Independent Review's Financial Analysis(2011)<sup>210</sup> and the Dolphin Report (2012)<sup>211</sup> state that a greenfield site would be **25% cheaper** to build on than an inner city site. The demolition and rebuild of the adult St. James's to facilitate an on-site Maternity hospital raises significant questions regarding Resource Allocation. Building at Connolly Hospital would not only recoup the sunk costs of the Mater and James's sites but money saved could be put towards the co-build of the new Rotunda Maternity Hospital, corridor-linked to the ICU of the NPH.

## **RECOMMENDATIONS**

In 2012 the National Sports Campus Ireland offered 90 acres of adjoining land, expandingthe Connolly Campus from 50 to 145 acres.This and the upgrading of the M50/N3 interchange makes the Connolly campus emerge with the potential to be a truly superb 21<sup>st</sup> century Academic Health Sciences centre.A NPH here would reflect the requirements mentioned in the main body of this submission and allow it to be a superb hub of the integrated National Network for Paediatric Services for Ireland.

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<sup>207</sup> An Bord Pleanála Report PA0024, Jan.2012

<sup>208</sup> Report of the Emergency Aeromedical Support Service Working Group, November 2014 available <http://health.gov.ie/wp-content/uploads/2016/05/Report-of-the-EAS-Working-Group-final-version-11.11.14-minus-watermark.pdf>

<sup>209</sup> National Paediatric Hospital Independent Review DoH, 2011, available at <http://health.gov.ie/blog/publications/national-paediatric-hospital-independent-review/>

<sup>210</sup> DoH National Paediatric Hospital Independent Review's Financial Analysis available at <http://health.gov.ie/blog/publications/national-paediatric-hospital-independent-review/>

<sup>211</sup> Appendix 4 " Greenfield and urban sites: background note on the cost issues" available at [http://health.gov.ie/wp-content/uploads/2014/08/Dolphin\\_Full-Appendices-1-5.pdf](http://health.gov.ie/wp-content/uploads/2014/08/Dolphin_Full-Appendices-1-5.pdf)

**We recommend** that the Committee support the development of the National Paediatric Hospital with the re-located Rotunda Maternity Hospital on this site. This project would offer value for money and should be fast tracked.

Signed

Dr. Fin Breatnach  
C4KH spokesperson

Dr Roisin Healy  
C4KH spokesperson

<http://connollyforkidshospital.com/about-us/>

## Chronic Obstructive Pulmonary Disease Support Ireland

**COPD Support Ireland** is the only national patient led advocacy group for people living with Chronic Obstructive Pulmonary Disease (COPD). As a national charity, COPD Support Ireland was established to support all those living with COPD.

As a membership based national network, COPD Support Ireland is ideally placed to make recommendation to the Oireachtas Committee on the future of healthcare from a patient's perspective. Our membership is made up of those living with COPD and their families. Established in 2013 we have been documenting the impact of living with COPD on sufferers and their families.

It is estimated that in Ireland 380,000 people have Chronic Obstructive Pulmonary Disease (COPD), of whom over 180,000 have moderate or severe disease, only half of whom may be diagnosed<sup>212</sup>. It is a disease that becomes more common with increasing age.

COPD is the cause of at least 1500 deaths in Ireland each year. There are approximately 13,500 admissions to our hospitals each year with an average of 9.5 days in hospital, representing approximately 130,000 bed days utilised. It is the main cause of acute medical hospitalisation of those over 35 in Ireland.

The National Healthcare Quality Reporting System (NHQRS) reported that Ireland has the highest rates of hospital admissions in the OECD for COPD with more than double the OECD average.<sup>213</sup> The total cost of COPD hospitalisations in 2014 was €70,813,040.<sup>214</sup>

It is the only significant cause of chronic disease which is getting more common and as reported in Health in Ireland – Key Trends 2015, COPD is the most common disease-specific cause of emergency admissions and is a major contributor to overcrowding in our hospitals.

Chronic obstructive pulmonary disease (COPD) is a chronic disease of the lungs associated with narrowing of the airways and producing symptoms of cough and shortness of breath. The damage in the lungs is not reversible but does respond to treatment. Patients are liable to suffer acute

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<sup>212</sup> Schirnhofner L, Lamprecht B, Vollmer WM, Allison MJ, Studnicka M, Jensen RL, et al. COPD Prevalence in Salzburg, Austria: Results from the Burden of Obstructive Lung Disease (BOLD) Study. Chest. 2007

<sup>213</sup> Department of Health: National Healthcare Quality Reporting System, Second Report 2016

<sup>214</sup> HSE Ready Reckoner Available from:

[www.hse.ie/eng/services/list/1/schemes/cbd/Ready%20Reckoner.pdf](http://www.hse.ie/eng/services/list/1/schemes/cbd/Ready%20Reckoner.pdf)

deterioration in their disease associated usually with infections which lead to exacerbations. These exacerbations cause the patient to present to either their family doctor or sometimes to the emergency department of hospitals in need of intervention and unfortunately frequent admission to hospital.

The Health system in Ireland needs reform, we all need to use the health services at sometime in our lives. Unlike many of our European neighbours, Ireland never developed universal access to health services. The funding model for primary care in Ireland is radically different compared with our EU neighbours, which results in people without medical cards facing the highest GP charges in the EU.<sup>215</sup> Irish drug prices are high compared to other EU countries. Hospital waiting lists are increasing which impact on diagnosis, treatment and outcomes for people.

The National Clinical Programme for COPD (NCP COPD), as part of the National Clinical Programmes in the HSE, has a key role and function in reducing admissions to hospital and supporting best practice in primary care solutions. This clinical programme would be ideally placed to generate the overall plan for COPD Care into the future.

## **Recommendations**

- a). National COPD Care Plan be developed as part of a National Respiratory Strategy
- b). People have an entitlement to a health care system that is free at the point of access for all
- c). The scale of the problem should be accurately reflected in appropriate national documents including mortality in annual publication of Department of Health - Health in Ireland: Key Trends
- d). National campaign to raise awareness of key early symptoms among general public, those at risk and health care professionals together with timely access to quality diagnostic spirometry services
- e). Spirometry testing in Primary Care and a reimbursement scheme for General Practitioners
- f). Pulmonary Rehabilitation Programmes with follow up exercise programmes for all - regardless of geography tailored to ability as recommended by international best practice
- g). Investment in self-management programmes for people living with chronic illness
- h). Quality pharmaceutical treatment is required, key to which is instruction in inhaler technique in addition to appropriate prescribing. International and national evidence (see appendix) indicates that inhaler technique is frequently poor and can be a key factor in exacerbations.
- i). Flexibility in structures for the more complex cases, between General Practice and specialised respiratory expertise including Outreach programmes, Rapid access clinics etc.

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<sup>215</sup> Health Reform Alliance [www.healthreformalliance.ie](http://www.healthreformalliance.ie)

- j). Solutions implemented at a national level to address the social inequality aspects of the disease with an immediate focus on the hardship caused by the disease in terms of electricity, heating, travel etc.
- k). Oxygen therapy: Patients on oxygen should be provided with enough mobile oxygen cylinders as required to live an active and mobile life as possible. Current practice restricts the number of litres available per month which can seriously impact the mobility and social engagement of a person with COPD, thereby causing unnecessary mental health problems and additional medical costs.
- l). Reimbursement scheme for home oxygen home therapy: Patients prescribed oxygen need to be supported to run the oxygen with a reimbursement payment for their electricity. On average, oxygen therapy can increase the monthly bill by up to €45.
- m). The health system is a universal, publicly funded system.

## Strategy

Key Priorities in a 10 year plan:

Access to diagnosis: It is estimated that there are in excess of 380,000 people living with COPD in Ireland but only 120,000 are diagnosed.<sup>216</sup> Many people with signs and symptoms of COPD are not being properly diagnosed in primary care. The most effective way to diagnose COPD is through a spirometry test. Spirometry testing can and should be provided in primary care. The NCP COPD submitted requests for funding for additional resources to support the diagnosis and management of COPD through the HSE's estimates process for the 2017 National Service Plan

Pulmonary Rehabilitation (PR): Pulmonary Rehabilitation Programme (PRP) is defined as "...a comprehensive intervention based on a thorough patient assessment followed by patient tailored therapies that include, but are not limited to, exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviours".<sup>217</sup> High levels of scientific evidence (IA, IIA, Cochrane Review) have demonstrated improved exercise capacity and health related quality of life and decreased breathlessness, fatigue and health care utilization following PRP.

PRPs need to be available on a continuous basis in every acute hospital or community with follow up programmes available. The new Respiratory Integrated Service, with a Clinical Nurse Specialist and a Physiotherapist in the community which is funded by the HSE's Primary Care Division, needs to be expanded nationwide as developing PRP is a key part of their role.

The NCP COPD continues to emphasise the importance of Pulmonary Rehabilitation in the management of COPD. Pulmonary Rehabilitation is now in 22 hospitals and 27 local areas. However capacity is very limited. In order to ascertain further insight into the services provided, the NCP COPD participated in a Needs Assessment and Audit for Pulmonary Rehabilitation in conjunction with HSE Health & Wellbeing Division.

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<sup>216</sup> Irish Thoracic Society, 2013. Lung Disease in Ireland - Prevalence and Trends: Implications for work force planning

<sup>217</sup> Spruit MA, Singh SJ, Garvey C., ZuWallack R., Nici L., Rochester C. et al. An Official American Thoracic Society / European Respiratory Society Statement: Key Concepts and Advances in Pulmonary Rehabilitation. Am J Respir Crit Care Med 2013. Vol 188(8);e13-e64.

Treatments at home: COPD Outreach programme is "a service that provides active treatment for a limited time period in a patient's home of a condition that otherwise would require hospital inpatient care" Shepperd & Liffie (1998). Outreach is an economic alternative to inpatient care, is safe, well tolerated, and offers patients a choice (Gravil et al., 1998; Davis et al., 2000 and Swarska et al., 2000).

The principle aim of a COPD outreach service is to improve services offered to people living with COPD in a quality safe manner. An outreach programme currently facilitates early discharge from hospital and enables people to build confidence in effectively managing their chronic condition. As services are established they may, over time, accept patients directly (admission avoidance) dependent on service capacity and appropriate governance structures being in place. Currently it provides a "Hospital at home" Programme for a select group of COPD patients that would otherwise require acute inpatient care within 72hrs of admission.

Programmes are consultant led and driven by an outreach field team (specialist respiratory nurse and senior physiotherapist) in collaboration with a multidisciplinary team across Primary and Secondary care. Patients enrolled in an early supported discharge programme remain under the care of the lead consultant for the first fourteen days following discharge when they revert back to the care of their GP.

The NCP COPD continues to support the COPD Outreach Programme with services located in 12 acute hospitals. Over 1,830 were accepted to the outreach services between June 2015 and July 2016.

This programme needs to be expanded to include all acute hospitals nationwide. Patient dignity and preference for home treatments when possible coupled with the economic savings should ensure that this programme is resourced over the next 10 years to allow for every acute hospital to put in place an outreach programme.

Respiratory Consultants: Many of the COPD care programmes need to be led by a respiratory consultant. Yet 3 major acute hospitals do not have a Respiratory Physician and this severely impacts on the programmes that can be delivered. COPD Support Ireland believes that given the current chronic situation of COPD care in Ireland a dedicated consultant for COPD should be piloted in major urban areas which have the highest rates of COPD to ensure a greater focus on COPD care and such a post should oversee the development of an integrated service between primary and secondary care.

Respiratory Integrated Care Services: Respiratory Integrated care is a new HSE/primary care programme designed to improve the care for people with lung conditions that are long term such as Asthma and COPD. Patients receive specialist nursing and/or physiotherapy support for lung conditions in their local primary care setting. This individual support will reduce the need for people with COPD to attend hospital. It will help people to learn how to manage your condition themselves.

This service will require annual investment to ensure that every primary care area has a respiratory integrated service.

Poverty Impact Assessment: People living with chronic diseases like COPD should not face financial hardship due to their illness. The financial threshold for medical cards should be extended for people living with a chronic disease.

Poverty Impact assessments (PIA) need to be comprehensive and include all relevant policy areas especially health policy. This requires a strong commitment by the Department of Health and Ministers to adhere to the spirit and provisions of the 1997 National Anti - Poverty Strategy (NAPS) and the current National Action Plan for Social Inclusion (NAPS Incl) 2007-2016. We need to see an assessment of all relevant taxation and spending decisions, including but not confined to health, welfare and public services.

Assessments also need to be a planning and not just reporting process. Poverty Impact and Social Impact Assessment must be overtly used to direct individual health policy decisions and overall budget strategy.

PIAs need to involve meaningful consultation with those impacted on by the health policy measures and be part of public debate, including debate in the Oireachtas, on the implications of different policy options for poverty and the impact of the choices made. They need to involve assessment using a range of indicators, not just the numbers at risk of poverty, and look at the actual impact on people's lives, following the central principle of Ireland's anti-poverty strategies which recognise poverty as multi-dimensional.

#### Key Challenges:

Resources for COPD care are limited in both human and financial terms. A National respiratory strategy needs to be financed appropriately within the health budget that would include resources for COPD.

GP contract negotiations regarding chronic disease management. GPs need to be incentivised to manage COPD in primary care settings. Contract negotiations need to include diagnosis (spirometry testing) and management of COPD and costed appropriately. This requires ongoing consultations with the GP representative bodies.

Changing perceptions of COPD. There is a stigma attached with COPD, often referred to as a smokers disease that affects older people. This can impact on mental health, investment in treatments and in the care of people with COPD.

Public awareness of COPD needs to change so that recognition of the signs and symptoms of COPD will lead to earlier diagnosis of the disease. Investment in such campaigns require long term planning as impacts are not immediate.

Engaging with people with COPD – COPD can be a very isolating disease due to the limited mobility of sufferers and the public perception of the disease.

### **Integrated Primary and Community Care**

There are currently 4 Integrated Respiratory Care Teams in place and the further 6 expected later in the year. Investment in the coming years in these posts will ensure that a focus on treatment and management of COPD in Primary Care is prioritised and should lead to reduction in hospitalisations of unnecessary COPD admissions.

<http://copd.ie/>

## CSC (Digital Transformation)

CSC is a global leader in digital transformation, providing innovative next-generation technology solutions and services that leverage deep industry expertise, technology independence, and an extensive partner community. As a global healthcare IT company we have intimate knowledge of healthcare systems all over the world and it is from this position that we are making this submission to the Oireachtas Committee on the Future of Healthcare.

It is CSC's view that the cost to Irish society, as well as the health and wellbeing of Irish citizens, should be central to any assessment of future healthcare reform. In this submission, we are proposing a model for mandatory health insurance coverage for the whole population of Ireland, based on a basic but comprehensive package of healthcare services. CSC's point of view is based on evaluating the components of the present healthcare system in Ireland, its system of financing, and the demographic and epidemiological trends for the next ten years.

CSC supports the introduction of a single-tier health system, where access is based on need rather than ability to pay, healthcare funding is ring-fenced and financed by taxation. The implementation of the new system should be phased in and first steps have already been taken by such measures as the introduction of the Special Delivery Unit, the provision of free GP care at the point of use for the most care-intensive sections of the Irish population, etc. We believe in the idea behind such steps - removing the barrier to healthcare access and encouraging them to seek treatment at an earlier stage, rather than delaying it until the point at which the illness requires hospitalization. We also believe in rewarding citizens for healthy behavior and engaging them in the management of their own health.

In our view, the government should introduce and finance mandatory universal healthcare coverage by subsidizing a basket of hospital, primary care, and medication expenditures accessible to all citizens of Ireland. The government should fully cover those on low incomes and subsidize healthcare expenditures for other demographic cohorts. We envisage a diverse system of healthcare providers, public, non-profit, and private, competing to deliver value for money to a single-payer agency, set up by the government. In CSC's opinion, a single-payer system is particularly adequate for Ireland - such a payment mechanism is an effective tool for controlling healthcare costs.

Ultimately, as an information technology company we believe in the integration and digitalization of all healthcare service tiers in Ireland and the introduction of a single electronic record for every citizen-patient. While technological change in healthcare may result in conditions becoming treatable, which were previously not treatable, and thereby increasing expenditure, there is a plethora of international evidence<sup>218</sup> that healthcare technology facilitates prevention, treatment in non-acute settings, and patient engagement and has a substantial long-term cost-saving effect.

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<sup>218</sup> Maev-Ann Wren, Sheelah Connolly, Nathan Cunningham, An Examination of the Potential Costs of Universal Health Insurance in Ireland (September 2015), ESRI Research Series, Number 45.

CSC believes that the key priorities for inclusion in a ten-year plan for the health service are as follows:

1. Transition from a physician-centered to a patient-centered healthcare system.
2. Expanding patient access to and choice of healthcare services.
3. Integration of all health service tiers – primary, secondary, and community care.
4. Single electronic patient record underpinning an integrated healthcare system.
5. Digitalization – move to a secure paperless system.
6. Inclusion of physicians and patients in healthcare governing bodies.
7. Move towards a cost-effective, outcome-based healthcare system.
8. Diversification of healthcare provision services with public, non-profit, and private sector participation.
9. Separating healthcare reform from political ideology and vested interests.
10. Achieving all of the above without disproportionately increasing healthcare spending as a percent of GDP.

### **Challenges, barriers, and some considerations for achieving a universal single-tier health service in Ireland**

In CSC’s view, the key challenges to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay” are:

1. Private and public hospital care not equally accessible to all patients.
2. Lack of focus on patient, prevention, and patient wellbeing and keeping people healthy in general.
3. Low quality of healthcare services.
4. Low levels of digitalization and system integration.
5. Lack of healthcare system efficiency, effectiveness, and incentives for innovation.
6. Sticking with cost-inflationary practices such as a pay-for-services system as opposed a pay-for-performance or any other kind of an outcome-based system.
7. Scarcity of qualified clinical labor force.

In CSC’s view, the key roadblocks that need to be addressed in the Irish healthcare system today, are:

#### **Key organisational and management barriers**

1. Bringing together primary medical services and community health providers around the needs of individual patients.
2. Addressing an unsustainable acute sector.
3. Developing capacity in primary care to take on new services.
4. Managing demand and developing new care models.
5. Establishing effective clinical leadership.
6. Overcoming professional tribalism and turf wars.
7. Addressing the lack of good data and healthcare IT to drive integration, e.g., in targeting the right people to receive it.
8. Involving the public and creating a narrative about new models of care.
9. Establishing new forms of organization and governance (where these are needed)

## **Key policy barriers**

1. Payment policy that encourages acute providers to expand activity within hospitals (rather than across the care continuum).
2. Payment policy that is about episodes of care in a particular institution (rather than payment to incentivize integration, such as payments for care pathways and other forms of payment bundling).
3. Under-developed commissioning that often lacks real clinical engagement and leadership.
4. Regressive policy on choice and competition.
5. Lack of political support and consensus for changes in healthcare centrally and locally.

Our considerations for the actions needed to plan for, and take account of, future demographic pressures, are:

1. Keep older and sicker people out of extended hospital stay - build a viable and affordable community-based health and wellness delivery system.
2. Incent the provision of digital patient engagement and wellness tools and applications.
3. Focus on disease management and prevention, especially for common chronic conditions (e.g., diabetes, hypertension, COPD).
4. Create a functional and sustainable system for long-term and palliative care.
5. Invest in healthy aging in order to achieve lower disability rates.

## **A single-tier health system, based on need rather than ability to pay**

Our recommended steps needed to move from the current model towards a model based on integrated primary, secondary and community health care are:

1. Transition from hospital-centered to patient-centered system.
2. Change from transactional and isolated treatment to a care-team managed model.
3. Shift care emphasis from care about the sick in the most expensive environment toward prevention, healthy lifestyle and wellness.
4. Move from a bureaucratic healthcare service to a patient-centered, proactive, and 24/7 responsive system.
5. Joint stakeholder planning with the following components:
  - a. Joint strategic needs assessment
  - b. promotion of a community focus and organizational autonomy;
  - c. guide for collective decision making;
  - d. multi-level partnerships;
  - e. focus on continuum of care with input from providers and users.
6. Integrated information and communication technology:
  - a. systems designed to support shared clinical exchange i.e., a shared electronic health record;

- b. a tool for systems integration linking clinical processes, outcomes and financial measures.
- 7. Healthcare management devolution:
  - a. Healthcare managed locally;
  - b. committed resources;
  - c. strategies to manage change and align organizational cultural values;
  - d. executive and clinical leadership.
- 8. Shared clinical priorities:
  - a. Agreed target areas for redesign;
  - b. role of multi-disciplinary clinical networks/panels;
  - c. pathways across the healthcare continuum.
- 9. Incentives to strengthen care co-ordination and for the development of innovative and alternative healthcare models.
- 10. Focus on population health by geography.
- 11. Outcome measurement:
  - a. Using data as quality improvement tool;
  - b. shared population clinical data used for planning, measurement of utilization, focusing on quality improvement, and redesign;
  - c. collaborative approach to measuring performance which provides transparency across organizational boundaries.
- 12. Continuing professional development:
  - a. Supporting the value of teamwork
  - b. Inter-professional and inter-organizational learning opportunities providing training to support new ways and align cultures;
  - c. clearly identifying roles and responsibilities and guidelines across the continuum.
- 13. Patient and community engagement.
- 14. Support for clinical process and technological innovation.

### **Ensuring buy-in from Irish health care professionals**

To ensure buy-in from health care professionals to progress towards an integrated health care model, we envision the following stepping stones:

1. **Clinical leadership.** If changes in healthcare delivery are to succeed, it is crucial that clinicians (especially physicians) play a prominent role. They must learn to see themselves not only as the professionals who deliver patient care but also as partners in - and, ideally, leaders of - the change effort.
2. Strong organizational and leadership commitment is crucial for an **integrated care team** to become as effective as it can be. Identifying an implementation leader who can facilitate the integrated care.
3. **Shared Vision.** Creating a vision builds a shared understanding within integrated care teams of their common purpose and future goals. A crucial first step in creating a shared vision is describing the healthcare you seek to give. A powerful vision outlines

a compelling reason for change, builds team commitment, and motivates people to move out of their comfort zone and away from the status quo.

4. **Clear Roles.** The success of an integrated care team relies to a great extent on each member understanding his/her role and believing he/she has the knowledge and skills necessary to fulfill that role. Care teams that focus on the functions of team members as opposed to narrowly defined professional titles and roles have a greater ability to navigate work flows, communicate effectively, and tackle unanticipated challenges.
5. **Shared Goal.** Effective integrated care creates a team in which all of the providers work together on a single treatment plan. This gives the team a clear focus, particularly when combined with a treat-to-target approach.
6. **Continued Nurturing.** Changing expectations and goals combined with personnel turnover requires continued nurturing and constant evaluation at the operational, process, and interpersonal levels, especially for junior physicians.

### **Best Practices**

As an example of best practices in coordinated care for the patient we would refer to the innovative Trafford Care Co-ordination Centre (TCCC). CSC is working with the Trafford Clinical Commissioning Group (CCG) in Greater Manchester to co-create a first-of-its-kind care coordination center. The TCCC aims to provide patients, families and care providers with significantly improved patient experience and efficiency across Trafford's healthcare system.

The TCCC is based on a new care model that works like an air traffic control system, tracking patients as they move through the system and guiding them to different services in an efficient manner. The journey begins with a referral from the patient's GP (doctor) and the care pathway is mapped out using recognized clinical tools and protocols, such as Map of Medicine, a clinical tool that lets physicians plan care according to the best information available.

Each patient is assigned a designated care coordinator who has a host of resources and interfaces available to make practical arrangements, such as booking appointments or arranging transportation to and from a hospital. The continuous tracking of patients allows Trafford CCG to understand what kind of services they access and what kind of services they need to access. Services range from initial patient communications via a unified communications system, to clinical workflow based on a catalog of services, to back-end analysis of the effectiveness and efficiency of care delivery.

### **Funding Model: Universal Access Single-Payer Insurer Healthcare System**

We support a universal healthcare single-payer insurance system for Ireland. Financing such a system would be mainly through mandatory health insurance contributions in the form of an earmarked income tax. The responsibility for financing emergency care for uninsured people, as well as for ambulance services and public health programs would be left to the

Department of Social Protection. The main purchaser of healthcare services for insured people would be a Healthcare Commissioning Agency (HCA). Responsibilities of the HCA would include contracting with healthcare providers, paying for health services, and reimbursing pharmaceutical expenditure as a part of a basic basket of healthcare services for all Irish citizens. We propose the phased-in implementation of free GP care at the point of use for all citizens as a part of this universal access model. Primary care is the first point of contact with the healthcare system with GPs carrying out a partial gatekeeping function for secondary care, although citizens under this proposal could access specialists directly. The HCA would purchase care for patients from primary care providers, independent not-for-profit Hospital Trusts and private hospitals.

Private insurance would remain a complementary and relatively small component of the total national healthcare expenditure. Despite the increased cost-sharing with the onset of the economic downturn, out-of-pocket expenditure should decrease proportionally. For the resource allocation healthcare mechanism, we propose a system of money-follows-the-patient (MFTP), under which treatment of additional patients will generate additional revenue for providers. The MFTP will also encourage treatment at the lowest level of complexity, in order to reduce system-wide costs. A longer-term aim would be to allow money to follow the patient out of the hospital setting.

The available evidence<sup>219</sup> suggests that health systems financed through social health insurance are more costly than systems financed through taxation. It may be that it is not the financing mechanism that causes higher expenditure but rather health system features which are associated with a particular financing mechanism. It is also true that multiple payers are common in insurance-based systems however, multiple payers are not a necessary design feature of insurance-based systems and there are examples of single-payers within insurance-based systems (i.e., Estonia and Slovenia). It should also be noted that health-financing systems based on multiple insurers have higher administrative costs, whereas countries with single-tier schemes, such as Estonia, Hungary, Poland and Slovenia have lower administrative costs. Caution is required when looking at such cross-country comparisons as the definition of health expenditure may differ across countries.

While tax-based healthcare systems seem to have come through the recent economic downturn relatively intact, concern has been raised about the long-term sustainability of the health financing system. Various economists<sup>220</sup> have raised concerns about relying solely on wage-based contributions when the population is ageing and the working age population share is decreasing. Some of them have recommended that in the long-term, healthcare financing should also include more tax revenue based on capital, dividends and consumption, as well as government contributions to the HCA on behalf of retirees<sup>221</sup>.

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<sup>219</sup> McDaid D, Wiley M, Maresso A and Mossialos E. Ireland: Health system review. *Health Systems in Transition*, 2009; 11(4): 1 – 268.

<sup>220</sup> Maev-Ann Wren, Sheelah Connolly, Nathan Cunningham, *An Examination of the Potential Costs of Universal Health Insurance in Ireland* (September 2015), ESRI Research Series, Number 45.

<sup>221</sup> Thomson, S., T. Habicht, et al. (2010). Responding to the challenge of financial sustainability in Estonia's health system. Copenhagen, WHO Regional Office for Europe.

### **Recommendations for action by the Government which the Committee should consider in preparing its report**

The Committee should consider setting up a national Healthcare Commissioning Agency as a single-payer agency to purchase healthcare services from a range of public, non-profit, and private healthcare providers. Primary care services would be a central part of an integrated package of services provided under the proposed system, with service entitlements on a stratified basis, linked to patient needs, as follows:

- At the basic level, every member of the population should have a universal entitlement to core primary care services provided by GPs, practice and community nurses. At the other extreme, the highest risk healthcare users (i.e., the top 3-5 per cent of the population who account for 40 per cent of all inpatient bed days and who are likely to suffer from multiple chronic conditions) should be entitled to formal case management support.
- The standard healthcare package should encapsulate acute inpatient, outpatient and day case care. Recognizing the fundamentally curative nature of rehabilitative care, such care should be included in the standard package subject to an overall time limit.
- Given the strong 'public good' nature of A&E department services, we suggest that, under a single-payer model, such emergency services might be most efficiently and effectively provided to the population by being excluded from the standard package and separately funded by the state.
- Everyone should be covered under the standard package for necessary mental health services provided a) by community mental health teams (including child and adolescent mental health teams), b) in out-patient clinics, day hospitals and day centres and c) in acute inpatient settings, when necessary. These services should include addiction counselling, social work and occupational therapy services.
- We also suggest that the Committee stipulates a time limit which differentiates between acute mental healthcare included in the proposed standard package and continuous mental healthcare funded outside of the package as part of long-term social care services. In line with this approach, it is proposed that the long-term services provided by community residential units and sheltered workshops would be excluded from the standard package and funded separately.
- Social and continuing care services which are long-term in nature would be excluded from the standard package. This would mean that services including meals-on-wheels, home help, home care packages, personal assistance services, day care services, rehabilitative training, sheltered workshops and long-term residential care would be provided on the basis of a care needs assessment and an individualized care plan, and funded separately.
- We suggest that the Government continues to cover the drug costs of the lowest income group, as currently applies to those with medical cards, either as part of the

standard package or through a separate eligibility scheme replacing both the current General Medical Scheme and Drugs Payment Scheme.

**Prepared by:** Boris T Rachev, Global Health Economist and Industry Strategist in CSC's Global Healthcare Group.

Boris Rachev is an experienced health economist, published author, and industry strategist with seventeen years of thought leadership in economic analysis and evaluation. He gained his experience working for big public and private sector domestic and international consultancies and think tanks. Throughout his career Boris has been involved in a variety of leadership and strategic research roles and has extensive global public and private health sector expertise. He holds a diploma from Stanford University and a graduate degree in economics and public policy from the Woodrow Wilson School at Princeton University.

[http://www.csc.com/health\\_services?ref=nmn](http://www.csc.com/health_services?ref=nmn)

## Danone Nutricia Early Life Nutrition

Danone Nutricia Early Life Nutrition is part of the Danone Groupe. Danone in Ireland is comprised of Danone Nutricia Early Life Nutrition (ELN), Danone Dairy Ireland, Danone Waters and Nutricia Advanced Medical Nutrition. A total of 520 people are directly employed by the Group in Ireland, with 100 people employed indirectly through out-sourcing of logistical services, merchandising and sales. We have two manufacturing facilities in Ireland, located in Macroom and Wexford. Worldwide, Group Danone employs over 80,000 people, across 5 continents, in more than 120 countries. Danone's mission is to deliver health through food to as many people as possible.

To highlight the importance of nutrition for women during pregnancy, for newborn infants and toddlers, Danone Nutricia ELN has developed a public awareness and information campaign on the importance of nutrition during the first 1,000 days of life. The first 1,000 days commences on the day of conception and continues right up until a child reaches their second birthday. A growing body of research has highlighted the importance of good nutrition in the first 1,000 days of life is key in determining the future health of an individual and is proven to help prevent chronic illnesses such as heart disease, diabetes and obesity.

Danone Nutricia ELN is making this submission to the Joint Oireachtas Group in order to highlight the importance of nutrition for the nation, and to ensure it is prioritised within Department of Health. As a leading company in nutrition and health, we believe that we have a responsibility to raise awareness of the importance of nutrition given its public health implications for pregnant, and breastfeeding mothers, parents and young children.

Our barometer conducted at the beginning of this year, found that there is a reasonable level of awareness about the First One Thousand Days, with 60% of mothers and over 50% of Health Care Practitioners familiar with the campaign or have heard something about it. If nutrition concerns are raised during pregnancy it is often because women are told what not to consume rather than what they should consume. Too often, nutrition is not even discussed. We would like to ask the Committee members to consider the importance of early life nutrition as part of the ten year health strategy. If integrated into public health planning and policy development, evidence suggests that it will have a positive impact on future health outcomes - this will in turn, help alleviate the current pressures on the public health system, benefiting both current and future users of the system.

Danone Nutricia ELN has developed the First 1000 Days movement, an un-branded non-commercial initiative, working in partnership with health care professionals, in order to put a spotlight on this important issue. First 1,000 Days has its own logo and brand. There is no commercial relationship between this initiative and any product sold by Danone.

### ***The importance of the First 1,000 Days***

The right nutrition during the first 1,000 days — 270 days of pregnancy and first two years of a child's life — has a profound impact on a child's ability to grow and develop normally. This period offer a unique window of opportunity to build healthier and more prosperous futures. Nutrition during pregnancy and in the first years of a child's life provides the essential building blocks for brain development, healthy growth and a strong immune system. A growing body of scientific evidence shows that the foundations of a person's lifelong health—including their predisposition to obesity and certain chronic diseases, such as diabetes and certain cancers—are largely set during this 1,000 day window. For this reason, it is critical that women and children get the right nutrition during this time. Malnutrition early in life can cause irreversible damage to children's brain development and their physical growth, leading to a diminished capacity to learn, poorer performance in school, greater susceptibility to infection and disease and a lifetime of lost earning potential. This in turn has

economic consequences, in terms of lost productivity and avoidable health care costs. However, by focusing on improving nutrition during the critical first 1,000 days, much of the serious and irreparable damage can be prevented.

### **Pregnancy**

A pregnant woman's diet and lifestyle can have a huge impact on her baby's future. A study carried out in Ireland in 2012 found that 35% of women with planned pregnancies didn't take folic acid, which reduces risk for baby of neural tube defects, such as spina bifida. The 2012 study also found pregnant women can be deficient in calcium, iron, and vitamin D. British epidemiologist David Baker is a leading proponent of the 'foetal origins' of disease theory — that lifetime health is a product of the first 1,000 days. His research found a baby's time in the womb can permanently affect everything from chances of developing diabetes or suffering heart attack in old age, to child's future weight and life expectancy — food scarcity or poor pre-natal nourishment can weaken vital organs like the heart and the odds of developing diabetes rise. He also found lower birth-weight babies are more susceptible to heart attacks in later life.

### **Breastfeeding**

The World Health Organization states with full confidence that breastfeeding reduces child mortality and has health benefits that extend into adulthood. Breastmilk is the natural first food for babies, it provides all the energy and nutrients that the infant needs for the first months of life, and it continues to provide up to half or more of a child's nutritional needs during the second half of the first year, and up to one-third during the second year of life. Breastmilk promotes sensory and cognitive development, and protects the infant against infectious and chronic diseases. It also contributes to the health and well-being of mothers, it helps to space children, reduces the risk of ovarian cancer and breast cancer, increases family and national resources, is a secure way of feeding and is safe for the environment

### **Weaning**

Irish research shows that 75% of infants are spoon-fed before 4 months of age. Findings have indicated that a significant proportion of 6 month old Irish infants consume foods high in energy, saturated fats, salt, and refined sugars (FSAI Best Practice for Infant Feeding in Ireland, 2012). This is associated with increased risk of allergies, coeliac disease, type I diabetes and respiratory illness. Longer-term, the excessive weight gain in infancy can increase the risk of obesity in later life. Parental education on best practice in infant feeding is critical to help promote healthier food choices on behalf of infants.

### **International Support and Recognition about the Importance of Early Life Nutrition**

Maternal, infant and young child malnutrition has been identified as a global public health priority. In May 2012, the World Health Assembly identified six priority areas for action and set out global targets to be met by 2025. These targets were reaffirmed by the United Nations in the Sustainable Development Goals adopted in December 2015, which will guide the international development agenda until 2030. WHO's Global Targets 2025 are vital for catalysing global change. Danone Nutricia ELN is taking an active role to help achieve them as we believe that we can make a difference -namely, through contributing to increasing breastfeeding rates, reducing anaemia, and stabilising childhood obesity rates.

Ireland has the lowest breastfeeding rate in the world. The latest *Perinatal Statistics Report 2014* published in June 2016, shows that fewer than half of Irish women (46 per cent) were breastfeeding at the time of discharge from hospital and that the figure had dropped since 2013. Furthermore, factors that increase the likelihood of a mother breastfeeding include high levels of income, higher levels of social class, higher levels of education and mothers who are older. We believe that breastfeeding is a powerful intervention – it's time-tested, backed by research and doesn't require preparation or expensive new medications. The

prioritisation of breastfeeding in the health service will directly impact public health outcomes, childhood obesity, maternal health outcomes and requires support at primary, secondary and community healthcare levels.

Danone Nutricia ELN is advocating that maternal health and nutrition in the First 1,000 of a baby's life should be a key priority in health service planning over the next ten years. Breastfeeding serves as a child's first immunization – providing protection from respiratory infections, diarrhoeal other non-communicable diseases later in life. Women who breastfeed are less likely to suffer from breast cancer, ovarian cancer and osteoporosis. A national priority to prioritise maternal health and child nutrition will yield defined social, medical and economic benefits. Specifically, it will lead to better health outcomes amongst our growing population, reduce the burden on secondary healthcare and place greater emphasis on primary and community care which is more cost effective.

### **Situation Overview**

Despite the litany of documented health benefits of breastfeeding for both mothers and babies, Ireland has the lowest rate of breastfeeding in the world. The figures are particularly alarming for mothers under 20 years of age and those between 20 and 29 years of age. This feeds into the wider issue of child and maternal health and the importance of nutrition in the First 1,000 days of the life of mothers and babies.

Early life development secures a base for health in later life. International evidence shows that providing support to mothers and infants during the prenatal period and first two years is vital. Appropriate and adequate nutrition during the period from before conception, to young childhood can have significant and profound effects on the later health of an individual. It is now recognised that individual development is determined not only by genetics, but through a complex interplay of genes and the environment. More importantly, that the developmental trajectories established in early life influence the response of an individual to later exposures. The health benefits of breastfeeding for babies include less risk of stomach upsets, coughs and colds, ear infections, diabetes, asthma and eczema, obesity (both in childhood and adulthood) and high blood pressure later in life. Minister for Health Promotion, Marcella Corcoran Kennedy TD recently outlined the health benefits for women which include, reduced risk of breast and ovarian cancer, reduced risk of osteoporosis and stronger bones in later life.

### **Folic Acid**

Professor Michael Turner, Director of the UCD Centre for Human Reproduction and UCD Professor in Obstetrics and Gynaecology at the Coombe Women and Infants University Hospital has long advocated for greater emphasis on maternal health and the need to update national guidelines on the required daily allowance of folic acid. His study, published in the Journal of Public Health shows that neural tube defects (NTD) appears to be on the rise but are preventable through adequate intake of folic acid. Professor Turner has repeatedly called for a renewed public health campaign to increase awareness about the potential of folic acid to prevent NTDs. Such a public health campaign needs to prioritise groups of women who are particularly vulnerable. Healthcare professionals nationally and internationally need to be consistent in their communications and to highlight the importance of pre-pregnancy supplementation. In addition, the issue of mandatory food fortification with folic acid needs to be addressed in a whole of Government approach.

### **Obesity**

In Ireland, one in four children is currently either overweight or obese. Obese children are at a greater risk of not only becoming obese adults but of suffering from chronic diseases such as Type II Diabetes, certain cancers, chronic heart and circulation diseases, musculoskeletal problems and mental health problems. The causes of obesity are multiple and include environmental, social, biological factors in addition to lifestyle choices. However, a mounting

body of evidence (WHO) suggests that breastfeeding may also play a role in programming non-communicable disease risk later in life, including protection against obesity in childhood. Together with other targeted nutrition interventions, breastfeeding can therefore, be an important component of strategies to tackle childhood obesity.

## **Recommendations**

### ***Education of the Primary Care Professionals***

There is a need to drive awareness amongst health care practitioners about the importance of nutrition for pregnant women and those planning to get pregnant. This includes engaging with GPs, community midwives and obgyn consultants to ensure they encourage patients to evaluate their diet and switch the focus from what to avoid, to the nutritional value of what should be eaten.

### ***Investment in education and supports***

It's vital that the right environment and supports are available to new mothers if more women are to breastfeed for the recommended 6-month period where possible. The inclusion of breastfeeding education in the school curriculum for transition year students is a good opportunity to provide the appropriate information to young people well before they are considering pregnancy. This will help counteract negative attitudes and perceived practical difficulties associated with breastfeeding but should also positively influence societal perspective. Provision of mother's breast milk to infants within one hour of birth is referred to as "early initiation of breastfeeding" and ensures that the infant receives the colostrum, or "first milk" which is rich in protective factors. Therefore, it is vital that new mothers receive the help and support they need straight after birth to give them the guidance and support they need.

We also need to address the way in which maternity services traditionally engage with men and fathers. Studies have shown that amid a range of social, cultural, socio-economic, and psychological factors, the father is one of the most influential persons in terms of a mother's decision to initiate and continue breastfeeding. This means that fathers can act as either key supporters or key deterrents to breastfeeding. A study in Dublin Institute of Technology through the *Fiosraigh* Scholarship which is funded by Dublin Institute of Technology and Danone Nutricia ELN found that a greater recognition of a father's importance in breastfeeding is needed.

### ***Targeted communication campaigns***

National public awareness campaigns are needed to communicate the importance of nutrition at every stage of the First 1,000 days, including the pre pregnancy/pregnancy phase regarding the importance of a balanced diet and the necessity of taking folic acid. We are playing our part through our 'Breastfeeding welcome here' campaign, which is designed to assure mothers that a location which displays the Breastfeeding Mark will provide a welcoming, supportive space where they can relax and take their time when feeding their child.

### ***Workplace policies***

With 26 weeks paid of maternity leave and a further 16 weeks unpaid leave, Ireland compares favorably with other countries in terms of maternity benefits. However, workplace policies are needed in both the formal and informal sectors to enable women to continue to breastfeed in the workplace, including measures such as onsite childcare, breaks for breastfeeding or milk expression and private comfortable accommodation in which to do so. This requires powerful political support and leadership from the Oireachtas and Government Departments.

**Data Collection**

Investment is needed to collect the relevant child health indicators and comparative data in order to contextualise interventions and track progress at both a primary and secondary healthcare level. This should include updating the National Dietary Surveys and collecting the weight and heights of infants and children in schools to better inform health policy interventions.

**Conclusion**

The health benefits of improved nutrition during the First 1,000 days lead to improved maternal and child healthcare outcomes. This is recognised nationally and internationally and are well documented by the WHO, UNICEF and Department of Health. However, the issue has not received the prioritisation and support it requires at national level. Its significance in terms of preventative healthcare is often overlooked and as is its economic impact on the cost of healthcare in a country with the fastest growing population in Europe. There are still significant barriers to achieving better maternal and child nutrition, such as the lack of investment in ambitious education and nutrition programs, hospital and community supports and effective public awareness campaigns. We believe that educating mothers and fathers on the importance of nutrition in the first 1000 days, including promoting good nutrition before and during pregnancy, promoting the benefits of breastfeeding and encouraging healthy feeding choices during weaning and toddlerhood will lead to better health outcomes for future generations.

<http://www.nutricia.ie/about>

## Deep End Ireland Group and Edenpark Surgery

To be considered alongside the submission by Professor Susan Smith et al from the Deep End GP Group regarding Primary Care in areas of deprivation.

Evidence proving the link between social class and illness and the truth regarding the “Inverse Care Law” has been available since the mid 20th century. However in spite of the evidence these relationships between illness, poverty and access to medical services remain. Over recent years our society in Ireland is has become more unequal with an increasing gap between rich and poor.

Edenpark Surgery is based in an area where several generations have suffered unemployment, poor housing, low educational achievement and significant social problems and now this population suffer the ill health and premature death that this creates.

The GPs of Edenpark Surgery support the submission made by the GPs involved in Deep End Ireland and agree that:

***“We need health policy that recognises both the reality that the people most likely to die are getting a much poorer health service than the rest of the population, but that also one that supports GPs and primary care teams working in deprived areas to effectively manage health problems in our patients”.***

In particular we echo the call of the Deep End Ireland Group for :

***“Primary care infrastructural development in disadvantaged areas.....”***

We in Edenmore were one of the first three primary care teams in North Dublin and have engaged fully in the process ever since. However our team remains a “virtual team” as we have without success been trying to get a Primary Care Centre built for more than 10 yrs. We can point to the recession, planning, lack of funding for developers for the delay but fundamentally it is the HSE’s current model that is not working. The HSE expect that once they have given the developer the go ahead for a PCC it will just happen. They want us to deal exclusively with the developer from this point and adopt a totally hands off approach.

What is needed is that the HSE engage with the GPs & other members of the Primary care team and the developer throughout the entire process. Only in this way can we ensure that the project moves along a to a strict timetable but also that it finally delivers a PCC that provides the services that are needed in that particular area in a building that functions efficiently.

***“The prioritization of primary care teams.....in disadvantaged areas”***

We have large numbers of “vulnerable families” with children who lack proper access to child and adolescent psychiatry/psychology and support. The current service is not fit for purpose and delayed access to care exacerbates already very difficult problems.

These vulnerable families frequently have crises brought on by illness, drugs, alcohol and domestic violence. Once again our families lack the rapid access to well resourced social work services in order to ensure protection of their children.

The elderly and disabled in our area cannot obtain comprehensive home support services in a timely fashion. Such services would allow them to remain in their own homes cared for in primary care rather than in hospital.

***“Recognition in any new GMS contract or primary care resourcing system of the need to incorporate some type of deprivation index that will allow additional support for practices to respond to those with greater medical need”***

We support the call for a new contract.

If we suture a patient with a laceration to save them a 6 hr wait in A&E even the new improved €50 fee does not cover the 20 mins it takes the GP, let alone the nurse, the disposable packs, sutures and instruments.

The current GMS fee of €24.80 to remove a skin cancer in the practice makes no economic sense and offers no incentive to treat such conditions in the community.

We want to advocate for our patients but cannot afford to attend case conferences because the fee offered does not cover the €250 per session cost of locum. In this way such advocacy opportunities are lost.

***“Access to secondary care is an on-going problem but current waiting lists for public patients for many specialties are over a year...”***

Only a minority of the patients attending Edenpark Surgery have private health insurance, most depend on the public service.

We need direct access to diagnostics for our patients. For example the blood test BNP and echocardiography for the accurate and timely diagnosis of heart failure.

We need a proper acute medical and surgical admissions unit so that patients who have been assessed by an experienced GP can be seen directly by the specialist they need and do not have to wait with the undiagnosed masses in A&E.

We need to be able to get MRI scans and Ultrasound scans for our patients within days not months.

We would like to see an expansion of schemes such as the new diabetes and asthma care programs, provided they are properly funded. Such developments allow patients to be discharged from follow up at hospital out patients and to be managed in the community and frees up much needed appointments in the clinics to allow more rapid access for our new patients who need specialist diagnosis or treatment.

### ***Structural change in the health service***

The changes that we call for cannot occur in the current broken system. We need to end the current two tier system to continue, we need some form of not-for-profit Universal health insurance system so that the many excellent private and public hospital facilities in the country can provide secondary care for the whole population of Ireland and not just those who can pay for it.

### **SUBMISSION**

Our submission takes the form of a case study to illustrate the typical day in a “Deep End Practice”. The cases have been modified to protect individual’s identities but otherwise reflect a genuine day in the life of one of the GP partners in the early summer of 2016.

**Friday started with a methadone clinic. Ten people in their 30s and 40s with life histories that can almost make you weep.**

**Then later I reviewed a middle aged lady who is on treatment for depression. She was abused by her father, with her mother's knowledge, a brother was shot, another is in prison for murder, and she is worried about her grandchild because her son is a drug addict who has slipped back into heroin use.**

**I had a phone call from a mother distraught because her 20 yr old son has a problem with drugs. They have very modest means but have paid off drug debts totalling €10,000. Thugs have been at the house with guns. She is worried about his safety and how he will cope with his young child who has cystic fibrosis.**

**I saw a grandmother who, after I dealt with her medical problems, broke down as told me of her devastation about her intellectually disabled granddaughter who has moved to the Middle East and married a man, twice her age and is now pregnant.**

**Just before lunch I did a minor procedure under LA to on an 83 yr old lady to remove a huge callous on her foot which had been stopping her from walking.**

**During the lunch "interval" I went to a nursing home to see a sick elderly man and then to the house of a young man, where I found him wrapped in nothing but a sheet, clearly psychotic and needing referral for urgent psychiatric admission.**

**Back to the surgery to see a mother wanting sleepers because of the stress of 6 children, one of whom at age 11 has been referred to social services for sending pornographic images and lewd messages to girls in the class,**

**I have seen 38 patients today, including sending to A&E a man in with palpitations.**

**Just when I thought the day was winding down in came a methadone addict who had missed the morning clinic. She had been beaten up last week by her partner when he turned up at her house. She suffered a sustained assault over a 2 hour period. He was under the influence of drugs and was seeking cash. When he went out to his car to get a blade she escaped over the back wall. Her children are not going to school and social services are involved**

**Finally a call from the carer of a woman aged 40 who is paralysed from the neck down after a fall, who has headache and is more drowsy than normal but just wanted advice.**

**The phones have just gone to answer phone mode. The waiting room is empty. I tidy up, check some results. The "footballers" outside my window began their daily assault, noisily kicking footballs against the shutters of the shop next door and my surgery; the drug dealers gather in another doorway, the disturbed man who hurls abuse at me walks past my window one more time.**

**I am the only GP in the surgery this afternoon because we were unable to get a locum.**

**Finally the end of my week.**

## **RECOMMENDATIONS**

- A GP contract that is fit for purpose recognises the extra demand of practices in deprived areas with improved funding.
- Proper staff of primary care teams in such areas with social workers, psychologists and home care supports
- Active management by HSE to ensure delivery of PCC in deprived areas, with an understanding that one size does not fit all
- Early introduction of “Not for profit” Universal health insurance, abolition of two tier medical system
- Proper integration of primary and secondary care to allow the former to deal with the majority of health care needs and to ensure that only the complex cases which need specialist input arrive in hospitals
- General measures to improve housing, reduce poverty, improve education, since such things will have the biggest effect on improvements in health

**Dr Mark Wheeler, Dr John O’Dwyer and Dr Fionnuala Joyce the Partners of Edenpark Surgery**

<http://www.icgp.ie/>

## Diabetes Ireland

### **DIABETES IRELAND SUBMISSION FOR ADULT AND CHILD DIABETES SERVICES**

Diabetes is a serious global public health issue which has been described as the most challenging health problem in the 21st century<sup>222</sup> with high individual, social and economic burden. The national expenditure on diabetes is estimated to be 10% of the health budget (€1.31 billion) with 60% (€800 million) spent on diabetes complications, many of which could be avoided with earlier detection and regular access to diabetes review appointments.

The high cost of diabetes is caused by the treatment of complications as they increase cost by as much as five fold<sup>223</sup>. Uncomplicated diabetes on average increase health costs 1.5 times more than normal while the presence of microvascular (eye and kidney) complications doubles the cost, macrovascular (cardiovascular) trebles the cost and the presence of both microvascular and macrovascular disease increases costs 5 fold.

There are different types of diabetes affecting the very young to very old but all require regular medical review with frequency dependant on age and life issues. There is much evidence supporting that more frequent medical review reduces health costs by preventing acute and chronic complications and inpatient hospital admissions.

Adults with Type 1 diabetes require regular expert diabetes review and referral pathway to other specialist areas. Adults with uncomplicated Type 2 diabetes require regular review by community professional staff (doctor, nurse, dietitian) and referral to other community specialists i.e. podiatry and retinal screening. Adults with complicated Type 2 diabetes need access to diabetes specialist multidisciplinary teams to address the resultant complex issues. Women with diabetes during pregnancy need specialist obstetric and diabetes care before and during the pregnancy to protect their and their offspring's health. Without this level of care for all people with diabetes, acute and chronic complications are developing, thus, a reorganisation of the current delivery of diabetes care is warranted.

The diabetes community, under the auspices of the HSE Diabetes Working Group, has developed a defined and clear strategy for managing diabetes (current & future patient cohorts) based on more effectively managing their condition on a daily basis and avoiding the development of chronic complications. This strategy needs political support and long term year on year funding commitments for immediate implementation.

### **Summary of Key Recommendations which the Committee is asked to support are:**

1. Encourage the HSE to publish the strategy (models of care for Adult Type 1 diabetes, Type 2 diabetes and Gestational Diabetes).

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<sup>222</sup> International Diabetes Federation. IDF Diabetes Atlas, 6th edn. International Diabetes Federation. Brussels, Belgium: 2013.

<sup>223</sup> Codeire (1999) Code-2 *Revealing the Cost of Type 2 Diabetes in Europe*. EASD Satellite Symposium: Brussels.

2. Extend the current Type 2 Diabetes Cycle of Care initiative deliverable at community level to all people with uncomplicated Type 2 diabetes.
3. Adequately resource Adult Type 1 diabetes, complicated Type 2 diabetes and antenatal care (including Gestational Diabetes) at secondary care level.
4. Develop an appropriate national information and communication technology infrastructure and support for service planning requirements.
5. Mandate annual training and structured education for all professionals delivering diabetes care – primary and secondary.
6. Promote ongoing patient and professional engagement to maintain links with Diabetes Ireland
7. Secure a dedicated finance structure based on standard patient cost per individual with diabetes.
8. Stem the rising incidence of Type 2 diabetes fuelled by increasing obesity levels by implementation of the Obesity Report Recommendations.

## **Background**

Diabetes affects 1 in 3 families in Ireland and is a major health and social burden on the country. Annual national expenditure on diabetes is estimated to be 10% of the health budget (€1.31 billion in 2015) with 60% (€800 million) of that spent on diabetes complications, many of which could be avoided with earlier detection and regular access to diabetes review appointments.

Diabetes occurs when the body is unable to use the sugars from food properly resulting in above normal blood glucose levels which over time cause blood vessel damage. There are different types of diabetes as a result of insufficient or ineffective insulin production:

**Type 1 diabetes** (body completely stops producing insulin) develops most frequently in young people of normal weight. It is not related to lifestyle choices and is not preventable at present. Type 1 diabetes is managed with multiple daily insulin injections or by using an insulin pump, along with healthy eating and regular physical activity.

**Type 2 diabetes** (the body stops producing enough working insulin) accounts for 90% of diabetes cases and is managed by healthy eating, regular physical activity and medication which may include insulin injections. Type 2 diabetes may be put in remission with extreme weight loss.

**Prediabetes** (blood glucose levels are higher than normal but not high enough to be diabetes). Healthy eating and regular physical activity will help to delay or prevent the onset of Type 2 Diabetes.

**Gestational Diabetes** (pregnancy hormones work against the body's insulin, resulting in insulin/glucose imbalance) usually only lasts for the pregnancy but the mother has an increased risk of developing Type 2 diabetes and the baby has potential lifelong health risk.

Global estimates predict annual increases in each of the above diabetes categories and Ireland needs to address this through the development and funding of models of care. Through the HSE's Diabetes Working Group, much work has been done on developing these models of care for each category but policy support and ongoing financial support is required.

## **Key Challenges**

### Prevalence

Accurate estimates of the incidence of diabetes are essential for planning services, support and surveillance. In Ireland, there is no diabetes register for adults and prevalence estimates vary but it is generally accepted that there are in excess of 225,000 Irish people with diabetes, which will increase to 278,000 by 2030.

The rising incidence of diabetes is predominately in Type 2 diabetes fuelled by the obesity epidemic due to reduced physical activity in all age groups and more frequent consumption of convenience foods. Type 2 diabetes is preventable or can be delayed by weight reduction and increasing activity. Based on the Healthy Ireland survey<sup>224</sup>, there are 1,158,547 adults in Ireland that need to consider making changes to their daily behaviours in terms of eating healthily and being more active or risk developing Type 2 diabetes.

### Current System

The current system encourages all people with diabetes to attend their local hospital diabetes service for their care as it's free of charge. With diabetes clinics having limited resources, waiting times for appointments are up to 2 years in some clinics.

With a lack of regular diabetes management review appointments, patients are more likely to develop chronic complications at huge cost to the exchequer. With increasing diabetes prevalence this is not sustainable and unless free access to regular review at community level is made available, services in their current format will only incur more spending dealing with increasing complications in future years.

### Cost of Diagnosed Diabetes in Adults.

Each person diagnosed with diabetes has a different medical regime which if not followed will lead to serious diabetes complications as evidenced by the 15% of acute hospital beds taken up by diabetes patients daily in Irish hospitals. Diabetes is the primary cause of:

- Heart Disease – 25% of all bypass operations

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<sup>224</sup> The Healthy Ireland Survey <http://health.gov.ie/wp-content/uploads/2015/10/Healthy-Ireland-Survey-2015-Summary-of-Findings.pdf> accessed 16th April 2016

- Kidney Disease –primary cause of kidney disease
- Eye Disease –commonest cause of blindness in under 65’s
- Limb Amputation –primary cause of lower limb amputations.

The high cost of diabetes is caused by the treatment of complications as they increase cost by as much as five fold<sup>225</sup>. Uncomplicated diabetes on average increase health costs 1.5 times above normal while the presence of microvascular (eye and kidney) complications doubles the cost, macrovascular (cardiovascular) trebles the cost and the presence of both microvascular and macrovascular disease increases costs 5 fold. Tracey et al<sup>226</sup> (2015) report the prevalence of microvascular complications as between 2.5% - 25% and macrovascular as 3.5%-32% depending on study population and methodology of individual studies.

The American Diabetes Association 2012 attributed these diabetes costs to;

- Hospitalisations (50%)
- Medications and diabetes supplies (30%)
- Physician office visits (9%)
- Nursing/residential facility stays (8%)<sup>227</sup>.

Furthermore, it is accepted that more frequent routine professional contacts reduces this cost substantially by reducing emergency care and potentially reducing cost of treating complications<sup>228</sup>.

The HSE Diabetes Working Group has developed a strategy for managing all people with diabetes in their appropriate setting (community or secondary) at their time of need. While the funding for this will need to be frontloaded, the reduction in complications will make significant savings for the exchequer over 10 years, making the support of the strategy a worthwhile investment.

## Key Priorities

Since the Department of Health identified diabetes as a high priority requiring investment, the HSE has through the Diabetes Expert Advisory Group and its Diabetes Working Group developed a defined and clear strategy for managing diabetes patients (current & future cohorts) to more effectively manage their condition on a daily basis and avoid the development of chronic complications.

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<sup>225</sup> Codeire (1999) Code 2: *Revealing the Cost of Type 2 Diabetes in Europe*. EASD Satellite Symposium:Brussels

<sup>226</sup> Tracey M, Gilmartin M, O’Neill K et al. (2016) Epidemiology of diabetes and complications among adults in the Republic of Ireland 1998-2015: a systematic review and meta-analysis. *BMC Public Health* BMC series – open, inclusive and trusted 2016 **16**:132. **DOI:** 10.1186/s12889-016-2818-2

<sup>227</sup> <http://managedhealthcareexecutive.modernmedicine.com/managed-healthcare-executive/news/top-drivers-diabetes-care-costs>

**1.** <sup>228</sup> Zhuo X, Zhang P, Hoerger TJ. (2013), Lifetime direct medical costs of treating type 2 diabetes and diabetic complications. *Am J Prev Med.* (2013) Sep;45(3):253-61. doi: 10.1016/j.amepre.2013.04.017.

## Integrated Community & Secondary Care

To date, successive Ministers have supported the strategy on a piecemeal basis which has seen some increased staffing resources but not enough. These added resources, while welcomed by the diabetes community, are only helping to stem the tide of complications and are not providing long term value for money in terms of educating patients on good management techniques and prevention of complications.

To achieve this, the committee needs to fully endorse, accept and commit to fully funding the proposed strategy before we can hope to see improved diabetes management and reduction in diabetes healthcare complications costs.

All sections of the diabetes community, through the HSE Diabetes Working Group, has agreed the proposed strategy which will deal with the current and rising prevalence of diabetes effectively. Successive governments have to agree to support it by providing the funding to implement the strategy in its entirety.

The strategy would see:

- (a) All patients with uncomplicated Type 2 diabetes (approx. 120,000) managed in the community (primary care). These patients would receive access to diverse community based, medical, dietetic, nursing, and care pathway referral to retinal screening, social care and podiatry services requiring robust care coordination, without which there is increased risk of diffused professional responsibility and fragmented care that does not meet patient needs.

In October 2015, the Type 2 Diabetes Cycle of care was launched to begin this work. The Cycle of Care is a model for strengthening primary care through the re-organisation of existing practices to provide patient-centered, comprehensive, coordinated, and accessible care that is continuously improved through a systems-based approach to quality and safety.

To be a "success", this needs to be dynamic, bottom up, flexible, integrated, multi-disciplinary, and equity oriented that is proactive rather than reactive focused. This requires ongoing support to modernise and build primary care infrastructure to support high quality primary care, which the Institute of Medicine defines as the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community<sup>229</sup>. The person with diabetes is entitled to quality care based on best practice. The primary care team must demonstrate a commitment to quality improvement by committing to ongoing continuous professional development.

Unfortunately, the Cycle of Care currently only sees Type 2 diabetes patients who have a GMS or GP Visit card, locking out many people of working age with the condition from availing of the service. These people tend to stay in the free hospital service, waiting on ad-

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<sup>229</sup> *Institute of Medicine (1978). A manpower policy for primary health care. Washington (DC): National Academy of Sciences.*

hoc appointments with frequently cancelled appointments as they are not priority cases resulting in them being more at risk of diabetes complications.

Many of those entitled to avail of the Cycle of Care service are still registered with their local hospital service as there is a view that GPs are currently not knowledgeable enough on diabetes and need further training to support their service.

- (b) All people with complicated (who have developed a chronic complication) Type 2 diabetes (approx. 60,000) would be managed in Secondary Care as they would need regular review by the consultant led specialist diabetes team who will determine an individualised care plan and implement it so that the individual receives an appropriate level of care in the most appropriate setting.

This is because people with an established diabetes complication have more complex health care needs requiring more intensive medical services coordinated across multiple providers, as well as a wide range of social supports to maintain quality of life. Access to vascular, nephrology, orthopedic, psychological specialist services must be available for these patients. We would see that elements of their care such as eye and foot screening would be delivered at community level, and their medical care would be consultant led.

- (c) All people with Type 1 diabetes (approx 15,000) would be managed in Secondary Care. Regardless of age, people with Type 1 diabetes need regular review and access to professionals with Type 1 diabetes expertise, an individualised care plan with ongoing education and support plus ongoing assessment for acute and chronic complications.

Internet access to information and the pace of technology development makes access to diabetes expertise essential. People with Type 1 diabetes would access elements of their care such as eye and foot screening at community level as well as for non-diabetes related matters and for annual flu vaccinations.

- (d) All women of childbearing years with diabetes should receive regular contraception advice and referral for pre-pregnancy care prior to conception. All pregnant women with diabetes should receive their medical and obstetric care in combined clinics as per national guidelines<sup>230</sup>.

Gestational Diabetes is a common medical complication of pregnancy affecting 12.4% of pregnancies which despite significant progress in care still results in significantly elevated

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<sup>230</sup> HSE (2010) Guidelines for the Management of Pre-Gestational and Gestational Diabetes Mellitus from Pre-conception to the Postnatal period, *Office of the Nursing and Midwifery Services Directorate*.

risk of multiple adverse complications for mother and offspring<sup>231</sup> compared to women who have normal glucose tolerance<sup>232</sup>.

### Recommendations

#### **Encourage the HSE to publish the strategy (models of care for Adult Type 1 diabetes, Type 2 diabetes and Gestational Diabetes).**

National Management Guidelines for Care in Type 1 diabetes, Type 2 diabetes and Gestational Diabetes are an essential component for visualising care, planning the implementation of a quality service and identifying outcomes as a basis for audit. The diabetes community has come together and developed strategies, in the form of models of care. Some aspects of these strategies have been implemented by the HSE but a long term view and funding commitment is required.

#### **Extend the current Type 2 Diabetes Cycle of Care initiative deliverable at community level to all people with uncomplicated Type 2 diabetes.**

The Type 2 Diabetes Cycle of Care initiative launched in 2015 is a very positive commitment by the HSE to manage uncomplicated Type 2 diabetes in the community. However, it should not discriminate towards people with the condition who do not have a GMS or GP Visit card and should be extended under the auspices of universal single tier health system to the estimated 120,000 people with uncomplicated Type 2 diabetes.

Extending this service to this cohort will move these patients from secondary to community care and also improve access to secondary care diabetes outpatient services for those with complicated diabetes and those most in need.

#### **Adequately resource Adult Type 1 diabetes, complicated Type 2 diabetes and antenatal care (including Gestational Diabetes) at secondary care level.**

Current secondary care diabetes services are under resourced. These cohorts of patients need regular access to consultant led care in order to maximise their daily management. These patients require review (3 appointments per annum) and ongoing assessment for acute and chronic complications and rapid access to vascular, nephrology, orthopedic, psychological specialist services must be available for these patients. The models of care proposed for these cohorts require a long term funding commitment.

#### **Develop an appropriate national information and communication technology infrastructure and support for planning requirements.**

Ireland does not have a diabetes patient register. The National Retina Screening programme, hosted by the NSS, register is the closest register available. Access to this register will enable highly effective planning, audit and evaluation to be undertaken by the HSE.

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<sup>231</sup> A.M. Egan, H.R. Murphy and F.P. Dunne (2015) The management of type 1 and type 2 diabetes in pregnancy. *QJM: An International Journal of Medicine*, 923–927. <http://atlanticdipireland.com/wp-content/uploads/2016/01/the-management-of-type-1-and-type-2-diabetes-in-pregnancy.pdf>

<sup>232</sup> O'Sullivan EP, Avalos G, O'Reilly M, Denndy MC, Gaffney G, Dunne FP; Atlantic DIP collaborators. Atlantic DIP (2012) the prevalence and consequences of gestational diabetes in Ireland. *Ir Med J*. May;105(5 Suppl):13-5.

## **Mandate annual training and structured education for all professionals delivering diabetes care – primary and secondary.**

These programmes are available but without mandate are only undertaken on an ad-hoc basis. Delivery of best practice requires ongoing commitment to professional education in all aspects of care.

## **Promote ongoing patient and professional engagement to maintain links with Diabetes Ireland**

Ongoing patient engagement is required to enable individuals to effectively manage their condition. Links with Diabetes Ireland, who provides a range of education and support services is an integral element of this.

## **Secure a dedicated finance structure based on standard patient cost per individual with diabetes.**

Currently there is an ad-hoc reactive funding system primarily focussed on dealing with chronic diabetes related complications. We need a preventative structure based on outcomes and efficient use of services that encourage patients to more proactively manage their condition and prevent the onset of complications, thus making financial savings for the exchequer.

## **Stem the rising incidence of Type 2 diabetes fuelled by increasing obesity levels by implementation of the Obesity Report Recommendations.**

Both rising obesity levels and an aging population will add future demographic pressures and further impact on diabetes incidence. It is essential that policies are implemented to address both these issues to encourage those with pre-diabetes to make the necessary lifestyle changes and avoid/delay onset of diabetes.

## **Funding Model**

In terms of funding the proposed diabetes strategy as outlined by the HSE Diabetes Working Group, consideration has to be given to how GPs should be funded for managing uncomplicated Type 2 diabetes patients and how secondary care diabetes services are funded.

Possible financial solutions are:

### **1. Primary Care Reimbursement**

The Type 2 Diabetes Cycle of Care service launched in October 2015 introduced a fee per patient solution where GPs are paid based on a maximum number of appointments per annum. An evaluation of how is working needs to be undertaken.

However, a further option would be to introduce a best “outcomes driven” payment based on achieving standard health outcome results which could attract a higher fee for GPs.

## 2. Secondary Care Reimbursement

Diabetes Ireland would support an accurate cost measurement system as referenced in Harvard Business Reviews from 2011-date (Kaplan, 2011, Porter, 2013). With good estimates of pathways for adults with diabetes, providers can use the time driven activity based costing (TDABC) system to assign costs accurately and easily to each process step along the patient pathway. Time driven activity based costing (TDABC) includes 7 steps listed below:

1. Select medical condition to be examined (e.g. Type 1 Diabetes)
2. Define a care delivery chain (hospital based)
3. Develop process mapping for each activity in patient care delivery (identify resources involved and any supplies used for the patient at each process)
4. Obtain accurate time estimates for each process step
5. Estimate the cost of each patient care resource
6. Estimate the practical capacity of each resource provider – calculate the capacity cost ratio
7. Compute the total costs over each patients cycle of care i.e. TDABC (Kaplan, 2011, Porter, 2013)

### Evaluation and Audit

Associated with these funding models would be the need to continuously evaluate services. Patients will be monitored with regular review and provided with appropriate management education with an aim to significantly improve outcomes of care over the next ten years. Patients who are not reaching standardised targets may need targetted interventions.

The 2014 Euro Diabetes Index<sup>233</sup>, a congress organised by the European Association for the Study of Diabetes, showed that Sweden had the best diabetes care in the EU based on 28 defined indicators and areas, including prevention, case finding, range and reach of services, access to treatment and care, procedures and outcomes. A register of people with the condition linked to medical outcomes is beneficial in determining the level of care received matched to outcomes.

### Summary

Diabetes is a complex condition requiring a multi-faceted approach for effectively management of patients.

The HSE Diabetes Working Group, encompassing wide representation from the diabetes community, recognising this has developed a strategy, encompassing best practice models of

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<sup>233</sup> Euro Diabetes Index (2014) <http://www.healthpowerhouse.com/files/EDI-2014/EDI-2014-report.pdf>

care for Type1, Type 2 and Gestational Diabetes which will positively change the way diabetes care is delivered. The strategy promotes an integrated model of delivery between primary and secondary care which will deliver good diabetes management to every individual in the appropriate setting.

The HSE's Type 2 Diabetes Cycle of Care has already begun to deliver this in part but to provide full value for money and enhanced quality of life for patients needs full long term political support and funding commitment.

The current system for diabetes management is fragmented and reactive with the majority of costs spent on dealing with associated chronic complications costing circa €800 million per annum.

Support for the implementation of the diabetes models of care will deliver a process driven service with clear pathways and minimum interruption which is key to minimising cost.

### **CHILD DIABETES SERVICES**

Type 1 diabetes is complex requiring care to be provided by specialist teams in hospital settings. Because of the complexity of the condition, it cannot be treated at community level. Type 1 diabetes is increasing in incidence year on year with a worldwide average annual increase of 2.8% per year and the greatest increase in children under 15 years of age (4%). Patterson et al. (2009) reported, as part of the EURODIAB study group, that if present trends continue a doubling of new cases of Type 1 diabetes in European children under five is predicted between 2005 and 2020 and prevalent cases younger than 15 years will rise by 70% (Patterson et al., 2009). Adequate healthcare resources need to be available to meet the needs of these children as Type 1 diabetes is not preventable.

Paediatric Diabetes is essentially a hospital-based service with opportunities for care delivery in settings such as the home, school and community-based organisations. The delivery of care (as defined in part by glycosylated haemoglobin, HbA1c<sup>234</sup>) varies throughout the Republic of Ireland and is behind benchmark nations such as Germany. Factors influencing this include varying staffing levels and skill sets along with social deprivation and ethnic diversity and attaining a standard of equitable care is a major challenge. The fundamental issue is not whether care is delivered centrally or not but whether that care is of value to the patient. This means moving from a supply-driven health care system, organised around what physicians do, to a patient-centred system, organised around what patients need.

In 2015, the Minister for Health launched a Model of Care for all children and young people with Type 1 diabetes that will improve access and quality of care for patient and reduce acute and chronic complications in the future. The model of care proposes the development of 7 Integrated Practice Units (IPUs) in Ireland which are patient-centric and results driven. A patient-centric and results driven IPU, focusses on the best way to deliver care using interdisciplinary groups, manages information, integrates decisions and ensures continuity, is responsible for the whole cycle of care even if other entities are involved, and the staff work exclusively in diabetes.

The HSE Model of Care for All Children and Young People with Type 1 Diabetes developed by the Paediatric Diabetes Working Group chaired by Dr Stephen O'Riordan requires funding of an extra

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<sup>234</sup> HbA1c- the average blood glucose level over three months.

€5.5m to fully resource a high quality paediatric diabetes service that meets the needs of patients and their families and will make very significant exchequer savings in future years through savings in related complications management reduction. The funding model proposed for this service which has to be based in hospital settings will provide, the medical, nursing and psychosocial support to deal with all patients, regardless of where they reside, in a systematic and accurate cost measurement system with specific quantitative and qualitative outcomes. These measured outcomes, in other countries where investment has been made, have shown a reduction in HbA1c over 5 and 10 years which will reduce costs for managing diabetes complications.

The paediatric diabetes community has come together to produce this model of care but a long term funding commitment is required to provide, audit and evaluate a quality system. The primary aim of this model of care is defining excellent diabetes care, and improving access, quality and value for all children with Type 1 Diabetes in Ireland for many years to come. Diabetes Ireland is seeking the support of the Oireachtas Committee on the Future of Healthcare to support this service.

**The Key Recommendations for Implementation of the model of care and which the Committee is asked to consider are:**

Services should be organised within Integrated Practice Units (IPUs) comprising a centre of reference and a number of additional units.

That IPUs are equipped with the core staffing requirements detailed in Paediatric Diabetes Model of Care document launched in November 2015.

Ongoing training and structured education of paediatric diabetes teams is required annually.

National, quality assured, educational programmes for children with type 1 diabetes and their families and carers should be developed.

Ongoing patient and parental engagement: maintain links with Diabetes Ireland

Appropriate national information and communication technology infrastructure and support is needed.

The availability of 24-hour telephone support is required within each IPU.

A dedicated finance commitment needs to be identified based on a unit cost per Child with Type 1 Diabetes to address current and future staffing deficits.

**Rational for the Model of Care**

Children with Type 1 Diabetes are a priority because of the high incidence of this condition, and effective interventions can reduce long term complications. To date, services have been configured and resourced for low disease incidence (Roche et al., 2002, Patterson et al., 2009), but there are now robust data confirming that Ireland is a country of high incidence (Patterson et al., 2009). Ireland underperforms relative to other European countries in outcomes such as higher HbA1c's and this must be addressed. It is strongly felt among

professionals, children and young people with Type 1 Diabetes, and their families, that action is needed to address the long term service deficits and improve outcomes.

The benefits for the patient are a partnership of excellence serving them, care delivered using state-of-art facilities and technologies, expertise always available when needed by the patient or their family, continuity of care and scale that allows development of dedicated teams rather than part time practitioners with shorter wait times and convenient scheduling of appointments. For the clinical service, common management allows for a unified process of care, shared staff training develops skilled teams, strong governance, efficient division of labour, more rapid evolution and deployment of effective techniques and care plans. The scale allows for richer feedback and support, better flexibility and efficiencies in scheduling. The model of care represents a radical departure from the classic model of delivering health care. It puts the patient and family at the centre of the process which is exactly where they should be.

### **Prevalence**

The number of people with all types of diabetes is predicted to increase rapidly over the coming years. Type 1 Diabetes is increasing in all age groups internationally, and in Ireland this is especially so in the 10-15 year old age group. The crude incidence of Type 1 Diabetes was 27.2 / 100,000 children in 2008, and 25.7 / 100,000 children in 2009, in those under 15 years of age in Ireland. The total child and adolescent population with Type 1 Diabetes in Ireland was estimated in a recent HSE audit of 19 centres in at approximately 2,600. Diagnosis peaks between 10 and 15 years of age. Patterson et al. (2009) reported, as part of the EURODIAB study group, that if present trends continue a doubling of new cases of Type 1 Diabetes in European children under five is predicted between 2005 and 2020 and prevalent cases younger than 15 years will rise by 70% (Patterson et al., 2009). Adequate healthcare resources need to be available to meet the needs of these children as Type 1 diabetes is not preventable.

### **Effectiveness of Interventions**

Improved diabetes control from diagnosis onwards can reduce the incidence of microvascular complications, and delay their progression. The ‘Diabetes Control and Complications Trial’ (DCCT) and the ‘Epidemiology of Diabetes Interventions and Complications’ (EDIC) studies provide us with conclusive evidence that intensive management and psychosocial support improves glycaemic control and diabetes outcomes in children and young people with Type 1 Diabetes (Shamoon et al., 1993, 2000, 1999). Intensive management should commence at diagnosis, with an extensive family-focused education package together with continued support (Swift et al., 2010). The converse is also true - poor control of childhood diabetes is definitely associated with poorer outcomes and a higher mortality rates in early adult life (Cooper et al., 2014).

The DCCT supports tracking of HbA1c in the paediatric population, where a “good start” – based on intensive diabetes education and multidisciplinary support – reduces HbA1c and maintains optimal glycaemic control. This approach highlights the importance of achieving

optimal control of diabetes from the day of diagnosis, and can reduce the burden of diabetes and maintain quality of life (Edge et al., 2010, Hofer et al., 2014). These studies have shown that when Type 1 Diabetes is effectively controlled, it can reduce the risks of developing complications as follows:

- New eye disease: 76% reduction
- Worsening of existing eye disease: 54% reduction
- Early kidney disease: 54% reduction
- More serious kidney disease problems: 39% reduction
- Nerve damage: 60% reduction

Current national expenditure on diabetes is estimated to be 10% of the health budget (€1.31 billion) with 60% (€800 million) spent on diabetes complications, many of which could be avoided with earlier detection and regular access to diabetes review appointments.

### **Future Adult Complications**

Macrovascular disease, e.g. heart attack or stroke, may not affect children with diabetes during childhood but is very likely in adulthood because of the length of time children live with diabetes.

Effective preventative education and motivation about diet, activity, smoking and weight management should be provided. Early identification and treatment of cardiovascular disease in young adults with diabetes is essential (Polak et al., 2011). The Wanless Report (Moore, 2002) stated that, based on best available evidence, the interventions known to be cost effective using a €24,000 cost per quality adjusted life year (QALY) threshold are:

Tight control of blood glucose and blood pressure

ACE (angiotensin converting enzyme) inhibitors for those with diabetes and one other risk factor not otherwise quantified, and for multiple risk factor management

Retinopathy screening for all with diabetes

Foot screening for those at high risk

Self-care, including patient education

### **Comparison of HbA1c in Ireland with other European Countries**

HbA1c is the most recognised key performance indicator internationally, and Table 1 (below) highlights Ireland's performance. Unfortunately, compared to other European countries, paediatric diabetes in Ireland is not meeting the same targets. It also highlights the lack of data that is available on a national basis, however it is proposed that a national diabetes register and a national diabetes audit will help address the deficit in data.

<b>Targets (ISPAD and ADA Guidelines)</b>	<b>Ireland</b>	<b>UK (2011-12 data)</b>	<b>Germany and Austria</b>
Under 5: HbA1c <8.5% (58mmol/l)	Mean of all children under 16 is 8.2-9.4% (66.1-79.2mmol/l).  Proportion reaching targets <7.5% <b>unknown</b> .	18.1% of girls and 16.7% of males reached targets of <7.5%.	50-55% reached targets.  Median all centres HbA1c 7.7% (61mmol/l) in all patients under 21.
Under 16: HbA1c <7% (53mmol/l)			
HbA1c >9.5% (80mmol/l)	<b>Unknown</b>	25.1%	10%

**Table 1: Comparison of HbA1c levels in children and young people with T1DM**

Based on international evidence (ISPAD & ADA, HbA1c should be measured every 3 to 4 months in an outpatient clinic. The target HbA1c for all children and young people is 59mmol/l (<7.5%) (ADA).

### **Outpatient Follow Up**

As standard care, it is recommended that children with type 1 diabetes are seen every 3 to 4 months in a dedicated paediatric diabetes outpatient clinic. All children with type 1 diabetes should have an annual review of eyes, feet and cardiovascular review along with routine bloods for thyroid, coeliac and fasting lipids.

### **Proposed Model of Care**

The proposed model of care for paediatric diabetes is via Integrated Practice Units (IPUs) which focus on the needs of children and young people (Porter, 2013). An IPU consists of one centre of reference and a number of additional units:

The proposed Centre of Reference, situated around the country are:

<u>Region</u>	<u>IPU</u>	<u>Outreach Services</u>
National /Dublin	Dublin (New Children's Hospital,)	Portlaoise & Mullingar
South/Southwest	Cork	Kerry & Clonmel
Northeast	Drogheda	Cavan
Mid-west	Limerick	
Northwest	Sligo	Letterkenny

Southeast	Waterford	Kilkenny & Wexford
West	Galway	Portiuncula/ Mayo General

All of these will provide outreach services locally providing all children, regardless of where they live, with standardised access to regular high quality care.

### Resources

The primary resources of equipment, infrastructure and staffing are outlined in the proposed model of care in more detail;

### Equipment

Adequate access for all multidisciplinary team staff to computers is essential for the successful implementation of this model of care. All patient records should be stored electronically to facilitate audit and database upkeep. A range of software packages are required to access information stored on glucometers, blood ketone meters and insulin pumps, but these are usually supplied free of charge by the companies providing them. Once this information is downloaded it can be reviewed and interpreted by the diabetes team, showing insight into each patient's behaviours and enabling appropriate recommendations made to insulin rate or ratio adjustments. A supply of pumps, infusion sets, cannulae, and continuous glucose monitoring (CGM) equipment are required to deliver insulin pump therapy. Centres will also need point of care HbA1c analysers and blood ketone testing equipment. The provision of 24-hour telephone support for clinicians and patients within the IPU is essential.

Patients also need access to latest technologies to ensure they can most achieve most effective management of their condition.

### Infrastructure

Dedicated diabetes education space is required for the delivery of group structured education programmes. Adequate outpatient clinic space is also essential for the efficient running of multidisciplinary diabetes clinics.

### Staffing

Staffing recommendations for the IPU can be determined on a pro rata basis from the following:

	<b>Centre of Reference (per 300 patients)</b>	<b>Additional Unit (per 150 patients)</b>
<b>Paediatric Endocrinologist</b>	2WTE (1.2WTE dedicated to Paediatric Diabetes)	1WTE (0.6WTE dedicated to Paediatric Diabetes*)

Paediatric Diabetic Nurse Specialist (PDNS)	4 (including dedicated pump and transition nurses)	2
Paediatric Dietitian	2	1
Psychologist	1	
Social Worker	1	
Access to Play Specialist	✓	

\*This is dedicated time to Paediatric Diabetes, so in the case of a 1WTE consultant paediatrician time would be allocated as follows 0.6WTE Paediatric Diabetes (0.2WTE outpatient clinics, 0.2WTE inpatient paediatric diabetes, 0.1WTE continuous professional development and 0.1WTE Paediatric Diabetes pump and service development and 0.4WTE General Paediatrics

### Gap Analysis

A staffing survey undertaken in October 2014 across all paediatric diabetes units nationally allowed comparison of current staffing to the above recommendations based on actual numbers of patients attending each centre. Two years after data collection for the national diabetes audit (Hawkes and Murphy, 2014), clear deficits still exist in the numbers of consultant, nurse specialist, dietitian and psychology posts. This deficit in consultant numbers is in line with the HSE, Medical Education Training, entitled Medical Workforce Planning document published in July of 2015 (MET, 2014). The total national deficit is summarised below.

	Consultant	DNS	Dietitian	Psychologist
<b>Total approximate national deficit (WTE)</b>	13.95	18.11	11.97	8.18

### Audit

The availability of data on patient numbers and outcomes are central to the planning and provision and continuous audit of appropriately resourced centres, and the highest quality of care. A national data management system integrated to daily clinical practice across all centres would contribute positively to workflow benchmarking and outcomes in paediatric diabetes.

## **Funding Model**

To finance an IPU, Diabetes Ireland would support an accurate cost measurement system as referenced in Harvard Business Reviews from 2011-date (Kaplan, 2011, Porter, 2013). With good estimates of the typical path a child with type 1 diabetes takes from diagnosis at the emergency department, to local centre, through basic diabetes education and via contact with a centre of excellence, providers can use the time driven activity based costing (TDABC) system to assign costs accurately and easily to each process step along the patient pathway. Time driven activity based costing (TDABC) includes 7 steps listed below:

8. Select medical condition to be examined (e.g. Paediatric Diabetes)
9. Define a care delivery chain (hospital based)
10. Develop process mapping for each activity in patient care delivery (identify resources involved and any supplies used for the patient at each process)
11. Obtain accurate time estimates for each process step
12. Estimate the cost of each patient care resource
13. Estimate the practical capacity of each resource provider – calculate the capacity cost ratio
14. Compute the total costs over each patients cycle of care i.e. TDABC (Kaplan, 2011, Porter, 2013)

## **Programme Metrics and Evaluation**

Associated with this funding model would be the need to continuously evaluate services. Patients will be carefully monitored with regular review (3 to 4 monthly) and provided with appropriate management education with an aim to significantly improve outcomes of care over the next ten years. Patients who are not reaching HbA1c targets may need targetted interventions.

Primary quantitative outcomes proposed in the Model of Care are:

- Establish accurate baseline data on national HbA1c, clinic frequency, admission rates, DKA rates, severe hypoglycaemia rates
- HbA1c target of <7.5% (<59mmol/mol) for Type 1 Diabetes (ADA Crtieria, Standards of Diabetic Care (2014))
- Improve Health-Related Quality of Life (HRQOL) and reduce family burden
- Set standards for the process of care deivery with regular 3-4 monthly review of patients.
- Reduce admission rates of known children with Type 1 Diabetes with diabetes-related acute complications (DKA and severe hypoglycaemia)

- Having established baseline data, set targets for planned improvement of HbA1c. A media HbA1c reduction nationally of 0.5% (5.5mmol/l) within 5 years and 1% (11mmol/l) in 10 years.

Secondary quantitative and qualitative outcomes are:

- Evidence of listening, communicating and collaborating with children and young people with Type 1 Diabetes, families, carers and healthcare professionals in all disciplines.
- Reduced variations between services and clinical outcomes.
- Improved quality of life and reduced burden of disease for children and young people with Type 1 Diabetes and their families.
- Improved patient experience of the service.
- Standardised and accredited training in place for all healthcare professionals who work with paediatric diabetic children and young people.
- Educating children to self-manage their diabetes using nationally standardised and evaluated programmes of education
- Clinically led service improvements.
- Screening for standardised complications screening as per ISPAD guidelines (Donaghue et al., 2014).

## Summary

The prevalence of diabetes is increasing. An estimated 60% of the annual exchequer spend on diabetes care is spent on caring for patients who have developed associated complications, which can be significantly reduced with regular review and support from their diabetes team. The HSE Model of Care for All Children and Young People with Type 1 Diabetes developed by the Paediatric Diabetes Working Group chaired by Dr Stephen O’Riordan requires funding of just €5.5m to fully resource a high quality paediatric diabetes service that meets the needs of patients and their families and will make very significant exchequer savings in future years.

The funding model proposed for this service which has to be based in hospital settings will provide, the medical, nursing and psychosocial support to deal with all patients, regardless of where they reside, in a systematic and accurate cost measurement system with specific quantitative and qualitative outcomes. These measured outcomes, in other countries where investment has been made, have shown a reduction in HbA1c over 5 and 10 years. The paediatric diabetes community has come together to produce this model of care but a long term funded strategy is required to provide, audit and evaluate a quality system. Diabetes Ireland is seeking the support of the Oireachtas Committee on the Future of Healthcare to support this service. <https://www.diabetes.ie/>

## Disability Federation of Ireland

According to Census 2011, there are 595,355 people with a disability in Ireland, equivalent to 13% of the population. Disability will inevitably impact on almost everyone at some stage in a person's life. People with a disability are one of the groups in Ireland at highest risk of poverty with an 'at risk of poverty' rate of 22.8%, a deprivation rate of 51.3% and a consistent poverty rate of 13.2%. The correlation between poverty, disability and health inequalities is widely appreciated and it is critical that any developments in the future of the health care system responds to these trends.

Ireland's demographic profile is set to change with an aging population and the corresponding rise in the occurrence of disability and chronic conditions. For an effective and efficient use of resources, the provision for healthcare needs to be planned along with these trends. Planning for the future provision of services will require a demographic analysis of the individual support needs for those with a disability. Moreover, a deficiency exists in the study of disease, prevalence, incidence, patterns, cause and prevention, mortality rates, and co-morbidity in relation to people with disabilities. This basic information is essential if we are to go on to establish the profile of health and care supports needed for the delivery of appropriate community services.

Currently, numerous strategies and government commitments exist which all outline a vision for inclusive community living and person-centred services. However, budgetary decisions made over the previous decade are inconsistent with these policies and have stalled implementation of strategies such as A Vision of Change, The Neuro Rehabilitation Strategy and indeed parts of the Transforming Lives Programme. Any plan for the future of healthcare should first ensure that these strategies are implemented and adequately funded.

A properly resourced primary and community care infrastructure is required to provide for people with disabilities' needs and to respond to the growing demand for services. Better outcomes can be achieved for people with disabilities when community supports and services are provided when, where, and how they are needed. An integrated community services framework will link in with people at important points during their life cycle, provide for person centred service that that respond in a flexible way to the needs of individual. These services must be rooted in the principles of person centeredness with flexible services that meet individual needs, and be designed in such a way as to give control to the individuals and /or their families. Supporting capacity at community level ties in with the vision for mainstream primary care provision. This framework will allow individuals to move between specialised disability services and mainstream services ensuring more flexible approaches of support.

### **Recommendations**

Employ a demographic and epidemiological analysis of the individual support needs for those with a disability to plan for the future provision of healthcare.

Fully implement and fund existing strategies before any new one are drawn up

Develop and adequately fund a person centred, integrated community services infrastructure under in following areas:

#### Personalised Budgets/Direct Payments

- Ensure that commitments to introduce personalised budgets are adequately funded.

### Personal Assistance Services

- Increase investment in Personal Assistant services to meet demand.
- A review of the service should also be undertaken with a view of establishing the Personal Assistance service on a statutory basis

### Self-management of Conditions

#### Assistive Technology

- Develop and fund Assistive technology should be given more attention and importance in health policy for people with disabilities, as well as in policy on wider issues facing the health & social care system

#### Medical Card

- Eligibility for medical card must therefore be based on need, and not income.

#### Neuro-rehabilitation

- Address the critical shortages in staffing and specialist services for people with neurological conditions both in the hospital and community.
- Implement the framework for neurology and neuro-rehabilitation services outlined in the models of care for Neurology and Rehabilitation Medicine and the National Neuro-rehabilitation Strategy

#### Carers and Unwaged Care

- Recognise the social value of unpaid care and remunerate it accordingly.
- Develop a second version of the Carers Strategy with ring-fenced funding to provide for adequate income supports, service improvements, as well as community care being placed on a statutory footing.

#### Mental Health

- Fully implement A Vision for Change and invest in mental health services in primary care to ensure that a person's mental health needs are addressed in their own community.

Ensure all health and social care services are accessible for people with a disability.

Improved information systems to facilitate seamless communication and information flow between different stakeholders, as well as monitoring, evaluating and improving outcomes.

### **Introduction**

According to Census 2011, there are 595,355 people with a disability in Ireland, equivalent to 13% of the population. Disability will inevitably impact on almost everyone at some stage in a person's life. Some people experience disability from birth but for the majority it is acquired. Disability is often age related, as the likelihood of acquiring a disability or disabling condition increases greatly with age. With progress in social and health areas, people in Ireland are living longer than at any time before. Yet with this positive advance comes a sharp increase in the number of people living with a chronic illness or disability.

Notably, one of the high-level goals of Healthy Ireland is to reduce health inequalities; preventable and unjust differences in health status experienced by certain population groups, with the burden of ill health and disability borne disproportionately by those in lower socio-economic groups. People with a disability are one of the groups in Ireland at highest risk of poverty with an 'at risk of poverty' rate of 22.8%, a deprivation rate of 51.3% and a

consistent poverty rate of 13.2%.<sup>235</sup> As a group they are one of the heaviest users of health services. Their diverse and complex care needs exist on a spectrum and range across all divisions of the system; from acute and primary care, to specialist services. However, the health system as it is currently constituted lacks a clear understanding of the range of care required by disability and does not take cognisance of its often episodic nature which necessitates different levels of service at different stages of a person's condition. Presently, the health system is orientated towards singular categorisation of health status (older persons, mental health, disability etc.) or isolated health delivers (for example acute hospitals, primary care, and disability services), leading to segregated, ineffective and inefficient modes of delivery. It is critical that, in developing the future health system the person is placed at the centre, that we can understand and plan for future needs, and the services interact in a way that provide a unique response to the needs of that individual.

Central to this reorientation of health services will be the provision of a comprehensive, integrated health services delivered through in a community services framework. Having appropriately funded community supports to alleviate the added financial burden of having a disability is crucial.

This reorientation of services is also mandated under articles 19, 25, and 26 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which the current government is due to ratify in the coming months. The articles stipulate access to a range of in-home, residential and other community support services necessary to support independent living and inclusion in the community.

### **Planning for Demographic Trends**

Ireland's demographic profile is set to change with an aging population and the corresponding rise in the occurrence of disability and chronic conditions. For an effective and efficient use of resources, the provision for healthcare needs to be planned along with these trends.

There will be nearly 1 million people aged 65 and over by 2031, and some 136,000 people aged 85 or over.<sup>236</sup> Given that the percentage of the population aged 85 and over who have a disability is 72.3 per cent,<sup>237</sup> these trends will surely have serious implications for the health service. Co-morbidities will also become more of a factor, further increasing the pressure on healthcare costs. A restructuring of services along a continuum of health is therefore necessary, with the above factors needing to be assimilated into a population health focus that is person centred, based on a life cycle approach, and delivered in the community.

Planning for the future provision of these services will require a demographic analysis of the individual support needs for those with a disability. At present, there is a lack of reliable health information in relation to disability in the Irish population. No epidemiological information exists relating to the health and well-being of people with disabilities with regard to the full life cycle. Moreover, a deficiency exists in the study of disease, prevalence, incidence, patterns, cause and prevention, mortality rates, and co-morbidity in relation to people with disabilities. This basic information is essential if we are to go on to establish the profile of health and care supports needed for the delivery of appropriate community services.

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<sup>235</sup> CSO, SILC

<sup>236</sup> Department of Health, Health in Ireland Key Trends 2014.

<sup>237</sup> CSO, 2012

## **Deliver on Existing Strategies and Policy**

Currently, numerous strategies and government commitments exist which all outline a vision for inclusive community living and person-centred services. However, budgetary decisions made over the previous decade are inconsistent with these policies. Any plan for the future of healthcare should first ensure that these strategies are implemented and adequately funded.

The Value for Money review, for instance, promises “full inclusion and self-determination for people with disabilities through access to the individualised personal social supports and services needed to live a fully included life in the community”. While strategies such as those for carers and neuro-rehabilitation, as well as the National Housing Strategy for People with a Disability, the “Time to Move on From Congregated Settings” report, and “A Vision for Change”, are all progressive policy documents waiting to be implemented.

Funding for these already existing policies should take precedence before any new strategies are drawn up.

## **Person-Centred Community Services**

As noted above, a properly resourced primary and community care infrastructure is required to provide for people with disabilities’ needs and to respond to the growing demand for services. Better outcomes can be achieved for people with disabilities when community supports and services are provided when, where, and how they are needed. People with disabilities do not require permanent use of disability services. This has always been appreciated by those living with episodic conditions that require different levels of service at different stages of their condition. However, this flexible approach is also just as relevant to more traditional social care groups such as those living with intellectual disabilities or a physical disability.

An integrated community services framework will link in with people at important points during their life cycle. These services must be rooted in the principles of person centeredness with flexible services that meet individual needs, and be designed in such a way as to give control to the individuals and /or their families. Supporting capacity at community level ties in with the vision for mainstream primary care provision. This framework will allow individuals to move between specialised disability services and mainstream services ensuring more flexible approaches of support.

It should also be emphasised that better outcomes for people with disabilities are inextricably linked to their requirements for other practical supports in the community. A community services framework must therefore also include access and appropriate to housing, transport, education, employment and training.

Development and adequate funding of the following policies are key to effective, person-centred, community services.

### **➤ Personalised Budgets/Direct Payments**

Commitments for policy reform have already been made in this area, with the intention to devolve budgets to the person so they may choose service providers to better fit their needs. For this to be successful, adequate funding for personalised budgets is crucial. Personalised budgets are not synonymous with independent living. If the budget falls short of meeting the support needs of an individual or there is a lack of flexibility in how these budgets may be used, merely delivering services and supports in this way will not enable people with a disability to live independently.

### ➤ **Personal Assistance Services**

The Personal Assistance Service is, at present, the cornerstone of the Community Services Programme. The service not only assists with tasks that the person with a disability cannot do by themselves, but also supports that person's efforts to engage fully in the community and enables them to live an independent life. However, despite its importance and growing demand for the service, PA hours delivered have remained static over the last two years. Increased investment must therefore be an immediate priority.

A review of the service should also be undertaken with a view of establishing the Personal Assistance service on a statutory basis. Legislating for a Personal Assistance service would provide a right to the service for people with disabilities who need it, in line with Article 19 (b) UN Convention on the Rights of Persons with Disabilities (UNCRPD).

### ➤ **Self-management of Conditions**<sup>238</sup>

Funding also needs to be directed towards the area of self-management. This involves individuals and service providers working together to support a person in dealing with the very real implications of living the rest of their life with a chronic condition. Self-management could also be seen as being key in the underpinning of the policy of mainstreaming.

The challenge for the health service is in translating effective self-care from specialist (most often acute hospital) settings to the community. The community and voluntary sector are integral for this transitions as these organisations play a key role in supporting linkages and in acting as a bridge between individuals, their families, and their health professionals and between health professionals in specialist and general healthcare settings. They also provide a vital link in what is often a bewildering array of specialist and general services for a person with a chronic illness or disability. In the case of neurological conditions, for example, individuals may see up to forty health professionals as part of their care. They receive a significant amount of information and advice over time and have the challenge of translating this information into effective self-care.

There is good evidence that self-management support helps to reduce the number of emergency hospital admissions and unscheduled use of GP services.<sup>239</sup> In addition, recent research evaluating self-management has pointed to one of its benefits as leading to a better use of health services, for example, supporting people to proactively access their primary care team or specialist service or seek treatment at an earlier stage.

### ➤ **Assistive Technology**

Assistive Technologies can support people with disabilities and older people to self-determine, increase their independence and support their self-management. In the context of serious challenges which includes acute strains on social services, reductions in public spending and an aging population, assistive technology can be viewed as an integral part of the future of healthcare in Ireland. Therefore, it is our contention that Assistive technology should be given more attention and importance in health policy for people with disabilities, as well as in policy on wider issues facing the health & social care system.

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<sup>238</sup> The Voluntary Disability Sector as a Key Partner in the Delivery of a Self-Management Framework within the Irish Health Service. Neurological Association of Ireland (NAI) and Disability Federation of Ireland (DFI) June 2013

<sup>239</sup> Philips et al, (2010) EPP Expert Patients Programme Self Care reduces costs and improves health: The evidence: [www.dh.gov.uk/expertpatients/publications](http://www.dh.gov.uk/expertpatients/publications)  
Challis D., Hughes J. et al. (2010) Self-care and case management in longer-term conditions: the effective management of critical interfaces. London. HMSO. Accessed via [www.sdo.nihr.ac.uk/files/project](http://www.sdo.nihr.ac.uk/files/project)

Since the focus within primary care is on prevention and with policy intending to help people to live longer and healthier at home or in their communities using assistive technologies as an enabler will have a positive effect on the lives on people in Ireland. With an aging population and increasing prevalence of disability and chronic conditions in Ireland there are many people who could benefit from the use of Assistive Technologies to maintain and improve their daily functioning. Assistive Technologies offer cost effective alternatives to medical or institutional care.

There is already an acknowledgment of the positive impact of Assistive Technologies by the HSE.<sup>240</sup> Additionally, the increase use of assistive technologies is one of the pillars of the National Policy and Strategy for the provision on Neuro- Rehabilitation Services. With respect to neurorehabilitation services it is appreciated that the use of assistive technology “has not always been optimally harnessed... and assistive technologies can be a cost effective means of empowering individuals and providing enhanced quality of life”.<sup>241</sup>

What is important is that for the first time there is a focused policy commitment by the HSE that includes assistive technologies, which has been missing to date. Such an approach should be disseminated across all the health service. By taking a strategic view of Assistive technology DFI believes is the way forward to strengthen the future of healthcare in Ireland.

#### ➤ **Medical Card**

The medical card offers a vital lifeline to some people with disabilities whose incomes cannot match their medical needs. Its perceived value as an insurance against poor health often outweighs the perceived risk of taking up employment. Eligibility for medical card must therefore be based on need, and not income.

However, there are a number of issues that should be considered in this regard.

- The episodic nature of disability: The medical needs of individuals with certain disabilities are cyclical in nature, which raises a concern of the timing of the review of their medical card eligibility.
- The use of medical diagnosis as a key criteria: It is concerning that the expert panel will be prioritising conditions- it is important to approach this review with a holistic framework in order to ensure that a “league table” of conditions is not developed.
- The socio-economic repercussions of disability: A person living with a disability has medical costs that are recurring and on-going, which could lead to poverty and deprivation if denied a medical card because of the previous points.

Awareness is needed of the “cyclical” nature of many conditions, which may mean that although they are conditions which exist for the remainder of life, the “severity” of their symptoms can vary hugely on a yearly, monthly, weekly and even daily basis. Therefore if these individuals are forced, despite a diagnosis of a life-long condition, to reapply every three years, their re-assessment may take place during a relatively “good” period, and they risk their medical card being removed. This may have drastic consequences on their health, and their ability to seek timely intervention from their GP or attending hospital.

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<sup>240</sup> Health Service Executive (2016). National Service Plan 2016. Available from <http://www.hse.ie/eng/services/publications/corporate/serviceplans/nsp16.pdf>

<sup>241</sup> Dept. OF Health and Children (2011). National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland.

### ➤ **Neuro-rehabilitation**

Effective integrated care for people with neurological conditions is key to any future healthcare strategy because of the growing numbers of people with these conditions and the impact across the health system.

The principal barrier for the realisation of this continues to be underinvestment and underdevelopment of specialist services, leading to gaps at all stages of the care pathway. An immediate priority should be to address the critical shortages in staffing and specialist services for people with neurological conditions both in the hospital and community. Furthermore, it is essential to implement the framework for neurology and neuro-rehabilitation services outlined in the models of care for Neurology and Rehabilitation Medicine and the National Neuro-rehabilitation Strategy.<sup>242</sup>

### ➤ **Carers and Unwaged Care**

Gender inequalities in the division of care work are deeply embedded in our society and need to be addressed. The vast majority of those who care for people with disabilities are women<sup>243</sup>, and 89.5% of carers are unpaid.<sup>244</sup> Therefore the immense social contribution of unwaged care is largely ignored and unrewarded.<sup>245</sup> Formal state provision will never be able to meet care needs in full so without the appropriate structures in place, women will continue to be the default caregivers and as a result will be materially disadvantaged.

The National Carers' Strategy, which was published in July 2012, sets the strategic direction for future policies, services, and supports provided by Government Departments and agencies for carers. There are 42 Actions in its Roadmap for implementation, yet these are to be achieved on a cost-neutral basis. Given that the state providing the same level of care would cost an estimated €2.5-€4 billion annually, this is unacceptable. A second version of the strategy should therefore be drawn up, with ring-fenced funding to provide for adequate income supports, service improvements, as well as community care being placed on a statutory footing.<sup>246</sup>

### ➤ **Mental Health**

The current demand for mental health supports is greater than ever and services are becoming more and more overextended due to a lack of adequate investment.

The World Health Organisation has stated that by 2030 depression is expected to be the largest contributor to disease burden,<sup>247</sup> yet services in Ireland are under-staffed by approximately 20%. The implementation A Vision for Change is long overdue and must be an immediate priority, with a particular focus on investment in mental health in primary care to ensure that a person's mental health needs are addressed in their own community.<sup>248</sup>

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<sup>242</sup> Neurological Alliance of Ireland.

<sup>243</sup> National Economic and Social Council (NESc) (2014) Jobless Households: An Exploration of the Issues, Dublin: NESc, p.37.

<sup>244</sup> Yumiko, K.et al. (2012) Profile of Community Dwelling Older People with Disability and their Caregivers in Ireland.

<sup>245</sup> <http://www.progressive-economy.ie/2016/08/womens-unpaid-care-is-pivotal-factor-in.html>

<sup>246</sup> <http://www.carealliance.ie/userfiles/file/Care%20Alliance%20Ireland%20Pre-Budget%20Statement%20-%20Budget%202017.pdf>

<sup>247</sup> WHO, The Global Burden of Disease

<sup>248</sup> Mental Health Reform

## **Accessibility and Information**

### **➤ Accessible Health and Social Care Services**

The Disability Act 2005 mandates, on a statutory basis, that mainstream public services provided to the general public must also equally serve people with disabilities. The health service is obliged to ensure that its buildings, its services, the information it provides, and how it communicates with people, are all accessible to people with disabilities.<sup>249</sup>

### **➤ Improvement of IT Systems**

At present there are numerous strands of the health service operating in isolation. Improved information systems are needed that would facilitate seamless communication and information flow between different stakeholders, as well as monitoring, evaluating and improving outcomes.

Improved and more integrated health records would link service users and providers across the continuum of care and provide relevant information to these stakeholder groups.

## **The Work of the Disability Federation of Ireland**

The main object of DFI “is to benefit the community by supporting the contribution, protecting the rights and valuing the roles of persons with disabilities and disabling conditions in its community and encouraging their fullest participation in shaping a society that promotes the wellbeing and quality of life of such persons”.

The main object is further supported by the principles enshrined in the United Nations Universal Declaration of Human Rights, 1948, and the United Nations Convention on the Rights of Persons with Disabilities, 2006.

The governing body comprises of at least 50% of people who have a disability or who has a personal and enduring experience of disability.

The governing body, namely the Company Members, agree the multi-annual Strategic Plan to promote the objects of the Company and this Plan is regularly reviewed by them.

There are over 120 organisations as affiliates or associates, of DFI. DFI also works with a growing number of organisations and groups around the country and internationally, that have a significant disability interest, mainly from the statutory and voluntary sectors. DFI, as a critical and knowledgeable entity on behalf of the disability movement in Ireland, provides information, training and support, networking, advocacy and representation, research and policy development / implementation, and organisation and management development. DFI is Ireland’s National Council member on the European Disability Forum.

DFI works on the basis that disability is a societal issue and so works with Government, and across the social and economic strands and interests of society.

Disability Federation of Ireland, Fumbally Court, Fumbally Lane, Dublin 8

Tel: 01-4547978 Fax: 01-4547981

Email: [info@disability-federation.ie](mailto:info@disability-federation.ie) Web: [www.disability-federation.ie](http://www.disability-federation.ie)

Follow us: [twitter.com/DisabilityFed](https://twitter.com/DisabilityFed) Like us: [facebook.com/DFIIreland](https://facebook.com/DFIIreland)

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<sup>249</sup><http://www.hse.ie/eng/services/yourhealthservice/access/NatGuideAccessibleServices/NatGuideAccessibleServices.pdf>

**EQUITABLE SINGLE TIER HEALTH CARE AND THE PRINCIPLE OF SOLIDARITY.**

Professor Timothy Stoltzfus Jost states that solidarity is considered a Western European Principle of Health care and that it means that all members of society must have access to health care, regardless of their ability to pay. Stoltzfus Jost states that it is a concept enshrined in the basic laws and traditions of Western European countries and recognised by the European Court of Justice. Ireland does not follow the principle of solidarity. As a country we are committed to the European project and to such health care principles as expressed in a previous plan for Irish Health care in 2001, “Quality and Fairness, a Health System For You”. 15 years later this current Committee considers the same principle on the Future of Health Care as a key defining principle. Our hospital system has been confirmed by OECD research to be highly inequitable. The main driver of the inequity is PHI and the holding of a medical card. The Primary Care system has been found in the same research to be pro poor.

**OPTIONS FOR FUNDING HEALTH CARE.**

Equitable single tier health care will only be successfully politically achieved by moving to a system of funding health care by creation of an insurance pool. This could be a tax funded insurance pool as in Canada, Australia or through an archetypal Social Health Insurance Pool such as in France, Germany, or Holland. Each country has either complementary or supplementary forms of Private Health Insurance (PHI) that are not duplicate insurance which covers hospital care that is already provided within the public system. Ireland has a duplicate form of PHI that is primarily responsible for our two-tier hospital system.

**The Meath/Adelaide hospital group** has sponsored a number of reports carried out by Professor Charles Normande and Stephen Thomas at Trinity College on a Social Health Insurance Model for Ireland, which would in effect be a single payer model of funding health care and create the single tier. All the above models have the capacity to remove the two-tier system and create the single tier system that the Oireachtas committee desires.

**RATIONING HEALTH CARE AND WAITING LIST OECD RESEARCH.**

Rationing in health care is inevitable and that the way tax funded systems, like our own have done so is through waiting. An OECD report on waiting lists in health systems in 2002 found that the countries with waiting list problems Australia, Canada, Denmark, Finland, Ireland, Italy, New Zealand, Norway, Spain, Sweden, and the United Kingdom were all tax-funded systems. Holland was the only Insurance nation to have waiting list issues. The other methods of rationing health care are by price and health technology assessment, the longest and most successful system been the National Institute for Clinical Excellence in the UK (NICE). Such a system would have to be introduced in Ireland similar to the National Centre for Pharmacoeconomics in St James, headed by Professor Michael Barry.

## **INTEGRATION OF HOSPITAL, COMMUNITY AND PRIMARY CARE. BUNDLED PAYMENTS.**

If the committee wish to have a detailed overview of Integrated Health Care then it would do well to review **the Health Research Boards report for the department of Health in 2013, on Integrated Health and Social Care, by Brigid Pike and Deirdre Mongan.** It is a comprehensive review of how to integrate health and social care and I personally agree with its findings. If one truly wants integrated care, then the best models of such care come from care systems in the United States such as Kaiser Permanente, Puget Sound and the Geisinger Health System in Pennsylvania. These are known as Integrated Health Care Delivery Systems (IHCDS). These are vertically integrated health systems. Such systems depend on a number of characteristics for success. See full submission. A model of payment that has found success in achieving the goals of high quality, cost effective care is the **Prometheus Payment Model**, one of the bundled payment systems referred to above. This was designed by Francois de Brantes Executive Director, and others, of the Health Care Incentives Improvement Institute in the US. See full submission.

### **Ageing and Population Growth.**

Given word limitation, I am unable to address this issue but I would refer to the many publications on funding of Long Term Elderly Care by the OECD.

### **Principle of Solidarity.**

Professor Timothy Stoltzfus Jost at the Washington and Lee University School of Law defines the concept of solidarity in his contribution to an issue of the Journal of Health Politics, Policy and Law, in 2006. He states that solidarity is considered a Western European Principle of Health care and that it means that all members of society must have access to health care, regardless of their ability to pay. Stoltzfus Jost states that it is a concept enshrined in the basic laws and traditions of Western European countries and recognised by the European Court of Justice.

Ireland does not follow the principle of solidarity. As a country we are committed to the European project and to such health care principles as expressed in a previous plan for Irish Health care in 2001, “Quality and Fairness, a Health System For You”.

15 years later this current Committee considers the same principle on the Future of Health Care as a key defining principle. The reason for our failure to implement such principles is a political. As a hospital consultant who has worked in the system for 25 years, I have been deeply uncomfortable and ashamed of the inequity in Irish Health Care, regarded by Sarah Burke, as Irish Apartheid.

Achieving a single tier system and hence equity in Irish health care is an enormous challenge given the current system of funding health care in this country. We have essentially a single payer system of funding health care, the vast bulk of funding comes from the public purse of 67% on basis of most recent OECD data which, includes capital funding. The remaining funding comes from a combination of duplicate/supplementary voluntary private health insurance, (duplicate meaning covering health services already provided for in the public system), and out of pocket payments accounting for 30% of health funding.

### **Irish Hospital Services Inequity, OECD Research.**

It is prescient to remind the committee of some OECD research on equity of access to health care in relationship to both primary care and hospital care. The only research looking at the Irish model comes from a study done by the Health Equity Research Group of the OECD in 2004. The main author was Professor Eddy van Doorslaer from the University of Rotterdam.

That research revealed Ireland had the third most inequitable access to hospital care in the 21 OECD country study, with just Portugal and Finland worse than ours. They found that Ireland's hospital system was pro rich. Our primary care system and access to General Practice was in fact pro poor. Holland had the most equitable system of access to hospital care with the UK also shown to be equitable, but the data for the UK was based just on outpatient access to a consultant and not on access to hospital treatment and care.

As the UK has a relatively small parallel system of private health insurance, access to hospital care where there is a relatively high take up of PHI, such as in London, will be fundamentally inequitable and pro rich. Professor van Doorslaer and his team analysed the reasons for such inequity of access to hospital care in each country and found that the two major reasons for hospital inequity in Ireland were Private Health Insurance (PHI) and a medical card. The funding of private care comes essentially from a fee system of payments to doctors through out of pocket payments to consultants for private consultations and a fee based system of payment to consultants through the health insurance system, which incentivises these doctors to ensure more rapid access to hospital treatment for individuals with PHI. Similar research in Australia by the OECD Health Equity Research group found the same effect of PHI on equity of access to hospital care.

Our system of funding health care has helped promote our two-tier system which, with the birth of inequity commencing in 1956 by enactment of laws allowing the formation of the VHI. The Dail is the only institution that can change this situation. The question is does it have the will to do so? It is fundamentally a flawed system of funding in the context of European and Irish health care principles.

Health policy development over the last decade and more has contributed to the inequity, with tax payers money being used to help fund the development of private hospitals that primarily care for individuals with health insurance, the wealthier members of society. The problems in the public hospital system have not been resolved by this policy. Professor Carolyn Hughes Tuohy from the University of Toronto has published papers dealing with this issue in the global context.

### **Rationing Health Care and Waiting List OECD Research.**

It I believe is important for committee members to understand that rationing in health care is inevitable and that the way tax funded systems, like our own have done so is through waiting. Our waiting list problems confirm this reality and as you all know attract significant media attention. An OECD report on waiting lists in health systems in the OECD in 2002 found that the countries with waiting list problems Australia, Canada, Denmark, Finland, Ireland, Italy, Netherlands, New Zealand, Norway, Spain, Sweden, and the United Kingdom were all tax-funded systems bar the insurance funded system of Holland. The waiting list problems in that country were not as marked as in the other tax funded systems and have since been resolved. The main reason for this is that in tax funded systems, departments of health are competing with other departments for funding, and cost control is the key desire of any

department of finance, not patient care. This is highlighted by a comment by Professor Rudloff Klein, emeritus Professor of Social Policy at the University of Bath who referred to the funding model of Britain's NHS, a tax funded system, as somewhat disadvantageous: "that the method of funding inhibited the development of the service was acknowledged from the start. The NHS had to compete with education, housing, and other public services within budgets constrained by the desire of all governments to avoid losing elections by raising taxes and largely shaped by series of economic crises in the 50's, 60's and 70's. The 1948 model of funding the NHS served the interest of the most powerful department in the British Government, The Treasury". A similar situation applies in our own single payer system, as the committee is well aware. Other countries ration by price and most recently by health technology assessment, the most successful in the world currently, is probably the National Institute for Clinical Excellence in the UK (NICE). We as you know have our own infant system in the National Centre for Pharmacoeconomics in St James, headed by Professor Michael Barry.

### **Options for Funding Health Care.**

How does the Oireachtas Health Committee develop a plan to move our system to a single tier system? In order to move to this system it would have to recommend one of two options:

1. Provide for all health care funds through general taxation.

This is the method as at present in Ireland, the UK, Sweden and Denmark for example, but ban PHI for all health services within the basket of hospital and primary care services but allow PHI for a certain set of service such as accommodation facilities and others. The UK is essentially a single tier system for 90% of the population with 10% also using PHI and thereby queue jumping for hospital treatment.

The committee could alternatively recommend:

2. The creation of an insurance pool, with funds dispersed by an Insurance agency or agencies, a Social Health Insurance (SHI) model either publicly or privately administered, but if in the latter case, government regulated, similarly to our current PHI model but with a basic basket of health service mandated for all the population. The collection of funds and their disbursement could be done a number of ways:

2.1 The insurance fund pool could be generated from insurance premiums, tax and premium based, a model of Social Health Insurance, administered by agencies, health insurance companies (multipayer) as in Switzerland with profits allowed on ancillary health services, or Holland, with companies allowed to make profits on insurance for acute hospital and primary care but not long term care services such as nursing home or long term mental health service. Critics of the Dutch system refer to it as private insurance system but the OECD record the funding of health care there as social security funding similar to France or Germany, as it is regulated by the laws of government. Holland fused its public and private insurance systems together in 2006, in order to create equity in the insurance sense and just have insured patients not private or public. These systems are single tier systems.

2.2. The committee could recommend a purely tax funded Health Insurance model akin to that in Canada (one of the most progressive in redistribution from rich to poor in the OECD) that legally bans PHI for any service covered by the public insurance system through the Canada Health Act. This represents most hospital and GP service but there is a large PHI

market for pharmaceuticals that are not as well covered by the public insurance system. All patients in Canada are patients, not private or public, and it is a single tier system.

2.3. It could recommend another form of SHI as in France providing a basket of key health services to all the people to include hospital and primary care services but allowing PHI to complement the basic insurance package, or as in Germany that allows an opt out from the SHI system to PHI coverage based on income.

The Meath/Adelaide hospital group has sponsored a number of reports carried out by Professor Charles Normande and Stephen Thomas at Trinity College on a Social Health Insurance Model for Ireland, which would in effect be a single payer model of funding health care and create the single tier.

All the above models have the capacity to remove the two-tier system. Unfortunately the French and Canadian models, despite their insurance mechanisms still have inequity of access for lower income individuals. The insurance funded model does not guarantee equity and there are therefore other reasons why inequity occurs in the delivery of health care for reasons I cannot expand on here as a result of the submission word count limitation.

### **Political, Population and Government Departments Opposition to Funding a Single Tier System.**

Moving to a single tier system will provide enormous challenges as it will necessarily require essentially a change to a different funding model. This cannot be dealt with in this submission in its entirety for word count limitation, but none the less if one moves to a completely tax funded, budgetary model as we have at present without PHI, then political repercussions will occur and the 45% of the population that feel as you all know that “they must have PHI”, will be protesting, the Private Hospital sector will be depending on state funds and the department of finance are unlikely to provide the additional €2 billion to fund the current private hospital system. This model does not appear to be a realistic option.

The classic Social Health Insurance funding model of several European systems will result in political difficulties as it requires contributions from employees and employers, which has implications for individuals and employers, and which is again beyond the scope of this contribution given word limitation. I would be happy to expand in a further forum. The department of finance would vigorously oppose this model, as it requires it to cede power over most health funding. Such opposition by different government departments to the introduction of a health insurance model occurred in Mexico’s Seguro Popular, as highlighted by Jason M Larkin of the International Budget Partnership in Washington D.C., in the June 2010 issue of the Journal of Health Politics, Policy and Law. We have most recently seen the opposition in this country from the departments of finance and the public expenditure to the last governments proposed single tier insurance model of funding. Political opportunism resulted in media scaremongering of the population in respect of health insurance premiums as you all appreciate.

### **SHI models and Private Health Insurance.**

None the less, most SHI models in Europe also have either complementary or supplementary PHI systems, which provide for top up payments to providers of health services not covered by the SHI fund, or provide for services not included in the basic package. It needs to be appreciated that whatever system is used to cover the basic package of health care, be this through a tax funded system as is currently in place in Ireland, New Zealand and the UK; a

tax funded Insurance system as in Canada or an SHI system as in France or Germany, additional private voluntary health insurance as currently allowed in predominantly single payer countries such as New Zealand and France, display pro rich inequity in visits to GPs and is particularly marked for specialist visits in New Zealand. I have referred to the inequity that PHI gives rise to in Ireland. The most inequitable country for specialist visits in the most recent study of inequity in health care by the OECD in 2012, and considered a significantly single payer nation, was France. On the other hand, Canada a country that legally does not allow PHI for core hospital and GP services also has a pro rich inequity for both GP and specialist visits, confirming that the creation of a single tier system through the funding model does not resolve the issues with regard to equity. The United States of course has the greatest inequity of all OECD countries studied. The two countries in the most recent 2012 survey with the greatest equity for both GP and hospital access were the UK and Denmark. Both countries, according to Professor Sherry Glied's categorisation of single payer countries in an issue of the Journal of Health Politics, Policy and Law in 2009, ranks both countries as single payer nations. Her definition none the less is based on a countries revenue concentration for health care finance resources rather than actual payers.

### **INTEGRATION OF HOSPITAL, COMMUNITY AND PRIMARY CARE. BUNDLED PAYMENTS.**

If the committee wish to have a detailed overview of Integrated Health Care then it would do well to review **the Health Research Boards report for the department of Health in 2013, on Integrated Health and Social Care, by Brigid Pike and Deirdre Mongan.** It is a comprehensive review of how to integrate health and social care and I personally agree with its findings.

Our system of primary and hospital care is a classic example of disintegrated care. There are no incentives within the system to allow integration to occur. What would be required are a number of actions to occur to include funding models that deliver funding for an episode of care from Primary Care to Hospital Care and back to Post Hospital Care. **Bundled payments** can be for an episode of acute illness or indeed for chronic care. It has been estimated that such payments may result in cost savings of 5.6% in the US.

### **Best Models of Integrated Care. (A Sample)**

If one truly wants integrated care, then the best models of such care come from care systems in the United States such as Kaiser Permanente, Puget Sound and the Geisenger Health System in Pennsylvania. These are known as Integrated Health Care Delivery Systems (IHCDS). These are vertically integrated health systems. Such systems depend on a number of characteristics for success. Gwyn Bevan, Professor of Policy Analysis and Deputy Head of the Department of Management at the London School of Economics and Katharina Janus, Professor of Health Care Management, Ulm University, Germany and Director of the Centre for Health Care Management, Hamburg, Germany describe these characteristics in their contribution to the Journal of Health Politics, Policy and Law in 2011 dealing with Comparative Health Politics in the United States and the UK.

They are as follows:

**Governance by Hierarchy** (ownership) or a mode that is close to a hierarchy (through long-term contractual relationships). Successful IHCDSs have been found to have hospital

services, specialists, primary care physicians, and a health plan all organised into one economic unit.

**Systemness.** One system provides the consumer with health care services across the whole continuum of care (including primary, tertiary, long-term and home care) with multidisciplinary care teams integrating and coordinating a continuum of services across providers. Members of the IHCDS are required to accept restrictions on their choice of physician and primary care physicians employed by the IHCDS act as gatekeepers to specialists. Because the system is integrated they are able to manage resource consumption at each level along the continuum.

**Financing by Capitation.** Reimbursement method is by payment for coverage of all care provided by the IHCDS through an annual contract with monthly payments.

**A Commitment to Cost Control and High-Quality care.** It is crucial that the IHCDS show the providers of care that they are committed to high quality care through continuous improvement. Successful IHCDS are designed to improve, and compete on quality and are able to signal high quality to their current and potential members and staff.

**Good Management and Information Systems.** Tight management within an IHCDS controls its bureaucratic costs, and sophisticated data management facilitates standardisation in care management and health care provision. Professor Peter S Hussey of the non profit Research and Development Corporation (RAND) has indicated that there are potential savings of 1.5% in health care costs in the US context by instituting appropriate health information technology (HIT)

**Durability and Size.** Both Kaiser and Puget Sound are large organisations with integrated care across a broad range of services with each offering coverage to a large population.

The development of these ideal organisations has been hampered in the US for reasons that I cannot refer to now because of word limitation but can be found in the article by Bevan and Janus. They have not occurred in the UK for reasons that the authors highlight in the article, but relate to the history of medical professional development in the UK into generalists and specialists.

### **Hybrid Models.**

In short, the organisations that have successfully developed in the US are known as **Hybrids**, which encompass a mode of governance with characteristics of both market and hierarchy. The authors recommend such Hybrids for the UK health service.

Gwyn Bevan and Katharina Janus define them as long term contractual relations that preserve autonomy but provide added transaction-specific safeguards, compared with the market. The goal is to achieve the advantages of hierarchies through functional, physician, and clinical integration without the disadvantages of creating bureaucracies that antagonise physicians and are slow to respond changes in health care and markets. They can be regarded as a kind of vertical integration, which is “a combination of various care-delivery services provided by different organisations that offer services under contract to each other and are organised seamlessly”. Sutter Health they say is an example of a successful hybrid that is able to respond flexibly and quickly, manage future uncertainty, and enable its affiliates to have

common interests with some autonomy, which is of particular importance for physicians. IHCDS are the antithesis of the purchaser provider models of financing.

### **Payment Models (An Example).**

In attempting to provide integrated care, the payment mechanisms to health care providers must be considered. Fee for service payments must change, as they are responsible for overuse of services, duplication, use of specialised services and involvement of multiple physicians. This is typical of our health insurance payment structure at present. Our capitation payment method as applied in General Practice has deficiencies as highlighted in the following section. Salaried hospital doctors have no incentive to provide high quality care.

A model of payment that has found success in achieving the goals of high quality, cost effective care is the **Prometheus Payment Model**, one of the bundled payment systems referred to above. This was designed by Francois de Brantes Executive Director, and others, of the Health Care Incentives Improvement Institute in the US. They bundle services and provide a budget with three components: Evidence informed case payment, patient specific severity adjustments (the payment is altered for complexity and severity not unlike our own case based early efforts at prospective payment systems for hip replacement), and also an allowance for potentially avoidable complications. The system encourages collaboration of General Practitioners, Hospitals and other providers of care to avoid preventable complications. This system avoids one of the major weaknesses of capitation, the undifferentiated reduction of services in order to maximise financial gain. Further elaboration is not possible given word limitation.

I believe that our hospital and GP service is a classic example of disintegrated health care. Unless governance structures such as those referred to above are implemented, our health care service will remain disintegrated, expensive and providing limited quality care. The history of Irish medicine is highly influenced by the UK where generalists and specialists work in a system without significant integration. If one looks at our current system, it follows this pattern, with primary care group development and hospital groups been the most recent development occurring separately with no link up between them. Neither is integrated with each other. I believe a first step to integration would require the current hospital groups to have General Practitioners and indeed Social Care members on their executive boards. The funding of groups would then need to include some form of bundled payments system to encourage greater collaboration between Hospital and Primary Care as indicated above.

### **My Health Service Area Road Blocks.**

The roadblocks in the area in which I have worked for 25 years as a consultant physician are typical of the health service throughout Ireland.

### **Health Information Technology.**

This is badly lacking. There is no surprise that it is, as the last governments eHealth Strategy indicates that we have been spending 0.85% of our health budget, whereas the EU countries as a whole have been spending 2-3%. This is another manifestation of political failure on health care. The acute hospital service is provided predominantly by doctors in training and as a result the over use of tests is enormous. There are no decision support tools that would allow a more appropriate use of tests and technology. Most communication between hospitals and

general practice is paper based though there are improvements in the laboratory area. Paper based records results in duplication of testing both in the public and private sector. Such tools have the capacity to reduce costs significantly as indicated by the Vanderbilt Information System that saved \$1.3 million on inappropriate orders for ECG and Chest X Rays. This system along with many other information technology systems is referred to in Newt Gingrich's book in 2003 "Saving Lives & Saving Money". Yet the HSE have procured an online radiology system without the ability of the system to indicate to doctors that a particular test is appropriate or inappropriate.

### **The Two Tier System in our Area. Causes.**

#### **Infrastructural Capacity Deficiency.**

Public Hospital consultants are incentivised to do private practice because the main public hospital in the case of University Hospital Galway in particular and Portiuncula to a lesser degree does not have the infrastructural capacity – the manifestation of a department of finance controlled tax funded system as highlighted above, rationing by waiting - such as theatre time and staffing to deal with the demand placed on it, with the result that substantial numbers of public hospital consultants are literally encouraged to work in the two private hospitals in Galway, the Bons Secours and the Galway Clinic, to meet demand. Has anyone ever tried to estimate the cost to the public hospitals of this inefficient system of public hospital operation?

#### **Our of pocket and insurance payments of doctors, cost shifting.**

In addition the fee per item system of payment within the private sector further encourages private practice, as for some specialists this provides significant additional income. Cost shifting occurs from General Practice to Hospitals as manifested by significant charges for blood testing and ambulatory diagnostic tests such as ambulatory blood pressure monitoring. Over use and duplication of tests is significant. Critically ill patients cannot be managed at the Bons Secours and several critically ill patients cared for at the Galway Clinic have to be transferred to the public hospital for care.

Certain tests not available in our hospital have to be purchased in the private hospital, as the capacity within Galway University Hospital radiology department is not present. Publicly appointed consultants have left the public sector to work solely in the private sector, another drain on public hospital services.

#### **Administration.**

Our system is over administered and while clinical directorships have improved management slightly, there is insufficient autonomy for medical professionals and inadequate financial responsibility because of the nature of hospital funding.

#### **The indignity of patients on trolleys in overcrowded A&E Departments.**

Those higher income individuals having had such an experience won't tend to suffer the indignity of this again, and in my 25 years of experience as a consultant physician at Portiuncula Hospital, patients are increasingly using the Galway Clinic to avoid such indignity since it opened its doors in 2004. Inequity increases as a result driven by the income groups who feel "you must have insurance". You all are aware of this.

**Ageing and Population Growth.**

Given word limitation, I am unable to address this issue but I would refer to the many publications on funding of Long Term Elderly Care by the OECD.

I would be happy to be engaged in assisting the parliament in moving our health system to a single tier equitable system of which we can all be proud. This will not occur without political leadership and an understanding by our parliamentarians of the nature of health care, its delivery and funding models and the strengths and weaknesses of each system.

## Dr. Truls Christiansen, Wicklow Primary Healthcare

- Get a 10 year Plan
- Involve health care workers in its planning
- Fund the Plan properly; from the taxes.

### Strategy

-Key priorities: to involve healthcare workers in the planning of the Government's Strategy

-Key challenge: to convince politicians via you to act on this very good Plan.

-Key action: to create this 10 year Plan to be a template for changing politicians.  
to try to reduce the increase in cost via preventive measures.

### Integrated Primary and Community Care

-Steps needed: convince politicians that the Government Plan needs significant funding.  
GP's will need a New Contract reflecting extra work involved in integration  
and to run primary care according to the Government Plan.  
Health care workers need to be part of the planning of the integration.

-Key barriers: political hindrances;

- 1.Changing politicians; especially Minister for Health not giving him/her time to attend to the Government Plan; and ...
- 2.Dept of Public Expenditure decided for the Minister of Health (Varadkar) that he cannot afford Universal Health Care...

This Committee can recommend changes in rules, and influence such attitudes from all parties.

-My experience:(GP)

- 1.apathy from fellow healthcare workers, due to lack of involvement in decision processes.
- 2.a split profession of doctors also leading to apathy; worsened by a poorly structured/run trade union.
3. very difficult to deal with HSE; too big/ bureaucratic.
- 4.lack of resources for better community care; home help services/physiotherapy
5. two tier system - unfair and wrong for both provider/consumer

To get GP's to work the Strategy we need a New Contract.

It needs to reflect the 10year plan, and to represent all GP's at the negotiating table. If the pay structure is done right, we will be able to take on chronic disease management - thereby lessen pressures on outpatient and emergency departments .

Scandinavia has a one tier system with universal health care; ie delivery of care is according to need ; not ability to pay.

GP's are truly in the centre of primary care delivery, and are well resourced

to account for premises and staff.  
(I did my internship and GP training in Norway, after having graduated in Ireland)

## **Funding Model**

Through the taxes. We already pay for health delivery with 80% from our taxes. Experts in health finance told us at IM AGM 3 years ago that we pay less tax in Ireland than the European average, and that a small increase in our general taxation will pay for our health in a fair way.

To get a one tier system the tax relief on health insurance has to go.

Specific to primary care health delivery via the GP - I see a system which operates very well in Norway - the GP's fee is constructed such:

- a registration/capitation fee (up to max 1500 patients pr doctor)
- a fee pr visit to stimulate chronic disease management
- a fee pr extra items done; e.g blood tests/warfarin management/counselling to be added to the existing list of existing items (suturing/nebulizing/ECG/etc.)
- a small co- payment from the patient; to act as a slight deterrent
  - avoiding overuse, and putting a little value on the provider from the consumer. This could be €5-10; up to a maximum e.g. of €100/pr. Year pr. family.

All construed so as to create a good income for work done, and no more.

## **Prescriptions**

- 1.Chronic disease medicines free.
- 2.Incidental illness medicines; everybody pays for; again to a certain max pr. year/family(this will automatically make both providers and consumer think more carefully about the need for a prescription....)

Greatly facilitated if E -prescribing and the new personal ID number are launched.

This operates in Norway; where they spend roughly the same on health pr.capita as Ireland; but where the proportion going to primary care is much higher.

Ireland deserves a good and fair health delivery and I believe the creation of this Committee with a 10year plan is a real beginning.

## **Dr. Elizabeth Cullen, Naas, Co. Kildare**

### **What are the key priorities for inclusion in a ten year plan for the health service?**

Timely access to a free GP and hospital care for all, including investigations and treatment.

### **What are the key challenges, in your view, to achieving a “universal single tier service, where patients are treated based on health need, rather than ability to pay”?**

1. Financial constraints. It would be interesting to note the cost of administration of the current medical card system. Considerable savings could well be made by abolishing this system, the administration and maintenance of which use up considerable financial and human resources.
2. In light of the increasing population and older population, more hospital beds are needed in every general and paediatric hospital. In addition, a another hospital is needed in Dublin to cater for patients with straightforward conditions in order to alleviate pressure on tertiary hospitals in Dublin whose primary aim should be to cater for complex referrals from all over the country
3. The indications for referral for the Assessment of Need process for young children with a possible disability are unclear. Nevertheless once a referral is made the process must be completed, often at considerable expense. Clearer referral processes for children with special needs would save a lot of money.

### **What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and its impact on the health system?**

As above

### ***Integrated Primary and Community Care***

#### **What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?**

Shared record keeping, with computerized databases with specific areas for GP, PHN, SMO, speech therapists, physiotherapists and allied health care professionals as required. GPs would have their catchment areas defined, and correlated with PHN, physiotherapists and other allied health care professionals. This would simplify the referral processes for access to services for children with special needs and clarify the system for parents and service providers alike.

#### **What are the key barriers to achieving this, and how might they be addressed?**

Early and close collaboration with all health professionals would be necessary. It will be necessary to rebuild pride in the health service.

#### **How would you ensure buy-in from health care professionals to progress towards an integrated health care model?**

As above. If public opinion supported this concept, it would undoubtedly help the situation.

#### **Are there any examples of best practice that the Committee should consider? Please refer to any evidence you have to support this.**

I understand that the French health system is very good but I have no experience of this.

Dr. Elizabeth Cullen, Senior Medical Officer, Naas, Co. Kildare.

## Dr. Aiden Devitt, Consultant Orthopaedic Surgeon

Healthcare provision in Ireland is in urgent need of restructuring. Current structures are inefficient, wasteful, cumbersome and inequitable. Despite this, the HSE is full of hard working, well meaning progressive and dedicated people at all levels within the organization who want to make the system work. The solution is to modernise what we already have and build on our strengths and experience rather than trying to import an entirely new system.

### Current Problems

1. Many inpatients in acute Irish hospitals do not need to be in an acute hospital at all. These include those awaiting tests which could be done as outpatients, awaiting discharge to nursing homes or other stepdown facilities or simply patients who refuse to go home because many Irish people prefer an extended hospital stay particularly in an elective setting.
2. Many patients attending or waiting for elective orthopaedic outpatient services will not benefit directly from their attendance because their problem is not an orthopaedic or surgical one to begin with. Most attendees to an orthopaedic clinic could and should be managed in primary care if diagnostic facilities were available to GPs and Physiotherapists.
3. The Emergency Department of a major hospital is but should not be the only entry portal to hospital for acute problems.
4. Information Technology in Irish Hospitals is decades behind what it should be. We cannot provide accurate data for clinical parameters, procedure costs, implant costs etc. The patient management system in our hospital, a major centre, runs on DOS.
5. Cost of drugs implants etc is not transparent and varies widely between hospitals even within the same region. The current procurement process is unwieldy and not cost effective.
6. Waste is everywhere. No one counts the cost if (as happens every day) if 30 extra surgical gowns or 50 pairs of the wrong gloves are opened.
7. The current system whereby emptying the Emergency Department at any cost to any available bed in the hospital regardless of impact on other patients is unethical and grossly inefficient.
8. The cost of inefficiency resulting in cancellation of procedures is enormous.

We need to fundamentally change how we deliver healthcare.

1. We need a National IT system with National patient database, computerised medical records for all, transparent costs for all hospital expenses.

2. We need to focus **first** on step down care from acute hospitals to community hospitals with capacity and expertise (such as Roscommon General) to decompress large hospitals which deliver high technology care. Community hospitals need to be resourced with medical (possibly GP) nursing and diagnostic facilities.
3. Patients with musculoskeletal injuries should only be taken to hospitals with orthopaedic services on site in the first instance.
4. Outpatient services should target specific disease groups for rapid access clinics. Examples are hip or knee arthritis clinics, acute sciatica clinics or sports injury clinics. With modern imaging including GP access to MRI it is possible to triage referrals such that only patients likely to require surgery are seen by an orthopaedic or spinal surgeon in a timely fashion.
5. There needs to be accountability for use of resources at every level. This means that individual departments need to be given control over certain aspects of their budget and they must be accountable for that budget. Financial and resource incentives should be in place to encourage efficiency and good governance.
6. Individual departments should have more autonomy over patient flow within the service. Each department should have dedicated beds, theatre time, daycare and diagnostics that are agreed and within which they must function.

I cannot provide hard data for much of the above because our IT simply does not capture it. I have worked in acute hospitals for almost 30 years and despite all the bad press the system actually works. We need to modernise, become more accountable, more equitable and more efficient. We must not discard a system that has evolved over generations and which we understand just for the sake of it, but need to build on what we have.

I commend the committee for your public consultation approach.

Aiden Devitt, Consultant Orthopaedic Surgeon, Galway University Hospitals.

## Dr. Ronan Fawsitt and Dr. Garry Courtney, Carlow/Kilkenny Hospital/GP Group

### Executive Summary

As active clinicians we support this Oireachtas project to provide political stability and direction to the health service with a 10 year plan, agreed by all stakeholders to change the direction of healthcare, towards more care in the community delivered by GP-led Primary Care (PC).

Our hospital-centric health system cannot survive the confluence of increasing demand, reduced capacity and the burden of chronic disease, multi-morbidity and an ageing population. Our hospitals and GPs must be supported through the transition process to deliver this new model of care.

A radical realignment of healthcare is needed towards GP-led primary care. More resources are required for general practice to lead community-based, team-care which is more preventive, predictive and anticipatory.

This can be delivered by general practitioners working through Primary Care Teams (PCTs), with additional practice nurses, ancillary staff and an enhanced PC network that is supported by Secondary Care (SC).

Funding for general practice must reach levels similar to other OECD countries.

The alignment of Information and Communications Technology (ICT) between GPs and hospitals with a shared Electronic Health Record (EHR) is critical.

This will require GP leadership and structural reform within general practice.

A new relationship between Primary Care (PC) and Secondary Care (SC) is required as equal partners in shared care.

Integrated thinking and care models should be supported by the state and health insurers.

Ambulatory Care using an Acute Floor model should be standardised at all Acute Hospitals, with direct GP STREAMING into Acute Medical Assessment Units (AMAUs).

Scheduled care in hospitals needs urgent re-thinking. New referral pathways for timely consultant advice are required.

Access to diagnostics in PC should become independent of hospitals.

Primary Care Resource Centres (PCRC) should be opened to all patients and GPs in a catchment area, and should act as service and diagnostic hubs.

Local clinician/management engagement should be supported through ICGP-sponsored Local Integrated Care Committees (LICCs) and should be funded and developed nationally.

Transitional Funding for Health Transformation is required. Efficiencies will return costs to state.

Early projects should focus on high users of health care, and medicines management.

All of the above is predicated on a new GP contract, agreed by all stakeholders, which addresses chronic disease management in the community through resourced GP-led PC.

### **Introduction**

This submission is from two front-line clinicians based in Carlow-Kilkenny. We are not here to represent any particular organisation but to support this reform project. The submission is not based on academic references but on real experience with practical change over three decades, some of which brought genuine improvement in healthcare delivery with benefits to patients and providers.

One of us (RF) works in general practice as a senior clinician in the community, the other (GC) as a senior clinician in the acute hospital service.

We are part of a group of like-minded clinicians and managers who have worked together over many years to build contact, respect, trust and change. This is the CK story.

Over the past 25 years the group has brought process improvement based on working together as equals in care. We began this liaison process in an *ad hoc* manner and gradually developed it into a scheduled monthly business meeting that is structured and formalised. It is an example of how clinicians and management can work together locally to improve patient care. We believe this integrated approach to shared patients can replicate in our health system.

However little will be achieved nationally to further integrate care until we address capacity in both general practice and hospitals. The key conclusion of the Oireachtas Committee for the Future of Health Care should be to advocate for increased capacity in GP-led PC to manage chronic disease. This must be allied with enhanced capacity in our hospitals to support PC. Integrated care can only succeed if both parties have the required capacities.

### **Challenges**

Our health system is under huge pressure. Rising demand for services in general practice and hospitals, combined with reduced resources, bed closures, budget cuts, manpower shortages and loss of morale, have all contributed to reduce confidence for service providers.

Our hospitals are at breaking point. 530,000 patients on waiting lists and up to 500 patients per day on trolleys show the scale of the capacity problem in hospitals. In general practice the disproportionate effect of repeated FEMPI cuts has destroyed confidence and reduced capacity to take on any extra un-resourced activity. A growing manpower shortage from GP retirements and emigration compounds the problem. This comes at a time when greater activity in primary care is needed to manage chronic disease, the over 65s with multi-morbidity and the rapidly increasing population of frail elderly with complex medico-social needs. (Figure 4)

### **Main Recommendations**

There are a number of steps needed to enable GP-led PC and reduce pressure on our hospitals:

- **Strengthen the base - increase capacity in primary care.** General Practice is under-resourced, under-funded and under-utilised. Manpower levels are inadequate to meet emerging need and the burden of chronic disease. The ICGP should be funded to increase the number of GP Training places from 170 to 270 in line with OECD levels. This would counteract the effects of emigration and retirement.
- **Strengthen the team** - increase the number of practice nurses in line with advice from ICGP, IMO and NAGP to assist in chronic disease management and some acute care. The role of Advanced Nurse Practitioners in General Practice needs to be developed.

- Adopt the **Farmleigh Principles for Comprehensive GP-led PC** as a consensus model - developed by Chatham House TCD Group 2015 - now Tomorrows Health (Appendix 3) [18].
- Support a **cultural and structural shift** from hospital care to more care in the community. Patient education/involvement in this shift is required.
- Negotiate a **new GP contract** with all stakeholders - one that it is supported and fit for purpose. The key to the new contract is management of chronic disease. A robust review process is mandatory.
- Strengthen **GP led Primary Care** through new GP leadership roles in PCTs, Community Health Organisations (CHOs), Hospital Groups (HGs) and LICCs.
- Support **quality care**: Assist GPs and practice nurses to participate in the Integrated Care Programs and Clinical Care Programs. ICGP and Universities to develop new education modules in advanced PC.
- Re-energise **Primary Care Teams**. Structure and resource GP leadership in new contract. Turn Primary Care Centres (many are empty and under-utilised) into **Primary Care Resource Centres (PCRC)** as service and diagnostic hubs that are accessible to all patients and GPs.
- **Develop independent access to diagnostics in PC**: Locate X-ray-ultrasound- ECHO–EST in PCRCs. Develop Service Level Agreements with hospitals to provide imaging/reporting at PCRCs and dedicated CT/MRI slots in hospitals for PC patients.
- Prioritise practical measures to **retain our healthcare graduates**
- **Increase capacity in hospitals** to deliver Acute and Scheduled Care to support PC
- Develop the interface between PC and SC using **ICGP-sponsored LICCs**
- **Integrate care** through shared service planning and delivery at local and national level with HGs, CHOs and GPs engaged actively as partners.
- **Maximise technology** to build efficiencies and reduce duplication: build a joint ICT interface using a shared EHR
- Improve **bi-directional care pathways** between PC and SC. e.g. speed up process for Home Care Packages to avoid delayed discharges from hospitals; develop GP access to Frailty Clinics for elderly with sub-acute illness.
- In **Acute Care**: Ambulatory Care should have direct access **GP STREAMING** to Acute Floor.
- In **Chronic Care** - new models required for **timely consultant opinion**, as alternatives to standard OPD referral. Virtual Clinics, Rapid Access Clinics, Hot Cases, consultant clinics in PC and consultant opinion without patient contact should be explored.
- **Align political direction with service need**: while free access (state funded) to GP care is laudable we should build the capacity of general practice first before further extension of free GP care.

- Instruct **Health Insurers** to fund Primary Care packages especially for chronic disease.
- Fund **end-of-life care planning** and funded care packages in PC. Develop a National Strategy assisted by ICGP to avoid unnecessary hospital interventions at end of life.
- Consider **Tax Incentives** that encourage GPs to invest in their practices.
- **10 year Transitional Funding** is needed for transformation of system towards GP-led PC. Seed funding for innovation and integrated care projects should be prioritised. Hospital funding should be protected during the transition.

### **Background**

Solutions for our health service are in Primary Care. Our hospitals cannot meet the rising demands both in Acute Care and Scheduled Care. We cannot fix the capacity issues in hospitals unless we first address the capacity in PC to reduce the inflow to hospitals and support outflow back to GP care. (See Figures 1, 2 and 3.) There is a need for increased capacity in general practice and a decisive shift to preventive, predictive and anticipatory care in the community through GP-led PC. This shift must be incentivized and aligned with sufficient capacity in our hospitals where deficits are shown to exist after the adoption of relevant Clinical Care Programmes. The connectivity between PC and SC must be enhanced. A new GP contract will be the defining moment to achieve radical change.

The days of medical silos are over, whether in hospitals, public health or general practice. We need to develop greater connectivity and integration between primary and secondary care. Integrated ICT, joined-up-thinking and shared projects are essential to drive reform. Effective connections between clinicians and management, between GPs and their hospital are the steps to progress.

### **The Carlow-Kilkenny Model**

Carlow-Kilkenny (CK) has a 25 year track record of formal GP-Hospital connections. It has been a journey based on contact, participation, respect, trust, innovation and service development. Because of this structured engagement CK has delivered many projects that improved services for patients. Incremental, agreed change has been a powerful tool for progress. Becoming a member of the largest Hospital Group, the Ireland East Hospital Group (IEHG), has created opportunities to scale health solutions regionally and nationally, while learning from other areas.

Beginning in the 1990s this CK connectivity led to many local initiatives which scaled nationally. Among them were the first Acute Medical Assessment Unit (AMAU) in Ireland, Caredoc (among the first GP out-of-hours co-ops), a GP-led Community Intervention Team (CIT), a Community Infusion and Venesection Unit (CIVU) and the liaison committee itself, which is now being replicated at each acute hospital within the IEHG area as an ICGP-sponsored LICC.

In recent years the committee formalised its structure, function, process, and Terms of Reference. It holds regular monthly business meetings between GPs, consultants, hospital manager, pharmacist and CHO. Agendas and Minutes are circulated to all GPs and consultants in Carlow Kilkenny, which generates inclusiveness, participation, transparency, trust and accountability. It has become an innovation site for integrated solutions to local and national healthcare problems.

Other initiatives from CK include the Home Care Team for end-of-life cancer care, the Stroke Unit, the Falls Clinic, shared diabetes care (with no waiting lists for new diabetics), a new GP-led Gynaec Clinic, a Heart Failure clinic, a Virtual Clinic in Heart Failure led by Prof Ken McDonald, an Acute

Arthritis Clinic and in 2015 we introduced direct GP access to an Acute Surgical Assessment Unit thus reducing ED waits and unnecessary admissions.

### **Integrated Ambulatory Care Centres**

In 2016, after 10 years of planning, St Luke's finally opened the first purpose built Integrated Ambulatory Care Centre (IACC) in Ireland. This houses a new ED, AMAU, ASAU, APAU, a Day-Care Unit for surgery, the Susie Long Endoscopy Unit, the Oncology Unit and Hepatology Unit. It also has a GP-accessible Resource Centre with Education/Library/Teaching facilities.

The principle of Ambulatory Care is to keep patients out of hospital by integrating all relevant acute and day-care services horizontally within the Acute Floor and vertically within the larger IACC and community. Direct GP access in CK is critical to streaming of patients to the right locus of care. This enables GPs and hospital to create care pathways in and out of St Luke's without the need for admission. The mechanism of Ambulatory Care is to stream, investigate, treat and return to GP care on the same day if possible.

The CK story has been one of increasing integration between PC and SC and has allowed us to develop services by agreement. The process of integration therefore is worth a closer look as leadership and culture remain key factors in healthcare reform, especially in PC. [15]

### **The case for integration**

There are two main reasons why the Oireachtas HC should focus on integrated thinking in service delivery. Firstly, the development of HGs and CHOs carries risk of further polarisation if not managed well. GPs are the natural liaison between both systems and their integrating role should be supported by the State. Secondly, new integrated thinking is needed if we are to address the escalating demand for hospital services both in Acute and Scheduled Care. (See Figures 1, 2, 3, 7)

Delivering integrated care is therefore an important political, economic and medical imperative. In 2013 the State spent €13.64 bn on healthcare (excluding capital spending). Including out of pocket expenses and health insurance the total spend was 10.2 % of Gross Domestic Product, or 12.1% of Gross National Income. [1] Most of this was spent in hospitals or in the community. Very little went on integrated care or integrated care systems. Paradoxically less than 3% went into general practice where more than 90% of daily patient contact occurs. (See Figure 4)

**The Kings Fund** has been an effective advocate for improved healthcare and has outlined the key benefits of Integrated Care [10]:

1. Better outcomes for patients and populations
2. Improved use of scarce resources
3. More care in people's homes/community
4. Care in an appropriate setting

Common principles identified by the **Kings Fund** [10], that lead to success at local level include:

1. Responsibility for defined populations
2. Accountability for performance
3. Information sharing
4. Collaborative culture/team working
5. Clinical engagement and leadership
6. Aligned incentives
7. Supporting the Sociological and Technological processes equally

These principles should shape government policy on healthcare and inform the new contract for GP-led PC in both design and structure. Curiously, these are similar principles to those that guided many of the CK projects over the years.

### **Integration in Chronic Care**

Properly resourced primary care clearly offers huge potential to deliver healthcare at a fraction of the cost at hospitals. Chronic disease and multi-morbidity drives hospital activity and costs. An increasing population with rising numbers of multi-morbid over 65s and frail elderly makes hospital based care for chronic disease unsustainable. (Figures 1, 2, 3). This care should be provided in the community by GP-led PC with support from SC. The interface between the two is where change must come. Both systems have been damaged by budget cuts, reduced infrastructure and manpower deficits. But both are interdependent and function better when incentives are aligned.

There are many examples internationally of improved health outcomes from Integrated Care [2]. In the US, the Home Based Primary Care initiatives (HBPC) [3] and the Patient Centred Medical Home [4] have shown clear benefits to patients and reduced costs to the provider. Other similar models that promote GP-led primary care system reform include Vermont, Alaska and the Veterans Administration (VA).

In New Zealand, the Canterbury integration model, using primary care reform has led to significant improvements in service efficiencies with reduced costs [5] [5.1]. GP-led, team-based primary care, with enhanced nursing roles, adds further benefit to integrated care [6]. Some research also shows “positive impact of integrated care programmes on the quality of patient care and improved health or patient satisfaction outcomes” [7]. [16].

The key to the success of these systems has been the radical resourcing of GP-led primary care as a team based approach.

However, other supports are needed [8].

At the 2012 **Global Health Policy Summit** (GHPS), the Report of the Primary Care Working Group (Oldham, Richardson, Dorling and Howitt) [8] identified seven challenges to be overcome for PC to achieve its full potential:

1. Poor patient access and perception.
2. Insufficient coordination and integration
3. Low professional prestige and workforce availability
4. Lack of infrastructure investment
5. Misaligned incentives
6. Underutilisation of information and technology and
7. Variable quality standards and regulation.

They advised governments to use these international lessons and “mandate, fund or support changes to improve primary care” [8]. They outlined how governments need to influence action on incentives, information and technology and quality standards/regulation.

It is notable that the Kings Fund Principles (see above) address many of these deficits.

In 2016, these learnings show how to assist PC and SC to integrate more effectively. Our small population and island topography make radical change possible within 10 years. The seven GHPS challenges can be overcome if the right leadership and resources are enabled.

The challenge in Ireland is critical given the growing burden of chronic disease, an older population, limited resources, a fragmented health system and a workforce beset by emigration and low morale. Our hospitals run at near capacity (93% compared to OECD average of 77%) [9].

General Practice, where the natural clinician leaders of PC are based has been disproportionately hit by FEMPI cuts and lacks the financial capacity to take on any further un-resourced activity. Yet here the change must begin.

New ideas, new thinking and new relationships are required. A radical rethink on how to deliver services must happen. Other health systems are also re-appraising. [17]. In Ireland there is need to shift the focus away from hospital care towards more care in the community to reduce the burden on hospitals.

It is not clear that consultant clinics in GP surgeries are cost effective despite patient satisfaction [13].

However one of five solutions for General Practice suggested by the Cambridge Centre for Health Service Research (CCHSR) is that is that new consultant job descriptions should include working more closely with GPs [14].

Either way, alignment of services will require cultural as well as structural change.

Transitional funding is needed to drive the desired shift. The funding for an enhanced PC should not come directly from hospital budgets. This will reduce the hospitals capacity further and lead to friction between the two service providers. If managed correctly the funding will eventually come from savings, economies of scale and efficiencies in both systems. (See Figure 6).

Managing chronic disease through GP-led PC, agreed through a new contract and delivered as a team approach, will be the key to progress.

### **Integration in Acute Care**

Similarly in unscheduled Acute Care, direct access from GPs to hospital services can drive efficiencies.

In Ireland, the introduction of the National Acute Medicine Programme (NAMP) opened up streaming of “acute medicine” patients (preferably referred directly by GPs) into Acute Medical Assessment Units (AMAU), which led to significant improvements in patient flow and length of stay: “A reduction of 1.6 days in average length of stay nationally was achieved between 2010 and 2014. CONCLUSION: Despite a 25% increase in hospital discharges and the severe financial constraints experienced during this implementation period, the NAMP achieved significant efficiency gains through process improvements, while ensuring patient safety and likely improving the quality of care delivered to patients in Ireland.” [11] [12].

This represents a 15% reduction in average length of stay (ALOS) which is the equivalent of gaining 750 beds. All this occurred despite an increase of 7% in medical admissions, year on year. The total number of medical patients seen via the AMAU pathways (as opposed to the ED route) has increased from 21% in 2012 to 36% in 2016 (almost 100,000 attendances). This reduces ED congestion and risk considerably. The NAMP has predicted that when the percentage of medical

cases seen via AMAU exceeds 40% this will be the tipping point to control ED Trolley Counts and reduce elective waiting lists. With support for direct GP streaming this target can be achieved in 2017.

The first AMAU in Ireland opened in Carlow-Kilkenny in 2000. Direct GP access to AMAU in CK remains the norm and allows senior decision makers in the community (GPs) direct access for their patients to senior decision makers (consultants) in the hospital. This is a win for patients, GPs, hospital and the State.

Clearly, integrated care can drive efficiencies in acute and chronic care that can fund further services. This is the core opportunity for the State from promoting more integration of services and service providers. State support for ICGP sponsored LICCs nationally offers a further opportunity to bring all local service providers together in partnership with community and hospital management to drive agreed change in service provision.

In any new healthcare model proposed by the Oireachtas HC we urge strong emphasis on local engagement through LICCs to drive integrated care and improve patient outcomes. The resources needed to fund LICCs are small but deliver significant benefits to PC and SC by improving local relationships, patient flow and service delivery. (See appendix 1)

#### **Integration with new Hospital Groups and Community Health Organisations**

The recent formation of Hospital Groups (HGs) in 2013 and Community Health Organisations (CHOs) in 2015 further emphasise the need to develop a more integrated health system. These structures need to align in thinking, activity and patient services.

With their formation, a new relationship needs to emerge between Primary and Secondary Care, where general practitioners and hospital clinicians can work seamlessly with management and community partners to deliver care to patients served by new structures. This process must be nurtured and resourced.

General practice should be involved in the design, governance and decision making of these new structures. The current environment in which GPs work is a barrier to their involvement in integrated healthcare planning and management. GPs cannot currently attend hospital or community management meetings during office hours without significant impact on the care of their own patients, with consequent practice disruption and financial loss. This must be addressed.

The HGs and CHOs proposal to appoint GP Leads is welcome. For these to succeed it is important that they engage with their peers locally in a structured, accessible and transparent forum such as the ICGP-sponsored LICCs. The proposed manner in which clinicians and management engage locally and regionally is outlined in Appendix 1.

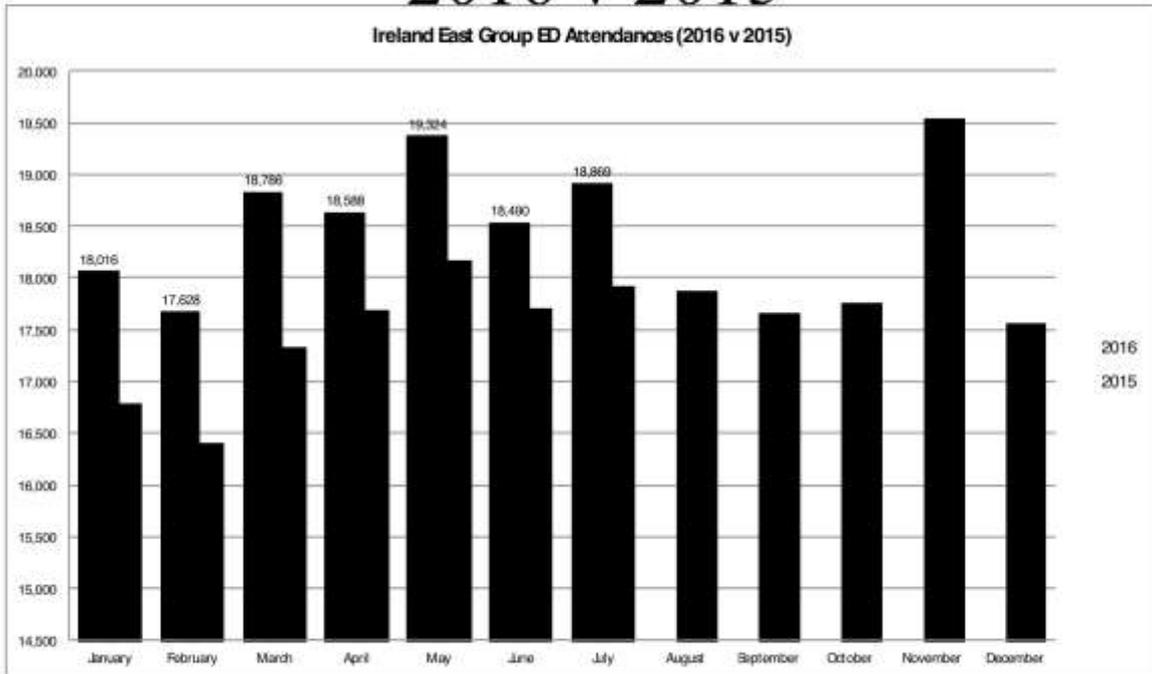
#### **Conclusions**

Integrated Care is a journey not a destination. We cannot fix the health system by strengthening the silos. More connections should be encouraged by the State to build trust, respect and agreed service change through integration of providers, care pathways and ITC systems. Innovation and change follows when this happens. This is the CK story. This, we believe, is the best future for our health system.

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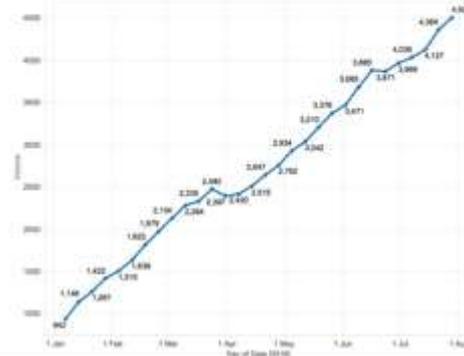
# ED Attendances Trend (All) 2016 v 2015



5

## Greater than 15 Months WL Trend

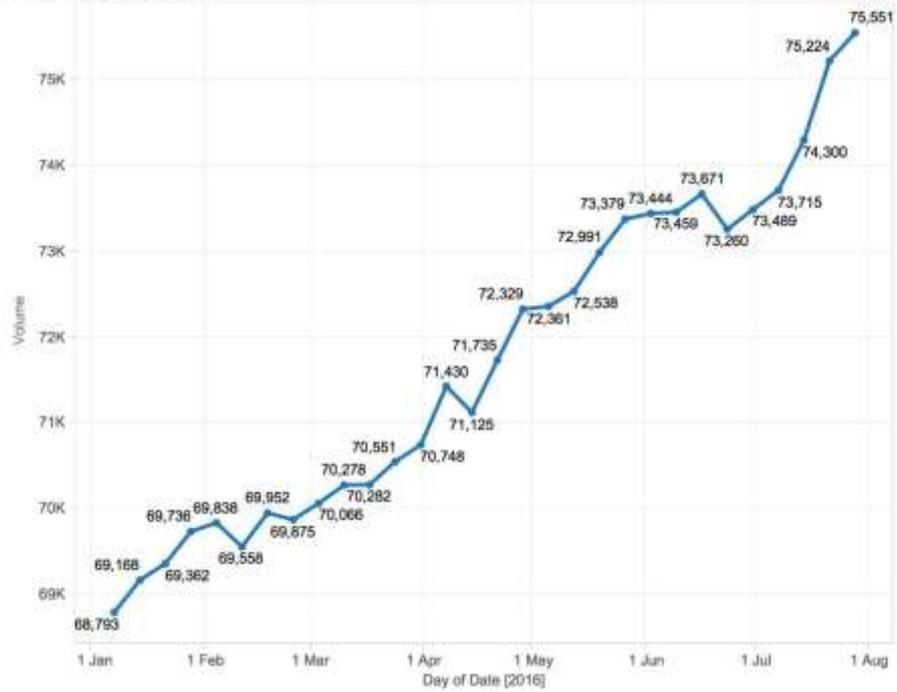
Total Group / Hospital Waiting List Trend: Group(s) - Ireland East Hospital Group: Hospital(s) - All: Year 2016



Figures 1 and 2 Rising demand. Courtesy: IEHG 2016

# Outpatient Waiting List Trend

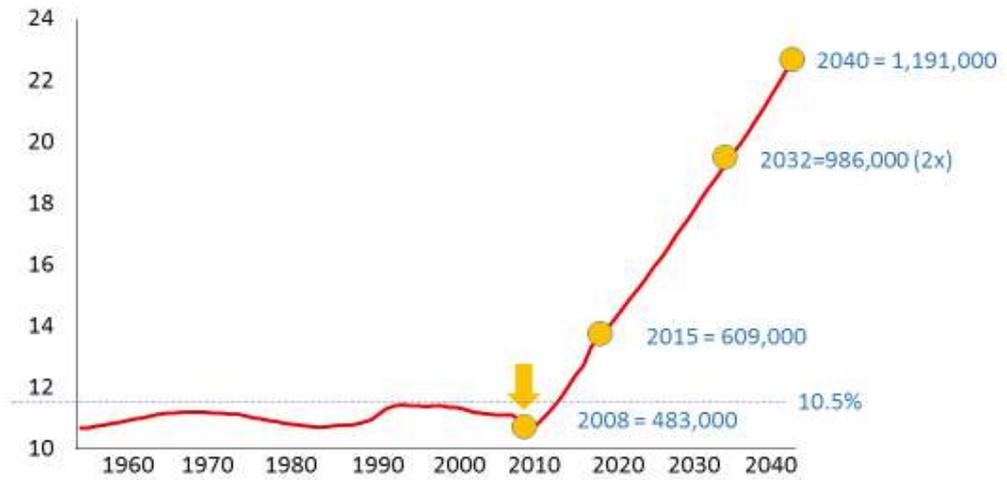
Total Group / Hospital Waiting List Trend: Group(s) - Ireland East Hospital Group: Hospital(s) - All: Year 2016



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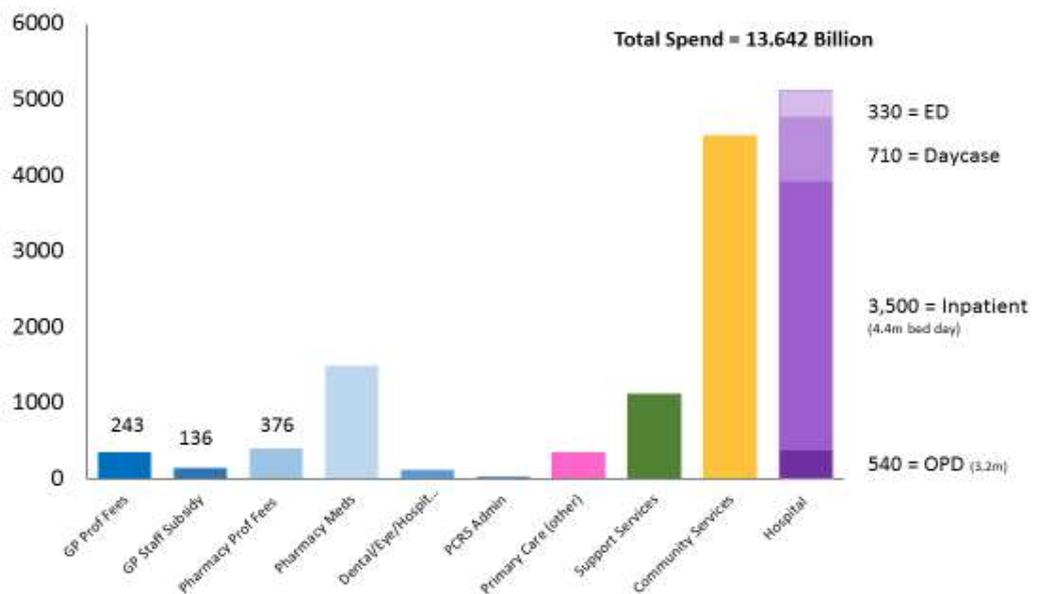
Figure 3 OPD demand. Courtesy: IEHG 2016

**Percentage of Population over 65 years**



**Figure 4** Over 65s. Courtesy: Dr Austin Byrne IMO  
OECD.stat Historical population data and projections (M2F2) 1950-2040 Ireland

**Health Spend 2013**



**Figure 5** GP Spend. HSE 2013 Annual reports and accounts. Courtesy: Dr Austin Byrne, IMO 2016

# DNA Rates by Hospital

DNA Rates by Group Hospital Detail  
Hospital Group(s) - Ireland East Hospital Group  
2016 - All

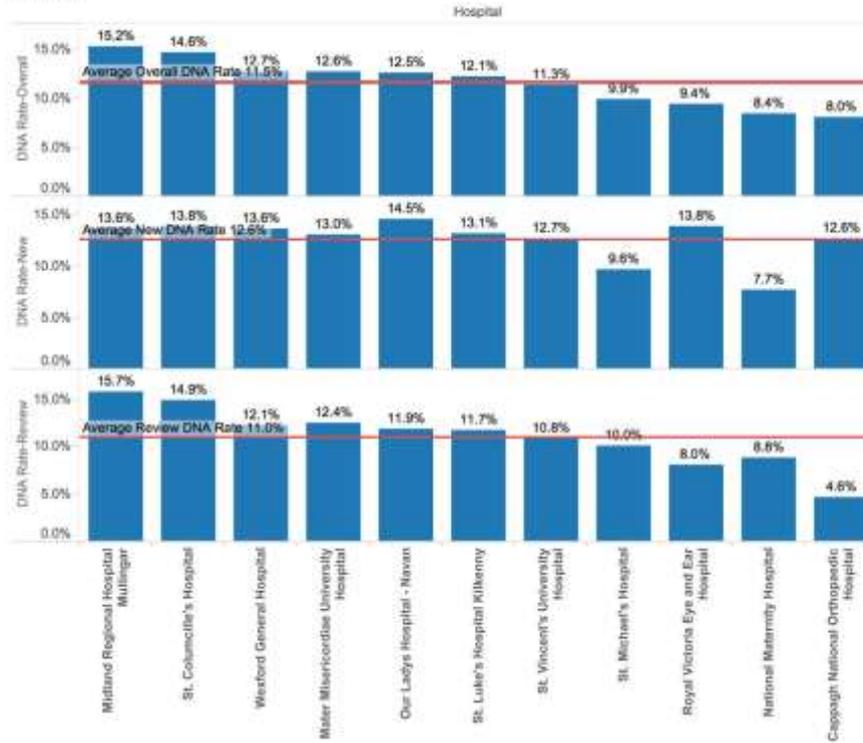
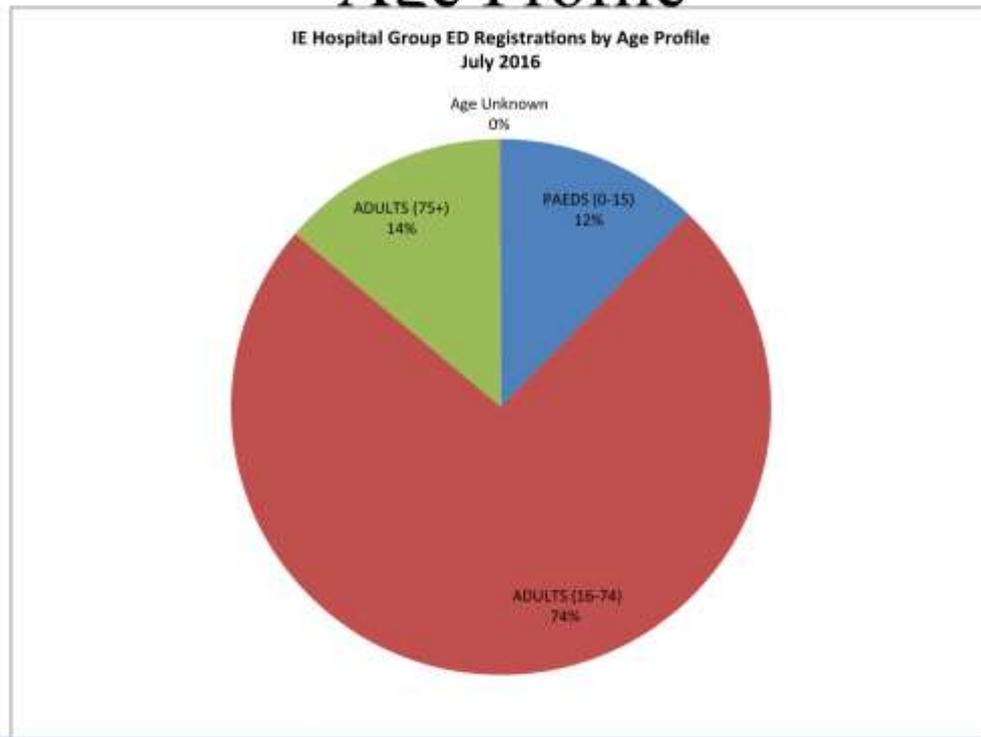


Figure 6 Inefficiencies in system. Courtesy: IEHG 2016

# ED Attendances Age Profile



**Figure 7** Demographics of demand. Courtesy of IEHG 2016

## APPENDIX 1

### Summary LICC Proposals:

There is a need to establish multi-tiered mechanisms that enable GP engagement with hospitals and community, based on two principles that enable cultural and structural change:

1. Clinicians, both in the community and hospitals, should be supported to develop integrated thinking and care for their shared patients in partnership with local management.
2. A mechanism to promote integrated thinking and care needs to be established at both local and regional levels.

We propose the following system of partnership (based on the CK model) which is supported by the ICGP, IEHG and Primary Care Division of the HSE:

- Develop ICGP-supported LICCs at each acute hospital and associated CHO, and scale this nationally. Formal LICC meetings should be held monthly at agreed venues.
- Encourage GPs, consultants, CHO and hospital management, public health and mental health clinicians to participate in each LICC.

- GP Leads should be funded on the Senior Management Team and Executive Management Teams of both CHOs and HGs respectively in a similar fashion to the funding of hospital Clinical Directors.
- Local HG GP Leads should be funded at each Acute Hospital to support PC-SC integration and LICC activity.
- Local CHO Network GP Leads should be funded within the CHOs to develop efficiencies and services within PCTs and to engage with their respective LICC.
- GP participation at each LICC should be funded through a new funded service leave called Health Integration Service Leave (a similar concept to GMS Study Leave). This can be based on the precedent of approved GMS funding for clinician attendance “at meetings of statutory bodies and GP committees” as contained in the current GMS contract.
- Establish a national governance and advisory group to support LICC development and scale successful projects. Members should include CHOs, HGs, ICGP, universities and Chairs of LICCs.

## **APPENDIX 2**

### **Twenty Recommendations for Government:**

1. Prioritise GP contract conclusion then build capacity in GP-led PC with 10 year plan
2. Fund Chronic Disease Management adequately in PC through new contract
3. Allow new PCCs to become PCRCs
4. Direct the Health Insurers to cover PC packages
5. Support end-of-life planning and care packages in PC
6. Deliver ICT connectivity between PC and SC and use shared EHR
7. Extend free GP Care when general practice has capacity
8. Consider a small co-payment for future State Funded GP-Care to avoid over visiting
9. Fund integration through LICCs
10. Fund more Ambulatory Care
11. Increase hospital bed numbers where deficiencies exist
12. Develop step-down bed capacity in Nursing Homes and community hospitals
13. Allocate ring-fenced Transitional Funding for the decisive shift to PC
14. Early projects should focus on high users of health care
15. Fund more post-grad training for doctors and nurses in PC
16. Incentivise inward investment for practice development through tax reliefs
17. Involve all Representative Bodies in implementation process
18. Create a National Transformation Group (NTG) to deliver agreed 10 Year Project.
19. Develop agreed process to resolve conflicts between participants in health system
20. NTG to be accountable to Oireachtas Health Committee and Minister.

## APPENDIX 3

### Farmleigh Principles of comprehensive GP led primary care 2015 (Tomorrow's Health)

#### Principle

#### Primary Care plays a key role

#### What this means

Primary Care at its best helps a person to remain healthy and well and living at home in his/her community and is able to address most of the patient's health and well-being issues.

*At the outset of ill-health and during periods of illness a patient often enjoys the support of family and friends in his/her community, with often one or more of these acting as an informal carer for the patient.*

#### How this may be achieved

The services in Primary Care need to be relevant, understandable, accessible, responsive and properly resourced by either the State or health insurers

#### GP led Primary Care

Patients know their GP and the GP knows them personally and coordinates their care when required. Often the GP knows the patient's family history. Each patient has an ongoing relationship with a registered, personal, indemnified GP, trained to provide prompt first contact, continuous and comprehensive care.

The GP leads trained staff in the practice, who collectively take responsibility for the ongoing care of patients. Other members of the Primary Care team are available when required and the GP will organize and co-ordinate their input.

#### Comprehensive care

When the patient, or his/her carer, is not able to do so, the GP team will take responsibility for ensuring that the patient's health care needs are met in accordance with the patient's preferences in his/her community as far as possible.

The GP team arranges appropriate care and supports for the patient, or his/her carer, with other qualified professionals and appropriate resources.

#### Co-ordinated care

Each patient has his/her own secure, electronic, up to date health record, eventually accessible on his/her personal computerised or smart device.

The GP has access to comprehensive electronic patient records and these, with the consent of the patient, are shared with and updated by other health professionals.

#### Accessible care

- **General practice**

Enhanced access to care is available through systems such as appointments, expanded hours, out of hours co-operatives and responsive electronic communications between patients, their GP, practice staff, other primary care professionals and hospitals/other care providers involved in the patient's care.

- **Access to diagnostics**

The GP arranges diagnostic tests for the patient in a timely fashion. Diagnostic reports are issued promptly and, where necessary, arrangements for urgent access and immediate reporting are available.

- **Access to hospital specialists**

If a problem arises that cannot be managed in the community the patient attends a secondary or tertiary hospital if the specialist is located there. The arrangement to attend hospital or specialist care is made by the GP on behalf of the patient. The reason for the patient's referral and type and urgency of specialist input is clearly communicated at point of referral. Integrated referral and care protocols/ standards are in

Where appropriate, GPs and hospital specialists work together for the benefit of patients at community level. Occasionally GPs and hospital specialists work together at hospital level.

Quality and safety

place between the hospital and GPs to make the process efficient and effective for the patient.

GPs have an essential role in monitoring the health and wellbeing of their practice population and their local community.

All GPs have an electronic register of patients, which is pro-actively used for alerts, recalls and the monitoring of chronic illness. It is an important safety net in circumstances where the patients have difficulty looking after their health.

## **Dr. Tom M. Kennedy, Gorey, Co. Wexford**

The provision of universal healthcare is welcomed and it should be funded from general taxation.

Equity of service provision based on need, will require above average investment in areas of deprivation.

Moving care to the community will require investment in general practice and indemnification for clinicians such as practice nurses, midwives and health care assistants.

Making the service more responsive to need will require active clinicians to be at the centre of the decision making process.

Separating service commissioning from service provision will enable pressure to be exerted to make change happen.

Proposed changes in health policy should undergo a process of evaluation by the Health Technology Assessment Directorate of HIQA.

In order to negotiate an efficient and effective transition in service provision the tensions between the interested participants will need to be actively managed through organised fora.

These changes will benefit from political leadership and a long term strategy that will be continued beyond the terms of the electoral cycle.

### **Key priorities**

#### **Policy and Strategy**

Shift the emphasis of care from acute responsive care to proactive health promotion and chronic disease management

Separate the two roles of the commissioning and provision of services.

Place active clinicians in a lead role in the realignment of the health services. Give GPs the key budgeting and decision making roles within commissioning groups and allow them to innovate. Entrust management with the executive function.

Provide care for which there is an evidence base and deliver it in the most efficient and responsive manner.

Rigorously assess health policy. A Health Technology Assessment (HTA) could be performed on proposed health service strategy/policy.

Develop the discipline of Public Health to assist in identifying health needs.

Make health a priority across society and in particular oblige all state departments and ministries to consider the health implications of their decisions.

Develop fora to manage the tensions of the often competing groupings in health care; clinicians, managers, private and public service providers, the pharmaceutical industry, politicians and the well and patient populations.

## **Equity**

Develop universal health coverage to be based on need and free at the point of care for all of the population

Address deprivation. In particular provide a deprivation payment to general practitioners working in deprived areas in a fashion similar to that provided in the UK.

## **Infrastructure**

Review current plans to develop large primary care centres. They may not be as responsive to health needs as are the existing structure of locally placed general practice surgeries.

Speed up the delivery of electronic recording systems.

Pass the scheduled legislation that is proposed to resolve deficiencies in the insurance liability and indemnity sector.

## **Human capital**

Develop the capacity to deliver health promotion and health maintenance at schools, at places of work and in the home.

Develop the role of practice nurses and midwives and enable them to deliver an increased range of services in general practice surgeries. Provide state funded indemnity to enable this as the present available cover is inadequate. Develop the role of health care assistants in general practices.

Identify clinical leaders and train them in management and health care financing. Enable them to maintain a dual clinical and management role. Encourage this as a career option. Give clinicians similar opportunities in education, research and policy development. Open access to this to GPs, practice nurses, midwives and allied health care professionals as well as to hospital based professionals.

Develop and reward general practitioners who acquire special clinical interests and facilitate their provision of state funded care, much of which is presently offered only in secondary care.

## **Key Challenges**

### **Integrating health policy:**

Integrate health policy vertically and horizontally. Vertically; from the healthy individual to the patient attending a tertiary care centre and horizontally; as a priority to be facilitated in the home, at school, at work and in the community. The clinician best placed to develop this is the GP, particularly if placed in a commissioning role.

Example: Irish people are overweight, sedentary and unhealthy. Unaddressed this situation will get worse exerting a cost on society in terms of morbidity and health care expenditure. An integrated approach will be more successful and central to that will be the political will to make it a requirement of planning and service delivery across a number of governmental departments e.g.; health, education, transport, work, sport and social services.

### **Resolving conflict between participants in the health care economy:**

The interactions between key players in health care; politicians, health care management, hospital and community services, private and public service providers and patients are often dysfunctional. They may have conflicting priorities; for example the provision of insufficient or inefficient care or even an unnecessary or dangerous service. Resolving these issues will improve efficiency and effectiveness.

Example: If general practice is to assist the health service then it can do so if GPs are involved in the decision making process and are facilitated in commissioning and developing services.

### **Giving a voice to clinicians in management and decision making:**

Place active clinicians, particularly GPs at the heart of the decision making process. Provide them with the structure, support, funding and authority to make the commissioning decisions for a population of patients. Provide management support to execute these decisions. Population groupings greater than 100,000 people are likely to be required for there to be sufficient financial pressure to effect change. Allow interaction, collaboration and even mergers to occur between these groups as required or decided by the GPs and other clinicians.

Example: Services would be developed around GP populations and not around geographic areas. Practice nurses, midwives, dentists, community pharmacists, physiotherapists and other allied health care professionals would be involved in the decision making process. Training in management techniques, in health care planning, in negotiation and in team work and financial management would be provided to established clinicians and to those in training to allow them to develop the dual role of clinician-manager.

Present examples: The successful interface between general practice and hospitals in the Kilkenny and Carlow areas. The development of out of hours co-operatives in general practice.

### **Ensuring the quality of service provision:**

Integrate the pursuit of quality in service provision by requiring audit, critical event analysis and continuous improvement processes. Clinicians will see these as natural constituents of their role and it will facilitate them in planning and delivering services.

Example: The inclusion of audit in the requirements for Continuing Medical Education for doctors; a necessity for the maintenance of registration

### **Developing the infrastructure of general practice:**

Most episodes of care are provided in general practice. The GP is central to the health needs of patients wherever they are cared for in his/her role as service provider, patient advocate, prescriber, organiser of care and guardian of patient data.

The present strategy of developing large primary care centres often removed from the population they service should be re-examined. An alternative is to enable GPs to develop their premises and services in a manner that has traditionally been more responsive to the health needs of the population and to rent such space from the GPs, so providing them with

the resources to be so responsive. Provide general practices with the same and better financial incentives that are currently offered to private investors.

Develop a comprehensive strategy for computerisation that establishes a state standard for health related Information technology and that allows importation of systems from other jurisdictions. GPs should be offered 100% reimbursement of the costs of computerisation.

Example: There are few providers of clinical software in the country and there is little drive for development.

#### **Not making things worse:**

Primum non-nocere. General practice has struggled with recent cuts in resourcing. Changes to workload without extra resources will result in further damage and risks ultimate failure. If general practice is to be the pivot of significant health care reorganisation it must not be broken. Small changes in referral or prescribing at the GP level will result in large changes in secondary care activity and in health care costs.

Example: Stabilise general practice and enabling it to access funds for service and infrastructure development.

#### **Supporting care in the home:**

Provide adequate support for people to remain in their homes when they have a chronic debilitating illness. Facilitate carers and provide viable packages of home care.

Example: Review the fair deal system as it is not resolving the care problem and it is costly. How is care at home to be funded and is this to be paid for from the person's estate or by the Irish state? How is equity of care to be maintained for deprived populations?

#### **Providing comprehensive access to diagnostic tests**

GPs are denied access to many radiological, laboratory and other tests necessary for diagnosis and management. This causes avoidable referral to secondary care with associated cost and delay. One visit to outpatients costs more than the average annual GP reimbursement per GMS patient. Where possible provide investigations close to the patient. Consider near patient "bedside" technology.

Example: near patient Beta-natriuretic peptide testing in heart failure combined with open access echo-cardiography. Also helicobacter pylori stool antigen testing with or without open access to upper gastro-intestinal tract endoscopy.

#### **Developing general practice; enabling it to deliver more**

Encourage and assist GPs in developing special interests clinical, academic or management and facilitate them in delivering services from this.

Develop the role of practice nurses, midwives, and health care assistants. GPs alone will not be able to deliver all of the intended care in the planned shift to the community. Developing the skills of and providing indemnity to the available personnel will be necessary. Creating additional teams of speciality specific nurse practitioners will be ineffective as many patients have multiple chronic illnesses. Develop the role of the practice nurse to include upskilling in health promotion and chronic disease. Reward and indemnify them for this. Similarly the shortage of GPs and the additional pressures of chronic disease management will require

midwives to provide services in general practices. Reward and indemnify them for this. Many services could be delivered by health care assistants and similar development is needed.

Reverse the loss of GPs experienced through emigration.

Example: GPs providing occupational health services to Irish workplaces. GPs servicing district hospitals.

Problem: The present insufficient indemnity cover for midwives in general practice. The present insufficient indemnity cover for practice nurses to provide chronic disease management.

### **Barriers to care**

- 1) The importance of political leadership in developing a long term strategy that will run past the electoral cycle. A ten year strategy is necessary.
- 2) The lack of universal health coverage has resulted in a larger than necessary societal spend on health services (public and private) that; do not meet identified needs, is fragmented, is over managed and is inefficient.
- 3) The difficulty in integrating health policy horizontally and vertically and involving many different agencies.
- 4) The often rival camps of management, consultants, unions, general practitioners, politicians, private medicine and the pharmaceutical industry. The relationships between these groups need to be actively managed.
- 5) The failure to acknowledge the centrality of general practice now and especially in the planned movement of care to the community
- 6) The absence of a purchaser/provider split in service provision.
- 7) The failure to place active clinicians in lead management roles.
- 8) Poor infrastructure (physical and IT), the dispersal of secondary care services and the lack of a plan for the development of general practice will limit the rate at which care can move to the community.
- 9) The precarious financial underpinning of much of present day general practice and the lack of security for those GPs who invest in the business of state funded general practice.
- 10) The loss of GP resource through emigration
- 11) The difficulty in forming effective working relationships between the Health Service Executive, the Department of Health and the GP representative bodies and the polarisation of positions as a result.
- 12) The complexity of assessing the options available for service development. This could be resolved by commissioning The Health Technology Assessment Directorate of HIQA to assist with this.

## Reflections

General practice is highly valued by the population and General Practitioners (GPs) are rated in polls as the most trustworthy of professionals. It is the most numerous of the medical specialities and GPs are the only health carers who provide care to all members of the population regardless of gender, age or health problem. They do this close to and even in the patient's home. General practice is the point of initial and ongoing contact with the health service. The majority of health care contacts occur in general practice and most of these are managed by GPs without need for onward referral to secondary care. Most medications are prescribed by GPs and most referrals to hospitals are made by GPs.

Because the GP role is so unique, general practice will be the pivot around which services will move from the hospital to the community. General practice will also be central to the change from a reactive acute health service to one that is proactive. Investment in services that deliver health maintenance and that manage chronic disease early and actively will of necessity involve general practice. Only the GP can enable this. This is the evidence from international studies and this is why there is such interest in the general practice among those designing health care systems.

General practitioners are responsive to the health care needs of their population and have proven to be innovative and resilient managers; developing services and facilities, collaborating with other health care agencies including Primary Care Teams, adapting to change and most recently guiding their practices through extraordinary cuts in funding. They have improved their services with the help of their college (Irish College of General Practitioners) and by investing in their practice buildings and equipment as well as in their administrative and clinical staff. General practice has been ahead of the hospitals in computerisation and in having structured specialist training programmes for general practitioners.

GPs have developed novel methods of delivering health care such as the out of hour's co-operatives that provide care after office hours. They have maintained a foothold in community hospitals and provide most of the occupational health services to Irish business and industry. Many general practitioners have developed areas of special clinical interest. It is surprising that the Health Service has not developed a structure to reward and encourage this and so reduce the burden on secondary care.

That general practice has managed to do this without the explicit support of the state is impressive. General practice is rarely mentioned by name when the health service is discussed. Instead it is cloaked under the term "primary and community care". This is in contrast to the manner in which it is treated in the UK and in The Netherlands, in Scandinavia and in Canada. In the UK, General Practice is identified as "the Jewel in the Crown of the NHS" and most recently the NHS has decided to reverse funding cuts to general practice due to concern that "if general practice fails the whole NHS fails". In contrast Irish GPs work to an outdated and dysfunctional contract. Attempts to negotiate a new GP contract have been piecemeal and challenging and have added to its complexity. These points are mentioned as they retard the development of general practice and reduce the impact that GPs have in assisting the health service to develop.

It is now recognised that the cost of health care may outrun our society's finite and scarce resources. As up to 90% of all patient contacts are in general practice, small changes in prescribing, in referral or in management decisions made by GPs have a profound effect on the ability of the health system to meet targets. In contrast a GP empowered to prescribe appropriately, and to investigate, diagnose and manage health care problems will reduce costs.

A generalist approach is also of benefit in resolving decisions made outside of general practice. This has been demonstrated in other jurisdictions. In the UK general practitioners have been given authority to place the contracts for 80% of that country's spend on health care. Their involvement has made the NHS more efficient and more responsive. In the UK general practice has been tasked to invest in preventive health care. This is most relevant to the younger and increasingly obese population.

Perhaps the principle obstacle to the involvement of general practitioners has been the failure to include it in the decision making process. There may be a number of reasons for this: General practice has been viewed as the Cinderella specialism. Hospitals by having more political capital have a greater fascination for politicians. The role of specialist services in performing complex interventions is truly dramatic.

There has been difficulty in developing a functioning relationship between the relevant representative groups and the HSE and Department of Health, reflected in the failure of these parties to agree a new contract for general practitioners and the presence of perverse incentives in the present contract. Management in general has had difficulty in understanding general practice and in developing relationships with general practice. GPs in return are reticent to commit to change.

## **Conclusion**

General practice can now be identified as being at the fulcrum of patient care. There is increasing recognition that a specialist reductionist model will not resolve the issue. Community Health Organisations and Hospital Groups have begun the process of engaging with GPs. Consideration could now be given to separating the roles of commissioning of services from that of the provision of services. This will strengthen the impact of the proposed model of "money following the patient."

If clinicians who maintain a clinical commitment were to be placed in the role of part-time clinical managers the system should become more responsive to the health needs of the population. This will take time to develop and a ten year strategy is necessary. Such policy change requires serious assessment. The Health Technology Assessment Directorate of the Health Information and Quality Authority (HIQA) could be tasked to provide this.

If more is to be done in general practice and in the community then resources must follow, infrastructure and human capital need to be developed and security and support must be offered to those providing the services, otherwise rescue packages such as presently proposed for general practice in the UK will be necessary.

Successfully led these changes will make a difference to the population's health and the proposed long term strategy is timely and wise.

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Dr. Tom Kennedy, Gorey, Co Wexford

## Dr. Mark Mathews, Co. Dublin

### Dr. Mark Mathews

M.B., B.Ch., B.A.O., D.C.H., D.Obst., M.R.C.G.P., M.I.C.G.P.

"Assisi" 1 Deerpark Road, Mount Merrion, Co. Dublin.

Tel: 01 283 4567 Mobile: 087 678 2315

E-mail: markmathews@eircom.net

Medical Council Registered Number: 006918



*5th August 2016.*

To: Mr. Ronan Flood  
Clerk of the committee  
On the future of healthcare  
Houses of the Oireachtas, Dail Eireann.

Dear Mr. Flood

I am writing to you in simple traditional format to offer very simple positive recommendations to the committee.

Long winded written submissions and reports are never read! Long winded E-mails are similarly ignored too as we all know!

I am a G.P. with 30 years experience. Also I have been a medical assessor in the department of social protection for 10 years. The needs of the future healthcare system are quite simple: The gateway to good healthcare in Ireland is general medical practice. It has been ignored and underfunded also for far too long. That attitude to primary care has left us in Ireland with a chaotic secondary care – hospital system. It is about time it was changed and soon.

For example General Practices in the UK are funded at 8% (it was 11%) of total N.H.S. health budget, and consequently the N.H.S. has fewer emergency departments – A/E attendances and greater patient satisfaction. General practice in Ireland with a 95% satisfaction rate amongst patients due to vocational ethos of GP's gets only just over 2% of the health budget! Greater investment in general practice would reduce secondary care costs enormously. So why don't we do it now.

Also the moral of young GP's has reached a pathetically low level, most of them do not wish to commit to the career / vocation any more. It is literally a dying speciality. In fact denigration of general practice as a career choice of young doctors is widespread in hospital and primary care training environments, as research has found!

The answer to this obvious pathetic dilemma is **funding Primary Care at a much higher level** and the expansion of chronic disease management in general practice.

GP's can handle chronic illness such as hypertension, diabetes, mental health, geriatric medicine etc.

**Every primary care centre should have G.P.S.I.S.** ie. GP's with special interests. I have personal interest in primary care psychotherapy. I have managed many patients in this field without referring them on to an overburdened secondary care service i.e. psychotherapists, *PSYCHIATRISTS*, psychologists etc. It takes time, increased consultation time however it is hugely beneficial and cost saving.

If we don't quickly install a G.P.S.I. service we will have the usual unacceptable trolley counts in our hospitals, increased inappropriate A/E department attendance and overcrowding and increased hospital waiting lists.

I feel very passionate about the future of our health service. I am very fortunate to have qualified very extensively in General Medical Practice I have 40 years experience in the world of medicine (see my C.V.).

I would be delighted to speak at your committee meeting. I have been a GP tutor in Trinity Medical School, a P.R.O. of the medical graduate association U.C.D. I am a member of the Medical Legal Society of Ireland, and of the Irish Society of Medical Writers.

**In conclusion:** These are 2 important solutions to our health crisis in Ireland.

1. Fund GP's properly
2. Establish G.P.S.I.S. in primary care

I am not going to write an Amazon~~e~~ rain forest worth of print (typed or electronic) which will which will fudge my contribution which is so simple. If you want to hear from a "soldier" who has had 40 years in the battle fields let me know. If you want to discuss the health service with "academics" from "west point military academies" with no personal or practical experience do so. The choice is yours.

With every good wishes



Mark Mathews

## **Dr. Joanne Nelson, Consultant Paediatrician and Forensic Examiner**

*This submission is made by Dr Nelson as an individual. Because of the season (August 2016) many of her valued colleagues through the Royal College of Physicians Ireland Community Paediatric Sub-committee are on (well earned) annual leave. The author plans to widely consult within this expert group at their next meeting 20/09/2016 and bring to the Oireachtas Committee on the Future of Healthcare their updated views and expertise. The author did not wish to miss the deadline for submission.*

### **Executive Summary**

All children and young people have a right to be protected from child abuse and neglect, and all doctors have a duty to protect children. Child Protection is a very important aspect of paediatrics, but the lack of service development and resource allocation in this area has put the most vulnerable children in society at risk. It is a complex and demanding area, which requires the involvement of many hospital, community health and non-health multidisciplinary agencies or services.

The child protection service in Ireland can be difficult to navigate and health service development has been under-resourced and neglected in Ireland. A national strategy addressing the child protection needs of children who present with inflicted injury, neglect, or child sexual abuse is the cornerstone to improving the delivery of care that reaches best practice standards. This submission focuses on paediatric forensic medical services for child sexual abuse in Ireland ( $\leq 13$  years).

In 2016 Ireland services for forensic medical examination in child sexual abuse for those 13 years and under are not standardised, under resourced, disjointed and in most areas outside of West and Mid -West Ireland non-existent out of hours especially at weekends. The reality for many child and adolescent victims of sexual violence in Ireland is that following a disclosure of sexual abuse there is likely to be a prolonged delay in accessing appropriate care, deterioration in potential DNA retrieval, exacerbation of psychological distress to child and family and a very slim chance of successful criminal conviction. Attrition rates are high. Under reporting common.

This submission seeks to highlight the inadequacies of service provision for those most vulnerable in Irish society – the victims of child sexual abuse who require to have their voices heard.

### **Child and Adolescent Sexual Abuse Forensic Medical Services in Ireland**

**Child Sexual Abuse** ‘Involves forcing or enticing a child or young person to take part in sexual activities, not necessarily involving a high level of violence, whether or not the child is aware of what is happening. The activities may involve physical contact, including assault by penetration (for example, rape or oral sex) or non-penetrative acts such as masturbation, kissing, rubbing and touching outside of clothing. They may also include non-contact activities, such as involving children in looking at, or in the production of, sexual images, watching sexual activities, encouraging children to behave in sexually inappropriate ways, or grooming a child in preparation for abuse (including via the internet). Sexual abuse is not solely perpetrated by adult males. Women can also commit acts of sexual abuse, as can other

children.’ (Ref: Children First Guidance, 2011; Department of Education. Working together to Safeguard children).

In 2009 there were 2,500 reports of child sexual abuse to Social Work Departments across Ireland (Ref: Mott McDonald). The Sexual assault and Violence in Ireland (SAVI) report in 2002 of over 3000 adults found that 1 in 4 experienced sexual abuse in childhood. Almost half (47%) reported that they had never previously disclosed the abuse to others indicating that the figures may actually be much higher. Few suspected cases of child abuse result in criminal prosecution or a conviction.

There are very clear international standards for the forensic medical care of children and adolescents who may have been sexually abused (Ref: Service specification for the clinical evaluation of children and young people who may have been sexually abused, RCPCH, FFLM, September 2015). These are outlined below

Such a service should include holistic assessment and care for children referred whenever there is an allegation of sexual abuse, sexual abuse has been witnessed, or when there is a suspicion by the referring agency that sexual abuse has occurred, whether this be recent or historic. The service will ideally see children up to their eighteenth birthday, but definitely children up to their sixteenth birthday.

Individual decisions regarding where a child is seen must take into account the needs of each child, and all services must have clear arrangements in place for children with learning disabilities, communication difficulties, or other special needs to ensure they are seen by an appropriate service regardless of their age.

**Organisational structure:** The preferred overall model for sexual abuse referral services is a ‘hub and spoke’, with a central hub, a paediatric Sexual Assault Referral Centre or equivalent, seeing all acute forensic cases for a defined geographical and demographic population. This service is often best provided through a managed clinical network arrangement. The service may also have ‘spokes’ which will consist of local community paediatric or other health services (where local expertise is available) which link to the central hub. Both the hub and spoke should work in partnership with Gardai and children’s social care (TUSLA).

Historical cases may be seen in the ‘hub’ or the ‘spoke’ depending on forensic requirements and local resources. Where there is a need for intimate body samples the child should be seen in the paediatric SARC or equivalent, however place of follow up will depend on the service and where the child lives.

**The combined service should:**

- Provide a rapid response when a child requires acute forensic medical assessment, including the provision of crisis workers and/or other similarly trained professionals.
- Provide a timely response to requests for historic CSA medical assessments.
- Provide follow up appointments for both acute and historic CSA.
- Refer to other assessment and therapeutic services as required (both immediate and long term).

- Have staff who are competent in both forensic medical examinations and in assessing and providing for the holistic needs of children, including safeguarding from all forms of maltreatment and in the assessment and management of physical and emotional conditions that may or may not be related to the alleged CSA.

The service will have links with other sexual assault services such as Independent Sexual Violence Advisors (ISVA), children's ISVAs or equivalent third sector providers to support the child and family through the criminal justice process as well as signposting them to counselling and other rehabilitative safeguarding services.

It is important that wherever the child is assessed the appropriate quality standards for the service are securely in place. In order to be of high quality, paediatric forensic assessments must adhere to agreed quality standards as outlined in the documents listed

Assessments for children up to their eighteenth birthday must be undertaken by a qualified medical practitioner with appropriate competences.

**Each service needs to address all of the following:**

- Issues around consent and confidentiality.
- The threshold for and the timing of a paediatric forensic assessment.
- The availability of an appropriate chaperone for the child during the examination. For children under sixteen years this role should be undertaken by a nurse with appropriate paediatric competences. However, young people aged 16 years and over may be offered a crisis worker (present either in the room, or on the patient side of a curtain screen). If a young person requests that a chaperone not be present, a record of the conversation must be documented in the notes.
- A suitable physical space, waiting area, age appropriate toys and distraction for the examination, including access to a play therapist where possible.
- The elements that such an assessment should contain, including a comprehensive history (covering developmental history); a full paediatric general and ano-genital examination; screening for sexually transmitted infections (STIs); and the provision of appropriate treatment such as emergency contraception, Hepatitis B immunisation, HIV post exposure prophylaxis and other STI treatment(s).
- Risk assessment for suicide, self-harm, child sexual exploitation and domestic abuse.

- An appropriate standard of documentation, using a specifically designed standard medical proforma.
- High quality photo-documentation using a colposcope or colposcopic-equivalent, adhering to guidelines for labelling and storage.
- That doctors undertaking such assessments have the training and qualifications required to achieve the specific skills and competences; maintain their competence by seeing a specific number of cases each year. Have protected time for preparation of statements and reports for child protection enquiries, criminal investigations, and the courts; have protected time for court attendance; and undergo case supervision and regular peer review. Continuing professional development requirements for all health staff.
- Appropriate pathways for holistic follow-up of all identified needs including counselling, Child and Adolescent Mental Health Services (CAMHS), and other rehabilitative needs of the child and family.

***There is no existing Paediatric Unit/ Service for child and adolescent sexual assault in Ireland adhering to the international standards outlined above.***

**Current Adult Sexual Services in Ireland:** offer acute 24hour forensic medical care to adolescents and adults subject to sexual violence from 14 years up. Services operate within a national network, adhering to specialized Guidelines agreed for Ireland and subject to regular

revision by multi-disciplinary stakeholders, There are 6 specialized Adult SATUs within this network (Dublin, Galway, Mullingar, Cork, Waterford, Letterkenny) most hospital based, and an additional Unit in Limerick able to provide out of hours care. Seamless pathways of referral have been agreed locally and all Forensic Nurse Specialists and Forensic Medical Examiners engage in regular peer review and maintain continuing professional education in the area.

### **Current Child Sexual Assault Services for Children in Ireland**

There are 2 types of assessment required for child sexual abuse:

- **acute forensic examination** which involves the identification and management of acute injury and the collection of forensic samples which ideally needs to be done within 72 hours of the abuse. There is only one regional centre in Ireland (Galway) providing dedicated 24 hour access to forensic medical care for child victims of sexual violence. All other areas provide ad hoc service provision ONLY if available. There is often no availability out of hours and often whole weekends may be uncovered.
- **clinical assessment** of a child who has alleged historical sexual abuse. Services vary throughout Ireland with respect to accessibility, facilities, expertise and equipment.

#### **Galway**

The Child and Adolescent Sexual Assault Treatment Service (CASATS), based in premises shared with the Adult Sexual Assault Treatment Unit, is the only Service in Ireland providing out of hours forensic medical care to child victims of sexual violence. CASATS offers an integrated forensic medical service for children aged under 14 (both male and female) who are victims of sexual assault or suspected child sexual abuse. The service also accommodates adolescents aged 14-18 years who allege historical child sexual abuse (>7 days previously). Currently, children who are victims of acute sexual assault from Counties Galway, Mayo, Roscommon, Donegal, North Tipperary, Clare and Limerick are referred to the Sexual Assault Treatment Unit (SATU) for children in Galway, which is at present the only established centre in Ireland. No progress has been made to date to establish the other recommended regional centers. There are two consultant paediatricians, one consultant gynaecologist and one general practitioner, who have completed comprehensive forensic training and work on an on call/ part time basis in combination with their other clinical responsibilities. There is shared access (with the adult unit) to one clinical nurse specialist, approximately 12 on-call support nurses, and one manager who provides administrative support. Since 2014 the charitable organization CARI has partnered with CASATS to enable a rota of trained crisis support volunteers to attend the forensic medical assessment to engage and support families and evaluate/ provide psychological aftercare as and when needed. Out of hours crisis support workers are not available to child victims of sexual assault < 14 years in any other centre in Ireland. The CASATS service operates 24 hours a day, 365 days a year for patients who report an assault to the Gardaí or social services.

#### **Dublin**

There is no formal arrangement for the provision of acute child sexual abuse assessments in the Dublin region at present, resulting in difficulties for patients, their families, and referring agencies. Currently there is an ad hoc service based on the goodwill of paediatricians with no

dedicated time allocated to these assessments. These assessments are highly time consuming involving examination, reporting and court cases.

### **Waterford**

Forensic, acute and planned medical examinations are provided at the Community Child Centre (CCC), the regional child sexual abuse assessment centre for the South East region, based at University Hospital Waterford (UHW). The CCC is staffed by a multidisciplinary team from psychology, social work, nursing and medicine with administrative support from 9.00am-5.00pm Monday to Friday. Diagnostic or therapeutic assessments are provided in suspected or alleged child sexual abuse for children up to 18 years. Referrals for medical examinations come directly from medical personnel, e.g. paediatric emergency departments or GPs, An Garda Síochána, social workers and others. Nursing cover for medical examinations is provided by the Public Health Nursing Department. The CCC has been part of Tusla, Child and Family Agency since January 2014, and maintains close links with the adult sexual assault and treatment unit at UHW. Unfortunately the one Specialised Paediatric Forensic Medical Examiner assigned to the CCC retired in February 2012, but has continued to work on a half-time temporary basis. She is not able to facilitate out of hours/ weekend examinations within any seamless referral system. There is currently no permanent replacement in line.

### **Cork**

Medical and forensic, acute and non-acute examinations of children who have alleged sexual abuse are provided at the Family Centre, St Finbarr's Hospital, Cork. Up until December 2009, a full-time Senior Medical Officer was employed to provide this service, but when she retired in December 2009, the medical service provision reduced drastically from 1.0 WTE to the current level of 0.1875 WTE (i.e. a more than 80% reduction in this resource). Currently, the medical examinations at the Family Centre in Cork are provided by a very small sessional commitment by each of three Consultant Paediatricians, the combined commitment totaling 1.875 sessions each week (0.1875 WTE) to the child sexual abuse service. This service is provided from 9 am to 5 pm Monday to Friday. Outside these hours, the on-call Consultant Paediatrician is responsible for assessing and managing children who report sexual abuse. Such a person may or may not have specialized training in this area and may not be available in a timely fashion depending on whether or not in hospital critically ill children require his/her attention. As the nature of child sexual abuse presentations is unscheduled this service is limited and supported by the goodwill of the clinicians involved. This service has a half time nurse specialist who supports the service but as she covers both Cork and Kerry, her availability for examinations is limited.

### **Sligo**

Community paediatricians in Sligo offer scheduled assessment of children in their catchment area who have disclosed a history of sexual abuse (non acute cases). Cases are referred mainly from social services, and the vast majority are historical abuse. Examinations take place in the colposcopy suite at Sligo Regional Hospital with the support of the Clinical Nurse Manager 2 (CNM2). Since 2010, both paediatricians perform the assessment jointly. Photo-documentation was used historically, but video-documentation has been explored more recently. Figures (average approximately 10- 15 per year). There is no forensically clean room for gold standard DNA sampling.

## **Cavan, Drogheda, Tralee**

The Community Paediatricians in Cavan, Drogheda and Tralee all provide assessments for acute and historical sexual abuse cases. Only one has specialized forensic medical training. There is no forensically clean room for gold standard DNA sampling. Children in these areas do not always access gold standard photo-documentation as this may not be accessible especially out of hours.

### **Proposed Model of Care for Acute Child Sexual Assault**

The model proposed is informed by the recommendations of the Ferns 4 report and the National Review of Sexual Abuse Services for Children and Young People (Mott McDonald, 2011) but may need to be extended to ensure 24 hour availability. Services will provide acute sexual abuse assessments in the proposed regional centres of excellence, i.e. SARC's, with each centre a 'one stop shop' providing medical / forensic examination, assessment, therapy, child protection liaison and Garda liaison as core components. Each SARC will coordinate, train, support and supervise the work of clinicians in the clinical network for the region.

There is an immediate issue with regard to the provision of medical / forensic examination in the country ideally in 3 specialised centres (Dublin/ Galway and Cork or Waterford). In the greater Dublin area pending the establishment of the national children's hospital, it is proposed to establish a single medical / forensic examination service for Dublin Mid-Leinster and Dublin North-East to be located at one of the three paediatric hospitals. This service should operate at minimum from 9.00am-10.00pm Monday to Friday and 9.00am-1.00pm on Saturday and Sunday all year round or ideally throughout the 24 hour period. Galway should be supported to continue 24 hour gold standard practice for West and Mid- West Ireland. Cork/ Waterford require significant investment in personnel/ facilities to enable one to provide regional acute expertise. All services require the appointment of a number of consultant paediatricians with a special interest in child protection and dedicated time within their posts to lead and provide the service and / or Forensic Physicians with expertise in Paediatrics, but not necessarily paediatricians who can contribute to a comprehensive specialised and expert 24 hour service. Sufficient specialist nurses need to be appointed to the service. Some of the existing general paediatricians and consultant paediatricians with a special interest in community child health may become involved in a Rota for acute sexual abuse assessment in the regional units in the country, however this would require alterations to their current workload to accommodate this additional commitment.

### **Both regional and local SARC's must be able to provide the following medical aftercare:**

- First aid for minor injuries
- Emergency contraception with appropriate care pathway
- Pregnancy testing with an appropriate care pathway
- Prophylaxis for sexually transmitted infections with an appropriate care pathway and follow up
- Provision of, or referral for, Hepatitis B immunoglobulin and/or vaccination with appropriate follow-up and care pathway
- Provision of, or referral for, post-exposure HIV prophylaxis with appropriate follow up and care pathway
- Screening for sexually transmitted infections when appropriate, e.g. when examining suspected historic sexual assault / abuse

**Seamless Timely Referral:** It is envisaged that there would either be either a single all Ireland 24 hour phone line dedicated to forensic medical child sexual abuse services or that each specialised centre would put in place a seamless pathway of referral with telephone line manned 24 hours/ day to facilitate referrals.

### **Recommendations for Medical Examination**

- All paediatric registrars and consultant paediatricians should be competent to take a brief history of a sexual abuse concern or allegation.
- Access to expert advice on whether a child needs an acute forensic assessment should be readily available via telephone 24 hours a day, 7 days a week. There is evidence that forensic assessments in children under 10 years old are much more likely to yield positive findings if conducted within 24 hours of the acute assault.
- Children referred for assessment following sexual assault should have ready access to a medical assessment by a trained and competent clinician, with appropriate equipment including magnification and dynamic photo-documentation and forensically clean examination facilities where required. It is recognized that children examined in a SARC are more likely to have injuries documented correctly and undergo sexually transmitted infection screening.
- Clinicians should engage in regular peer review in dedicated centres, and must be doing a minimum number of CSA assessments (the Faculty for Forensic and Legal Medicine in the UK recommends 20 per year per practitioner). Staffing resources should be provided to allow for joint examinations where required.

**To enable the proposed model of care Paediatric Child Sexual Abuse Services require funding sufficient to appoint a full time National Clinical Lead, three 0.5 WTE (whole time equivalent) Regional Clinical Directors with dedicated time allocated to their responsibilities and back fill for existing clinical posts, update of all existing premises to ensure appropriate photodocumentation and a forensically clean environment, funding for 24 hour telephone access, development of Child Sexual Abuse Guidelines Specific to Ireland, establishment of a clinical network specific for child sexual abuse and development of child abuse training within the existing Paediatric Training Scheme.**

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## Dr. Paul O'Connor, Letterkenny Hospital

I have been the Clinical Director of a large hospital with over 24,000 inpatient admissions per annum for the past 8 years. I have over 15 years' experience as a Consultant Anaesthetist in Ireland. I spent 3 years at the University of Alberta Hospital in Edmonton, Canada where I was Clinical Assistant Professor before returning to Ireland to take up my present post.

### 1. Scope:

The submission will describe the perilous state of surgical services across the country & the effects of failure to maintain scheduled surgery during the near-permanent crisis of ED waiting times. The submission will explore the full implications of this and will describe possible solutions.

### 2. Basic Premise: The HSE does not have a “plan for surgery”

There is no *integrated* framework which addresses the problem of timely access to elective and emergency services for cancer and non-cancer procedures. The basic questions of **where** surgery should take place, **when** operating lists will be supported, **who is** expected to perform the operations & **how** patients should access the services have not been addressed systematically for the whole of the country.

**The cost of prioritisation of cancer surgery outcomes at the expense of outcomes from non-cancer surgery will only become apparent when emergency surgical services collapse in many hospitals.**

### 3. There is no vision for a sustainable manpower model in surgery

If the manpower model fails then so too does the service so the manpower model is key. A recent report in the national daily newspapers (Irish Independent, 27<sup>th</sup> Jan 2017), quoting an unpublished HSE report commissioned by HSE Chief Executive Tony O'Brien, stated that “one-in-eight full-time posts advertised for hospital consultants received no applicants in 2015”. Incredible as it may seem, this *underestimates the true extent of the problem* since the figure does not include posts for which no appointment could be made due to a lack of *suitable* candidates at interview. The crisis in the recruitment of Irish-trained hospital consultants is particularly true for surgery and is most acute for model 3 hospitals (see Appendix 1: Classification of Irish Hospitals). Within the category of model 3 hospitals, those which are **outside** the roughly triangular area which includes the major population centres of Dublin – Galway – Cork – Dublin are most at risk.

### 4. Consultant posts in model 3 hospitals are often less attractive

Reasons for this include

- Single-handed consultant posts: Many model 3 hospitals provide services which depend on a single consultant only. These posts are not only unattractive but underpin services which, without manpower reform, are not sustainable in most cases.

- Supporting structures: The number and calibre of non-consultant hospital doctors working in a unit is a major consideration for job applicants. Allocation of specialist training registrars to model 4 hospitals is generous in the extreme. Conversely there is a paucity of such trainees in model 3 hospitals which provide the bulk of the service.
- Private income: Consultants who are based in larger model 4 public hospitals enjoy opportunities to work in adjacent private hospitals. This provides a significant income stream since 45 % of the Irish population carries private health insurance AND the HSE has used the NTPF as a vehicle to outsource much elective surgery to the private sector.
- Infrastructure: Many parts of rural Ireland do not enjoy access to motorway and railway infrastructure. This serves as a disadvantage in terms of attracting hospital staff and creates access problems for patients.

### **5. The HSE is responsible for service provision but not for training consultants**

The Higher Professional Training Bodies including the Royal College of Surgeons in Ireland (RCSI) and the Royal College of Physicians in Ireland (RCPI) are responsible for training consultants in various surgical & medical disciplines. Training programs, organised by the colleges but paid for by the State, are disproportionately based in model 4 hospitals with the result that trainees gain little experience in model 3's. This separation of the surgical training function (the RCSI) from the service function (the HSE) is a critical weakness of the system. The current training program produces surgeons who do not want to work in units outside the "golden triangle" of Dublin / Cork / Galway. This is a key driver of difficulty in recruiting & retaining consultants in model 3 hospitals.

### **6. Most "elective" surgery is urgent. The term "elective" is a misnomer.**

Most people readily understand the urgency of cancer surgery but fail to appreciate the urgency of non-cancer surgery. This attitude is deeply entrenched within the HSE and also in our media, which regularly treats & portrays elective surgery as a luxury item. The following examples may illustrate why this is not so.

1. Total hip or knee replacement: Patients requiring hip or knee replacement surgery are frequently in pain (sometimes severe) and usually experience a marked reduction in mobility and independence. Elderly patients who cannot access surgery within a reasonable time-frame (say 6 months) usually experience a dramatic deterioration in chronic health status which is not easily reversed.
2. Laparoscopic cholecystectomy: Public patients who get an attack of "gall-stones" frequently endure multiple hospital admissions before gaining access to surgery. These acute attacks lead to the formation of scar tissue and render eventual surgery more difficult than would be the case if the operation were carried out in a timely fashion – usually 6 weeks after the first attack. Multiple attacks also carry the risk of serious & potentially life-threatening complications including pancreatitis and consume scarce healthcare resources.

## **7. Manpower model for emergency surgery**

Ireland does not have “emergency” surgeons. Like many countries, we have surgeons who are recruited into a particular **elective** surgical program and who, by virtue of being on-call, provide emergency surgery out-of-hours. Thus, the emergency surgery function is completely dependent on elective surgery since both are provided by the same surgeons.

## **8. When elective surgery fails, so does emergency surgery**

The failure to provide robust elective surgery programs in model 3 hospitals is driving surgeons away. This will become manifest when existing surgeons retire and cannot be replaced. This will inevitably lead to closing departments of surgery (politically difficult) or accepting a lowering of standards and poorer outcomes for patients.

## **9. The centralisation of cancer surgery to prioritise cancer outcomes has costs as well as benefits**

It is critically important that the “Future of Healthcare” report encourages the development of an integrated approach to surgical services both cancer and non-cancer. The lack of such an approach has facilitated the centralisation of cancer surgery programs at the expense of emergency surgery in model 3 hospitals. Conditions requiring emergency surgery are frequently life-threatening and may lead to numerous (but avoidable) deaths from non-cancerous conditions.

## **10. When emergency surgery fails, patients die**

Patients who suffer from acute intestinal obstruction and/or perforation require emergency surgery within a very short time-frame to reduce the risk of death from sepsis. Outcomes are poor if surgery is delayed or not done to a high standard. Delayed surgery often arises from prolonged inter-hospital transfer times which are characteristic of model 3 hospitals in Donegal, Sligo, Mayo, Kerry and Wexford.

## **11. A hospital which cannot provide emergency surgery to a high standard faces inevitable down-grade.**

The provision of around-the-clock 24/7 emergency services in any hospital is dependent on the availability of in-house physicians and surgeons to treat patients who have been admitted. There is not much point in having an Emergency Department which is disconnected from an in-patient service. Hospitals which lose surgery will face inevitable down-grade of the Emergency Department.

## **12. The example of Portlaois Hospital**

Portlaois hospital is a very good example of this dynamic. The CEO of the Dublin Midlands hospital Group has stated publicly that the hospital will not be able to perform “complex” surgery such as laparoscopic appendicectomy. This is a procedure which is normally regarded by most general surgeons as being part of their “bread and butter” and is not considered to be of particularly high complexity. The question of surgery safety in Portlaois was highlighted in a recent HIQA report which stated that the hospital is at a “critical juncture” and faces an “uncertain” future because of continuing safety concerns. Portlaois hospital is of course at the centre of a nexus of other hospitals in Tullamore (25 miles), Naas (33 miles), Kilkenny (33 miles) and Mullingar (44 miles) which *could* provide a service if enabled to do so. Portlaois also enjoys good motorway and rail links to other centres. This is not the case with many other much bigger model 3 hospitals which depend on in-house surgery for which no ready alternative exists.

### **13. The HSE funds the training of surgeons at taxpayers' expense but fails to ensure adequate geographical spread of vital training posts**

Training programs for junior doctors in the UK and elsewhere are constructed on the basis of rotations incorporating periods in a variety of types of hospitals equivalent to our model 3 *and* model 4 hospitals. In contrast to this rotational training, a situation has emerged in Ireland whereby **training has been de-coupled from service provision** and has become highly concentrated in model 4 hospitals. This leaves the HSE (which funds the training programs) unable to recruit doctors into posts which are seen as “service posts” and has the potential to undermine the provision of services to large sectors of the Irish population.

### **14. The RCSI does not support surgery in model 3 hospitals**

The Royal College of Surgeons in Ireland does not support the provision of higher surgical training programs across a mixture of models 3 and 4 hospital training sites. Since it does not have a service mandate, the college is not required to consider the effect this might have on the provision of hospital services. Conversely, the HSE, which has a service mandate, has been unsuccessful in balancing the advice from the RCSI (training perspective) with the nationwide need for service provision and the principle that *training should be directly linked to service provision* has no place in HSE policy. This has resulted in an emerging paradigm in which **the HSE does not have a plan for surgical programs outside major urban centres.**

### **15. Scheduled surgery is effectively outsourced to the private sector**

This is entirely in keeping with the rudderless approach to surgery in model 3 hospitals. Failure to build surgical capacity has created ever-lengthening waiting times for surgery. The current solution, to outsource waiting lists to private hospitals, is hugely counterproductive on the grounds that private hospitals **do not provide emergency surgery 24/7** nor do they offer surgery to patients with significant chronic medical conditions because it's a bad business model.

## **Solutions for Surgery**

### **16. Focus on the development of integrated surgical services**

Much of the specialty-based advice on which HSE decisions are taken envisages a concentration of specialty-services in a small number of hospitals normally located in Dublin, Cork and Galway. This forms the basis for the golden triangle of Irish hospital services & is undoubtedly good for these specialty services (and for general surgical services for patients located within this area) but is equally bad for general & emergency services elsewhere.

### **17. Identify & prioritise core hospitals**

This refers to hospitals which will be required to perform emergency surgery 24/7 in the long-term.

Priorities for core hospital selection should include

1. Large hospital size
2. Geo-spatial significance
3. Access to transport infrastructure and
4. Availability of alternative service providers who have capacity to absorb services if required.

For all the reasons explained above, it is vital that these “core” hospitals **should be supported in the development of scheduled surgical programs.**

## 18. Develop sustainable manpower solutions

In order to develop sustainable manpower solutions it is vital that we

1. Recognise the need for the development of units with a critical mass of activity. Not all model 3 hospitals can support viable departments of surgery. A minimum roster of six surgeons is required for general surgery (perhaps 5 for orthopaedics)
2. Distribute HSE-funded RCSI training posts according to where services are provided
3. Appoint a minimum of two surgeons for each on-site elective surgery program to avoid a crisis when one is away or becomes ill.

## 19. Prioritise day surgery

The HSE has failed to prioritise day-surgery in Ireland as a result of which we are well behind the UK and other countries. Measures to promote day surgery should include the following:

1. Extended opening hours from 8.00am to 10.00pm to ensure all-day operating lists and allow time for patient recovery and discharge
2. Ring-fenced day surgery beds
3. Incentivise hospitals to follow best practice: introduce a higher payment for doing certain procedures as day cases versus the payment for doing the same procedure as an in-patient (NHS best-practice tariff)
4. Development of stand-alone day surgery facilities which are **protected** during the crisis response each winter.
5. Introduction of “23-hour admissions”: Day-surgery units in some centres in the UK and elsewhere have capacity to admit patients overnight for discharge at 08.00hrs on the morning after surgery. This significantly increases the complexity of procedures which can be carried out in these units.

## 20. Develop stand-alone satellite surgical units

The existing model for standalone units for orthopaedic surgery should be extended to general & other surgical specialties. Orthopaedic units in Cappagh (Co. Dublin), Merlin Park (Galway), Kilcreene (Co. Kilkenny) and Croom (Co. Limerick) routinely provide a large number of primary & revision hip and knee replacement operations per annum together with more complex spinal operations. Despite reservations about on-site physician cover during out-of-hours periods, these units are quite robust and, in contrast to other public hospitals, form a reliable part of our surgical infrastructure. The failure to protect beds for scheduled surgery during our ever-lengthening winter crisis is unlikely to improve. Instead, it is becoming a permanent feature of Irish hospital care and the underlying demographic driver suggests this is likely to get worse rather than better during the coming years.

With this background in mind it is evident that new solutions for surgery are required. On this basis I would like to suggest that the HSE should develop *standalone units for elective general surgery of intermediate complexity*. If properly configured these units could function from Mon to Fri only & would provide a mixture of intermediate and day-case procedures based on 100% day-of-surgery admission and a maximum length of stay of 4 nights. There would be limited requirement to transfer patients to the “mother” hospital in the event of a patient being unsuitable for discharge on Friday evening. In order to generate economies of scale, these facilities could easily be shared across two or more hospitals. They would be able to perform a large proportion of surgery of intermediate complexity in addition to the usual day procedures. Hospitals which enjoyed the benefit of these

units would be perceived to have a distinct advantage in terms of the delivery of elective surgery and would be much more attractive in terms of surgical recruitment and would be enabled to deliver a robust emergency surgical service which is currently under significant threat.

## 21. Summary

A radical solution for surgical services is urgently required in Irish hospitals. The solution will be required to address the following important questions.

1. What elective surgical programs will be supported model 4 hospitals?
2. Do model 4 hospitals have capacity to provide cancer and non-cancer surgery?
3. Is there equitable access for patients taking geography / infrastructure into consideration?
4. What model 3 hospitals will provide emergency general surgery at night-time & week-ends?
5. How many surgeons are required to provide this service?
6. To which elective surgery programs will these surgeons be appointed?
7. If a hospital has no elective surgery programs, how will it provide timely & safe emergency surgery?
8. If cancer surgery programs are withdrawn (centralised) which programs should be provided instead?
9. If a hospital cannot provide emergency surgery, how will it be able to retain a full Emergency Department 24/7 ?

It is very likely that failure to address these questions will lead to down-grading & closure of services at a time when demographic demand is rising significantly. If this is permitted to happen in a haphazard way it will inevitably impact on emergency and trauma surgery & will lead to an increase in the number of adverse outcomes up to and including (potentially numerous) avoidable deaths.

Dr. Paul O'Connor  
 Clinical Director for Peri-operative Care  
 Letterkenny University Hospital  
 Saolta Hospital Group

## 22. Appendix 1: Classification of Irish Hospitals

The terms “model 1”, “model 2” etc were first used to describe Irish hospitals in a report on the “National Acute Medicine Program” produced by the RCPI in 2010. There was no surgical input into this report and neither the HSE nor the RCSI has attempted to define a model 3 hospital in terms of surgical programs.

Model 1	A community hospital with no acute hospital beds
Model 2	Low acuity hospital for patients requiring medical (but not surgical) in-patient care. Two in-house doctors provide night-time and week-end cover. One consultant physician on-call. No intensive care unit (ICU). Possibility of day surgery envisaged.
Model 3	General hospital with 24/7 emergency services. General ICU on site.  Elective inpatient surgery on-site with 24/7 access to emergency surgery. Senior

	member of a surgical team (with other team members) present on-site 24/7.
Model 4	Tertiary referral centre providing specialist regional and national medical and surgical specialties. Specialist ICU service.

**Table1 Listing of Model 4 and Model 3 Hospitals**

	<b>Model 4 Hospitals</b>		<b>Selected Model 3 Hospitals</b>
1	Cork University Hospital	1	Our Lady of Lourdes, Drogheda
2	Galway University Hospital	2	Letterkenny
3	St James' hospital, Dublin	3	Mullingar
4	Mater hospital, Dublin	4	Mayo
5	Beaumont hospital, Dublin	5	Kilkenny
6	Tallaght hospital, Dublin	6	Sligo
7	Limerick University Hospital	7	Wexford
8	Waterford	8	Kerry
		9	James Connolly Hospital, Blanchardstown
		10	Portlaois
		11	Clonmel
		12	South Infirmary, Cork
		13	Tullamore
		14	Merci Hospital, Cork
		15	Portiuncla Hospital, Ballinasloe
		16	Naas

The classification does not include stand-alone maternity or paediatric hospitals.

### 23. Appendix 2: Inpatient activity profile (data 2015)

Hospital admissions are normally quantified by the number of “in-patient discharges”. These data are produced by the HSE every year. The number of “In-patient discharges” does not include day-case activity or out-patient numbers and it does not incorporate a measure of complexity. It is nevertheless a valid measure (albeit incomplete) of the quantum of inpatient activity in a hospital.

Table 2 illustrates the breakdown of inpatient discharges between model 3 and model 4 hospitals in 2015. It is evident from the table that model 3 hospitals account for over 50% of inpatient discharges and that the collapse of surgery in model 3 Irish hospitals (if it were allowed to happen) would have a massive adverse impact on hospital services.

<b>Table 2: Inpatient Discharges (2015)</b>			
<u>Model 4</u>		<u>Model 3</u>	
Galway University Hospital	37,736	Drogheda	27,320
Cork University Hospital	31,100	Letterkenny	23,262
Limerick University Hospital	27,877	Mullingar	20,016
Beaumont Hospital, Dublin	24,058	Mayo	18,960
St James' Hospital, Dublin	23,009	Kilkenny	18,672
Waterford	22,315	Sligo	18,275
Mater Misericordiae, Dublin	21,516	Wexford	16,848
St Vincent's Hospital, Dublin	19,708	Kerry	15,266
Tallaght	19,098	Connolly	13,883
		Portlaois	12,806
		Clonmel	12,577
		South Infirmary, Cork	12,407
		Tullamore	11,423
		Mercy	11,243
		Naas	9,796
	<u>226,417</u>		<u>232,958</u>

## **Dr. James O'Mahony, School of Medicine, TCD**

- Access to non-drug services need to be put on an equal footing to pharmaceuticals by reducing waiting lists.
- A common cost-effectiveness threshold should apply to drugs and non-drug services.
- The cost-effectiveness threshold should be determined empirically in relation to the opportunity cost of services foregone.
- Clear, detailed and costed policy proposals are required during the policy development process.
- Reforms should avoid instability in health financing by rapidly changing the incentives to pay private health insurance contributions.
- An honest appraisal is required of the limits on the ability to truly eliminate two tier care.
- Efforts should be maintained to eliminate entitlement cliffs between different income groups.
- A new system could balance the need to provide meaningful access to good value services while maintaining the freedom and incentives for private contributions by ensuring the public system provide timely access to a universal package of cost-effective services while individuals are still permitted to purchase cost-ineffective care if they wish.

### **A. What are the key priorities for inclusion in a ten year plan for the health service?**

#### **A1. Parity of access between drugs and non-drug services**

A key priority should be placing access to non-drugs services on an equal footing with drugs. Once a drug is approved by the HSE eligible patients typically have ready access to the therapy without any further rationing or limitation. In contrast, even though a non-drug service may in principle be provided by the HSE, in practice it may still be subject to rationing through waiting lists, either for the service itself or for prior diagnostic consultations. The current long waiting lists for a variety of services are ample evidence of this worrying disparity of access between drug and non-drug services.

This disparity is concerning from a cost-effective perspective. It may be the case that a highly cost-effective non-drug treatment is needed, but is not readily provided. Conversely, there will be no such delays or limitations on drug treatments once the drug has been approved. This may be the case even if the drug treatment is far less cost-effective than the non-drug services that remain subject to waiting list rationing. Indeed, it is sobering to reflect that nearly all of new cancer drugs approved and made available by the National Cancer Control Programme in recent years have failed to show cost-effectiveness, while access to cancer-related diagnostic services such as colonoscopies remain subject to waiting lists, despite being highly cost-effective.

I have previously published research pointing out that while Ireland has a relatively generous cost-effectiveness threshold (upper limit on what cost-effectiveness ratio we consider sufficient value for money when deciding to fund healthcare interventions), we have non-drug services that are known to be highly cost-effective that are subject to long waiting lists, including cataract removal and hip and knee replacements [O'Mahony and Coughlan (2015) The Irish Cost Effectiveness Threshold; Does it Support Rational Rationing or Might it Lead to Unintended Harm to Ireland's Health System; *PharmacoEconomics*]. I strongly suggest the HSE consider an audit of the published evidence on the cost-effectiveness of the common procedures currently subject to long waiting lists in Ireland.

## **A2. A common cost-effectiveness threshold for drug and non-drug services**

A secondary issue regarding parity between drugs and non-drug services in Ireland is the lack of an official cost-effectiveness threshold for non-drug services. The current threshold of €45,000/quality-adjusted life-year recently renewed in the agreement between the IPHA, DoH & HSE only applies to drugs. There is no officially stated cost-effectiveness threshold for non-drug services in Ireland. There is little justification from a theoretical perspective for not maintaining and applying a common threshold to all interventions. In practice, HIQA applies the €45,000/QALY drug threshold in its appraisal of non-drug services. Nevertheless, it would be a helpful commitment to clarity and parity if the cost-effectiveness threshold for non-drug services was stated officially.

## **A3. An evidence-based cost-effectiveness threshold reflecting opportunity cost**

There are a variety of suggestions how a cost-effectiveness threshold should be set. The most credible and theoretically consistent is that the threshold should be determined with reference to the cost-effectiveness ratio of the most cost-effective service that we currently limit access to due to resource constraints. The principle is that we should not adopt new interventions that are less cost-effective than services that are currently constrained. While it would be possible in principle to estimate the threshold in this way, the current cost-effectiveness threshold employed in Ireland is not based on any evidence whatsoever.

The current lack of an empirical basis for the threshold is a profound problem for the application of cost-effectiveness analysis. The current lack of evidence means we do not know whether our threshold is at an appropriate level or not. Consequently, decisions made with the current threshold might be harming our health system rather than enhancing it. In particular, the concern is that the present threshold is too high and that we may be paying too much for new services while neglecting to ensure sufficient access to existing services. If this is the case, the current threshold will be actively damaging the performance of the health system rather than improving it.

A major research project in the UK recently made an attempt at estimating the threshold from the opportunity cost of services forgone. The threshold estimate reached in that study was approximately £13,000/QALY. Clearly this threshold is far lower than what we are currently applying in Ireland.

The HSE should support similar efforts to estimate a cost-effectiveness threshold based on services foregone in Ireland. This may require a profound change in thinking from the norm

of generous reimbursement in recent years. Indeed, it is likely to prompt firm opposition from interests in the pharmaceutical industry. However, such a frank examination of what the real opportunity cost in the Irish setting is required. To persist with a cost-effectiveness threshold that is not in fact based on opportunity cost is totally inconsistent with health economic thinking and presents a profound challenge to the ethical justification for explicit rationing using cost-effectiveness analysis. If we are to take cost-effectiveness seriously as a tool for the improvement of Irish health services we must commit to efforts to finding a sound, evidence-based threshold.

**B. What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?**

**B1. Clear and detailed policy proposals are required for informed debate**

The previously published proposals for universal health insurance (UHI) signalled radical reform in Irish health funding and provision. They offered many new and interesting ideas on how health services might be improved. However, the policy was notably underdeveloped, as the White Paper lacked sufficient detail on many key topics. Furthermore, the proposals were not costed until after it was widely accepted that proposals were going to be abandoned. Together, these factors made it difficult to appraise the proposals adequately and left the plans seriously lacking credibility. This experience does not reflect well on policy development in Ireland. This was disappointing, especially considering the central importance our health system to the wellbeing of the population and the proportion of government spending consumed by the sector. It is imperative that future policy proposals embrace greater clarity, detail and rigor.

The present consultation signals to me a greater willingness to engage with others in the policy development process. I am hopeful that future policy proposals will be detailed and costed during development. Moreover, despite recent statements made by the Minister for Health against piecemeal reform, I would urge the merits of incrementalism and caution against changing many things at once.

**B2. Clarity regarding purchasing preferential access and hypothecated income tax**

One of the fundamental issues not addressed by the UHI proposals was what is the distinction between the purchase of preferential access to care and what is additional income tax hypothecated for health spending. The current system of voluntary health insurance creates an incentive to privately purchase insurance cover to gain faster access to care, potentially providing access to more services, possibly of higher quality. Enforcing a common tier of eligibility would remove this ability to purchase preferential access and fundamental changes the incentives. Understandably, many may respond by not continuing to purchase insurance voluntarily. This was acknowledged implicitly by the UHI proposals, given the mandatory nature of the insurance proposed. When insurance becomes mandatory the system then begins to resemble increased income or wealth taxation, with the revenue hypothecated to health spending. However, the UHI proposals had the notable disadvantage over such a hypothecated tax, in that the state does not necessarily have control over how the revenue is spent, as control is vested with private insurers.

When drafting new policy proposals greater clarity regarding the underlying concepts for health spending and its objectives regarding freedom to purchase care, the incentives created and likely consequences would be useful.

### **B3. Avoid instability in health financing by rapidly reducing voluntary private**

#### **contributions**

Any radical change to the incentives to purchase private insurance risks instability in the funding of healthcare in Ireland. The current willingness to pay in the private market is predicated on the perception (warranted or otherwise) of inadequacies of the public system. Although only around a quarter of health spending comes from private, the absolute amount of health funding that would need to be replaced by public sources would still be large if there was a rapid reduction in voluntary private health spending. Furthermore, there are a deeply entrenched set of interests that support the persistence of private health insurance in the form of the insurers themselves and those that provide care privately. Accordingly, while many understandably object to the segregated access that private health spending facilitates, a pragmatic approach to reform must ensure that there are no abrupt changes to financing streams and must be prepared to deal with opposition to change from private providers. Accordingly, the transition to a fairer system of financing and access must be managed carefully to achieve a smooth transition.

### **B4. Honest appraisal of the cost barrier to achieving full single-tier care**

We cannot feasibly restrict individuals spending private resources on privately purchased health services (inside or outside the State). This then implies that it will never be possible to fully eliminate two-tier access. What is a more pragmatic policy aspiration is to shrink the upper-tier of access and improve the efficiency of the lower universal tier. The failure of the previous UHI proposals to acknowledge the reality that true single tier access was not achievable hampered the credibility of the proposals.

Achieving true single-tier care requires making the public health system so good that there is no incentive to purchase healthcare privately, even for the better off in society. Clearly the cost of achieving such a comprehensive system for all services would require such a large increase in taxation that it would be politically infeasible. The recent work by the ESRI outlining the costs of the UHI proposals provides clear evidence of this. Similarly, any system that relied upon mandatory health insurance to achieve this high standard of care and access would likely impose large costs that many subscribers would find unacceptable.

Given that society is likely unable to fund a fully comprehensive single-tier system, then a system that achieves common access for all patients while also being affordable is likely to still require some form of rationing. If that rationing was achieved in part through waiting lists, as is currently practiced, this would be arguably more equitable than the status quo, as waiting for access to services would be spread over a greater proportion of the population. Although the waiting lists under such a common system might be shorter than those currently endured by public patients, forcing those private patients that currently enjoy rapid access onto common waiting lists will be unpopular. Again, even an affordable universal system is likely to have problems of political acceptability.

As mentioned above, since completely eliminating two-tier access infeasible a more meaningful and pragmatic policy goal would be the shrinking of income-based preferential upper-tier access. Careful consideration of incentive design regarding the interaction of taxation, government subsidy and private contributions could contribute towards this goal.

A coherent way of making two-tier access more equitable would be to adopt a funding system whereby a core of cost-effective services for all conditions were provided in the universal tier of care and other less cost-effective treatments were left for the private insurance market to fund if individuals wanted to pay for them. In this way, all individuals would be secure in the knowledge that the state had provided universal access to good value care and that gaining access to other services through private insurance only permitted access to services that were less value for money. This system would prioritise equity and access to good value care, while still maintaining incentives for voluntary private contributions and the freedom to make additional spending on health as desired. Careful design of the incentives would be required to make such a system workable, but in principle this could be a fair and efficient way of balancing universal access without compromising freedom to spend additional sums privately.

### **C. Do you have any views on which health service funding model would be best suited to Ireland?**

#### **C1. Avoid entitlement cliffs and the perverse incentives they create**

Although the previously published UHI proposals were underdeveloped they do represent a useful reference point and some principles should be retained. One particular strength of the UHI proposals was the potential to end the entitlement cliffs between medical card holders, the uninsured and privately insured. The proposals would have facilitated a useful blending of public and private contributions that avoided the distortions and inequities that stem from entitlement cliffs. If a reliance on private contributions is to be maintained, then new policy proposals should attempt to retain the features of blended contributions.

#### **C2. Facilitate appropriately regulated freedom of provision for publicly-funded services**

Another good feature of the UHI proposals was the ability of individuals to access care from any provider, public or private. Similarly, this reflects the activities of the National Treatment Purchase Fund in reducing waiting lists. While there may be resistance from public sector unions to the opening of publicly-funded care to private practice, the principle that patients in need can access care from whoever is willing and able to provide it at regulated prices is welcome from liberal economic perspective. Indeed, it is profoundly morally perverse to deny care to patients if the private sector is able to match on quality and provide the service at the same cost or less than the public service.

Despite the appeal of extending private provision of publicly-funded care, such an approach should be treated with caution. The current system already presents strong perverse incentives to providers that work both in the public and private sectors to refer patients to

private lists rather than seeing them publicly. Accordingly, a careful separation of public and private services might be required to ensure such referral patterns do not spread.

A second concern regarding an expansion of private provision of publicly-funded care relates to health information systems. The lack of common information gathering and reporting requirements between public and private providers is a serious problem in resource planning and efficiency assessment. Accordingly, private providers must be required to record and report information in the same manner that public providers currently do.

In summary, the use of private provision of publicly-funded care should be supported by carefully designed regulation and should not be inhibited by special interests or ideological preferences.

**D. Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating; what are the main entitlements that patients will be provided under your funding model?**

**D1. Universal access without further rationing to basic set of cost-effective interventions while retaining freedom to purchase cost-ineffective care**

The model I propose is a pragmatic retention of the two tier system, but with a prioritisation of access to cost-effective services within the universal tier. Services within the universal tier will be funded through general taxation and available to anybody, irrespective of income or insurance status. The universal tier would be to provide meaningful access to cost-effectiveness services without rationing; in other words “to do the basics well for all”.

The cost-effectiveness threshold used to judge what services are included would be adjusted so that meaningful access could be granted to all covered services without long waiting lists (under such a scheme waiting lists would only be as long as required to ensure capacity is utilised, not to ration care). The universal tier would include primary care, subject to some small co-payment paid by all individuals. Screening and immunisation would also be included in the universal tier, again subject to the proviso that the specific interventions met the cost-effectiveness criteria. The universal tier would cover pharmaceutical costs for drugs that met the cost-effectiveness criterion, but not those that did not. This would apply equally to community and hospital pharmacy.

Individuals would be free to purchase insurance or directly pay for services that do not meet the cost-effectiveness criteria. The payment for such private services would be carefully managed to ensure that private patients paid the full cost of such non-cost-effective care: i.e. private patients cannot rely on the public system to cover the majority of their care costs while just topping-up the difference to receive the best care, rather they have to step outside of their universal entitlement and pay the full cost of private provision.

Care provided within the universal tier could be provided through the public system, but private providers would also be free to offer services to anybody and receive reimbursement from the state as long as they met regulated prices for providing those services.

This freedom to avail of privately-provided access to services covered within the universal tier is an important component of the proposals, as it ensures that the universal tier cannot meaningfully withhold care that in principle it offers to patients. In short, it would mean that the market would ensure that waiting lists would not re-emerge for cost-effective care.

Ultimately, like many I would prefer to see a single tier health system. The proposal I have outlined above permits this as a possibility. If the public system performs well and becomes efficient, it should be able to expand the cost-effectiveness threshold to cover more and more available services, such that the voluntary upper tier shrinks to the point that it becomes negligible. The proposal is intended to be pragmatic in that it would allow Ireland achieve a universal single tier incrementally overtime, rather than attempting to impose it and fall short in the process.

*Dr James O'Mahony  
Centre for Health Policy and Management  
School of Medicine  
Trinity College Dublin*

## **Dr. Michael O'Mahony, Consultant Respiratory Physician**

The current Public health service, in particular the Hospital sector is increasingly difficult to work in. We have never seen morale as low. This is due in particular to issues regarding lack of capacity, old and decaying infrastructure, with overcrowded emergency departments more suited to 3<sup>rd</sup> world countries. There are poor management and decision-making systems in our hospitals. There is frequently a failure of management to listen to leading clinicians. The Clinical Directorate model works poorly because Clinical Directors have no direct budgetary control or power to drive change in the hospital.

Frequently we sit in meetings where no decisions are made or acted upon. In my hospital we are still waiting 5 years for a procedure room to do pleural procedures, despite this being highlighted at frequent meetings with management. There is also a level of institutional inertia that exists in the public health service unique to Ireland. I saw nothing like this in my 5 years in the US or 1 year in Australia. There is no accountability in the public health service so poor decisions, poor performance are tolerated and even ignored. A healthcare worker, administrator or technician cannot be disciplined, suspended, demoted or fired. This results in a complacency that contributes to a lack of urgency and lack of innovation or effort. Poor work practices results in a lack of productivity and we frequently see significant differences between the capacity of the public sector and private sector to do more cases and procedures etc. with fewer personnel.

The major developments that I feel should take place in the next 10 years should include the following.

1. Increase and improve capacity in Secondary health care system.
  - Develop our major acute hospitals to modern standards.
  - Increase the role of smaller hospitals to manage more step down and rehabilitation care.
2. Improve hospital management systems with more decision making capacity and better quality managers. In particular Clinical Directors should have some budgetary control.
3. The Irish health service should change to an Independent Hospital Group model funded by state and private health insurance. This could be similar to how our public University sector is managed and funded.

## **Strategy**

- **What are the key priorities for inclusion in a ten year plan for the health service?**

In order to address a strategy to progress priorities in Irelands healthcare system one must look in particular at the problems inherent in the system at the moment. Identifying the deficiencies and putting in practice systems and practices that can address them.

Irelands health service is made up of many components. Primary care, secondary (hospital) care, residential care (nursing homes and residential facilities for individuals with physical and mental disabilities), Psychiatric services and social welfare services. My area of expertise is in Hospital care; I have 20yrs experience working in the Hospital system as a junior doctor and Consultant Respiratory Physician. I have worked in 3 health care jurisdictions, Ireland 14 yrs, Australia 1yr and the US 5 years. I can compare many elements of the 3 systems from actual recent experience working there.

In Ireland, public hospital healthcare has many good things; its workforce is generally well trained. Patients once they get access to the system are generally happy with the care they get. Cardiac and Cancer care which has been the focus of development over the last 20yrs has significantly improved with the majority of acute cardiac care being provided in public hospitals. Irish patients have generally good access to cancer care and cancer drugs.

On many other fronts though Irish Secondary healthcare falls down in comparrison to other jurisdictions. In particular problems in the Irish Healthcare system result from

1. Lack of capacity resulting in poor access, with long waiting lists for elective in-patient and outpatient care.
2. Lack of step down care and rehabilitation
3. Sub standard infrastructure with old hospitals built for another era.
4. Overcrowded and unsafe Emergency departments
5. Poor hospital management systems with few decision makers and layers of administrators whose roles are unclear and no obvious accountability
6. Lack of innovation and progress
7. Lack of flexibility
8. Lack of institutional pride
9. Difficulty in recruitment, in particular for smaller hospitals

All these elements combine to produce poor outcomes and dissatisfaction and lack of faith or trust in our healthcare system from the public.

Key areas that need to be addressed include.

1. Capacity issues, acute hospital and step down facilities and residential care.
  2. Management and decision making systems.
  3. Accountability or lack of.
  4. Infrastructure and development.
  5. Recruitment and personnel deficits.
- **What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?**

In order to achieve a universal single tier health system access all citizens would need to be treated equal. Patients would be seen free at point of care initially by their primary care physician and then if necessary referred to a secondary provider who might be a publically funded hospital or who might be a private provider. In order to pay for this system then health insurance would have to be paid for by each individual, most likely on a tax based system with those with higher incomes paying more. But all individuals in the state even in low paying jobs would have to make some contribution (like the German model). This would more than likely be very difficult to sell politically as patients who hold insurance schemes would likely have to pay more with diminished access to private healthcare because publically funded citizens gaining access to the private health care system.

The most feasible system of funding a “Single tier system” and introducing efficiencies and increased funding to the public health service via increased competition would be for the state to become the payer rather than the provider. The State should withdraw from secondary healthcare provision and appoint independent Hospital group organisations similar to our University structure. Public patients admitted to a publically funded hospital for a procedure or medical admission would incur a charge. This charge would be paid for by the state through a ring fenced health tax that would be protected and can be adjusted to inflation and increased health care costs. If individuals want to take out supplementary insurance to cover them both in public and in private hospitals they can do so. To encourage them to take out supplementary health insurance they can incur a “ tax credit”, the overall goal would be to encourage those who can pay more to do so thereby increasing the funding streams both for public and private hospitals. They still benefit from increased access to healthcare but at a premium cost. The state can also purchase healthcare from private providers giving GPs greater choice and public patients greater access. This would be analogous to the Treatment Purchase Fund, but would be in the hands of GPs. Public

hospitals should also be allowed to compete for this “business” with the private sector, potentially increasing their revenue streams.

Independent Hospital Groups should be set up so as not to replicate the mistakes of the past but to develop and have management systems where the goals are improving patient care as well as access to healthcare for all citizens in a cost effective way. They should be broadly free of political interference and should be flexible to respond to the changing needs in healthcare.

- **What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?**

The principal actions needed to plan for increased healthcare needs include greater capacity in the acute healthcare system. Greater access to step-down care and geriatric rehabilitation facilities. This in particular as a practising physician is a major roadblock to discharging patients and reducing their time in acute healthcare facilities. Age specific health initiatives encouraging exercise and nutrition in the elderly would also be beneficial as well as improved community services in-order to keep patients at home. Continuing the fight against obesity and smoking would also impact on future healthcare needs.

#### **Integrated Primary and Community Care**

- What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?

Integrated primary, secondary and community health care involve having shared communication systems. In practice there is very poor links between primary and secondary care.

- What are the key barriers to achieving this, and how might they be addressed?

The biggest barrier against integration is poor computer systems that allow the primary care provider to access the information that the hospital provider has and similarly the hospital provider is frequently in the dark regarding events in the community.

**In your experience**, what are the key roadblocks you encounter in your particular area of the health service?

In my area of the health services the health information systems are so poor that often we cannot access patients blood results. Nothing is connected and innovation is sorely lacking. IT in my hospital is backward in comparison to previous health systems I have worked in.

How would you ensure buy-in from health care professionals to progress towards an integrated health care model?

A key goal should be improved information technology with some form of national electronic medical record (EMR) or improved connectivity across the healthcare system. Health information and a communication platform could be set up involving the hospital provider, GP, Social worker, OT and public health nurse allowing seamless communication. An EMR could also avoid unnecessary tests and replication of investigations.

Are there any examples of best practice that the Committee should consider? Please refer to any evidence you have to support this.

Please refer to US development and support of information technology as part of the TARP initiative in 2008. <https://www.healthit.gov/providers-professionals/electronic-medical-records-emr>

### **Funding Model**

Do you have any views on which health service funding model would be best suited to Ireland?

A mixed funding system should be utilised with a ring fenced health tax and the option of additional health insurance similar to our current system but giving primary care providers greater choice on where to send patients and public patients greater choice and access to healthcare.

Dr. Michael O'Mahony MD MRCPI FCCP  
Consultant Respiratory Physician  
Galway University Hospitals

## **Dr. Eoin Sheehan, Tullamore, Co. Offaly**

The setting up of this committee is a welcome first step in the reformation of the Irish Healthcare system. There is no doubting that it will be a difficult task but the overriding ambition should be in the interest of patient care. There is a myriad of healthcare systems and populations that mirror the universal ambition. Different countries have contrasting philosophies on how healthcare should be delivered. It behoves the committee to set out a framework guided by all stakeholders. There will be many interested parties and individuals submitting recommendations. What is principally required is a visionary roadmap as to how we as a nation can achieve what is best for our people.

Integration of care both vertical and horizontal is the keystone to any quality healthcare delivery system. The vast majority of Irish healthcare is publically funded albeit at a lower level per capita than many of our neighbours. The private sector through partnerships and insurance payment supplements the overall healthcare spend in Ireland. Ultimately it is the taxpayer that will shoulder the burden as the system evolves.

There will be iterations and failures as is expected in any multifaceted delivery of social change. The goal should be to strive for harmony and must at its core be “patient centric”. Government should lead the healthcare change and couple this with social ,community, civic and private partnerships. A strong supportive social and community network is the foundation. The population need to ‘buy into’ the philosophy of equality and the fact that change will bring about a better society, and the healthcare system envisioned will be the generational legacy for future citizens.

Whatever system of healthcare is chosen, change leaders need to be cognisant of the fact that we have a large infrastructure in place that requires modification. We also have a well trained workforce across all disciplines. There is definitely an appetite for change within this workforce considering the fiscal storm that has just been weathered by all and sundry.

The task is onerous and everywhere in the system there are examples of smart adaptations and work practices. Once goals and ambitions have been set, the process should begin with small proven changes whilst the bigger picture is being sketched. This allows incremental gains to be achieved over time and will keep the spirit of evolution alive.

As a healthcare worker for the best part of 20 years both in Ireland and abroad I can only advocate on behalf of the patients I treat as well as the people around me as users of the current system. It is time that we as the countries “century generation” do the spadework for the future citizens of our nation.

As part of this submission I will attempt to address the questions posed by the committee and will structure it accordingly with commentary and references where applicable.

## Strategy

- What are the key priorities for inclusion in a ten year plan for the health service?

-Set a National imperative to provide a healthcare system that becomes a system to serve future generations. A system that has the capacity to deal with planned and exceptions as they emerge.

The UK has the NHS, a national institution which despite its imperfections is still an example of a system that UK nationals are proud of. One cannot but be impressed by the fact that it featured as a showcase during the 2012 Olympic games. A system that people are proud of, could we emulate it?

-Empower patients and educate the population with public health initiatives.

This encompasses many facets of life, the current and present danger in Ireland is obesity. Education serves to lessen the burden on acute and chronic illnesses and when coupled with fiscal penalties can save lives e.g.: "sugar-taxes".

-Building a system that is fully inclusive, comprehensive and allows fluidity of care between sectors.

A system that allows flow of information and governance between community, acute, rehabilitation, disability etc. spreads ownership of patients and allows seamless transitional care.

-Embrace electronic healthcare initiatives that allow for a paperless "real-time" dashboard for healthcare workers to maximize information on patients presenting.

The electronic medical record needs to be made a reality. Kaiser Permanente in the United States pioneered this and through several iterations and failures managed to produce a system that works. A national electronic card such as the French Health card SESAM vitale system would allow patients to maintain their own data, properly encrypted and allowing access by healthcare units that they attend.

-Record all parameters of healthcare data for proper and rigorous statistical analysis, to allow outcome analysis of treatments as well as appropriate costings.

As per above electronic records and a strong ICT system will have the dual effect of improving outcomes and allowing proper fiscal assessment of treatment costs.

-Foundation of full and comprehensive hub and spoke system between acute and community services.

Again founded on management fluidity.

-Empowerment of primary care and medical centres with extended day case facilities as well as GP access to diagnostics on site.

General Practice are the gatekeepers to the healthcare delivery in Ireland and as such should have increased access to diagnostics in medical centres.

-Acute services only reserved for acute medicine and surgery to allow a first world acute system of care.

Establish a comprehensive trauma network, modelled on the UK NHS system.

-Partner the public with the private sector in the provision of affordable sustainable and competitive elective surgery/medical/diagnostic/rehabilitation services. Allow tax incentives for build and supply of same.

Partner with the private sector as they are established and are currently used as a safety valve for waiting lists. The NTPF is the main body charged with purchase of care packages for public patients in the private sector and as such could easily be used as the payer for bundled care in both sectors. Their remit crosses through the 'fair deal' initiative into the rehabilitation and nursing home care domain.

-Incentivise staff with flexible working contracts, safe modern environments and retain them with educational opportunities as well as continued professional advancement.

Salary cutbacks need to be reversed and fairness needs to be returned to 'new entrants' across the board. Paramedical staff as well as consultant contracts need to be made more flexible. I will expand upon this later.

-Each medical unit (however small) should have an affiliation with and a role in a higher level educational institution both clinical and management.

This allows development of all practices within the sector. The academic partnerships of the established trusts is a step forward. Better affiliations need to be fostered between healthcare managers/administrative staff and the management academic institutions. This allows a huge resource to third level bodies as well as creating a reciprocal arrangement for educational opportunities as well as research.

- Encourage and fund assisted living at home for elderly and people with disabilities

People do better at home, the ICGP would support this as it devolves patients from nursing homes. Thought needs to be given to assisted living developments with tax incentives. It would allow investment and would free up housing stock nationally.

- Improve ratios of GP's and consultants to international norms per capita.

All medical representative bodies would support this, IHCA, ICGP, NAGP, IMO etc..

We have some of the poorest ratios across the OECD nations. Rural General Practice is on its knees and needs urgent attention.

-To begin with straight forward simple packages of treatments that can be costed and executed with little change within the public sector system.

-To allow innovation and change to occur in systems without blame or repercussions for unexpected results.

- What are the key challenges, in your view, to achieving a "universal single tier health service, where patients are treated based on health need, rather than ability to pay"?

-Addressing the current fragmented delivery of care.

-Geographical and parochial agendas

-Public and media opinion

-Poor data on current activity

-Legislative changes required to create trusts between voluntary and state hospitals

-Deciding on methodology of finances, to build or to buy services? To allow trusts to collect as PPO's or HMO's? To allow patients to choose and let the payments follow the patients as opposed to assigning payments in Trusts?

-Single payer or multiple payers

-Regulation and penalties for poor service

-To decide on set packages or bundles of care or to allow volume and outcomes dictate bundled payments.

-Staff engagement in change.

-Medical professional agendas

- Professional body tribalism

-Nursing and paramedical agendas

-Trade union cooperation

-Legal agendas, indemnity and legislation.

-Payment system whether through taxation, co-payment, obligatory insurance.

-Insurance providers resistance to a single payer system, and private health insurance schemes currently on offer being used as supplementary cover to state/Trust policies.

-Community rating and whether insurance companies will continue to honour same as well as "cherry picking" patients based on risk stratification.

- What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?

-Public health initiatives, medical, social, psychiatric, community.

-Independent living should be supported within communities.

-Vulnerable patients should be prioritised, best practise tariffs should be utilised to insure acute hospitals are rewarded for caring for agreed medical conditions to international standards.(NHS best practice tariffs and outcomes)

Step down rehabilitation and the Nursing home sector need to be bolstered, standardised and regulated by "payers'.

Community and home care packages should be included as part of bundled payments for conditions and for treatments.

### **Integrated Primary and Community Care**

- What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?

Experts of proven systems need to be engaged to set an agenda for this. The NHS has already done a lot of the spadework in this regard and there would be no point re-inventing the wheel. (Torboy, NHS ICP)

Other healthcare models need to be engaged and experts need to be recruited onto any panel that drives this change.

The United States and Canada have differing funding models and as such organisations such as Kaiser Permanente should be engaged for expertise.

International panels have a better sense of objectivity and have the experience. On a local level General Practitioners need to be incentivised to be involved in the management of acute hospitals. They need to be involved in the senior management levels on hospital management teams. There should be clinical leads in each GP catchment area that refer to hospitals. There must be a sessional commitment allocated by the Trusts to successful GP's for this initiative.

Similarly community care and managers of institutions and networks need to integrate into trust management structures as well as hospital boards.

Again secondary care ( assuming this is community based in medical centres rather than hospitals) needs to have a seat at the table on trusts senior management committees.

- What are the key barriers to achieving this, and how might they be addressed?

Change management.

This all depends on leadership.

- **In your experience**, what are the key roadblocks you encounter in your particular area of the health service?

From my own perspective as a healthcare professional in the public sector for the past 20 years in Ireland and the United States in the specialty of Trauma and Orthopaedics.

Acute Services/ Trauma

Step down facilities

Rehabilitation beds

Availability of diagnostics in the primary care sector

Shortfall in acute beds (however if length of stay efficiencies and step down beds are realised we could do more with less)

Staff shortages courtesy of recruitment embargo and fiscal constraint

Poor collection of real time data and analysis of same

Performance and efficiency are not rewarded.

Enhanced adoption of virtual clinics and telemedicine in spinal and fracture management.

Patients and primary carers not fully informed of systems in place.

Poor ratios of consultant to population.

- How would you ensure buy-in from health care professionals to progress towards an integrated health care model?

- National interest
- Lift embargo on recruitment
- Incentivize staff as mentioned above : education etc.
- Reverse fiscal initiatives introduced, new entrants salaries etc.
- Restore ratios
- Support innovation

- Are there any examples of best practice that the Committee should consider? Please refer to any evidence you have to support this.

Hip/knee money follows the patient HSE

**[https://www.hse.ie/eng/about/Who/clinical/natclinprog/orthopaedicsprogramme/Model of Care.pdf](https://www.hse.ie/eng/about/Who/clinical/natclinprog/orthopaedicsprogramme/Model%20of%20Care.pdf)**

Neck of femur best practice tariff NHS,

**<https://www.gov.uk/government/news/update-to-best-practice-tariffs>**

Virtual fracture clinics, Glasgow NHS

**[www.fractureclinicredesign.org/](http://www.fractureclinicredesign.org/)**

Kaiser Permanente Electronic data and medical records.

**<https://share.kaiserpermanente.org/total-health/connectivity/>**

Musculo skeletal physiotherapy triage initiative HSE

**[https://www.hse.ie/eng/about/Who/clinical/natclinprog/orthopaedicsprogramme/Model of Care.pdf](https://www.hse.ie/eng/about/Who/clinical/natclinprog/orthopaedicsprogramme/Model%20of%20Care.pdf)**

Integrated care model, Torbay NHS.

**<http://www.kingsfund.org.uk/publications/integrating-health-and-social-care-torbay>**

### **Funding Model**

- Do you have any views on which health service funding model would be best suited to Ireland?

Perhaps a mixture of systems tailored to each Trust or for each section of healthcare.

Single payer allows economies of scale and better bargaining power to halt spiralling costs as per USA.

Set bundles that are easily patrolled and then roll out MFTP in these spheres first.

Acute and rehabilitation services are costly and as such need to be protected to insure hospitals and facilities maintain standards.

Either ends of the spectrum i.e. acute healthcare and rehabilitation elderly care are prone to exploitation in the MFTP and therefore need to be closely monitored.

- Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating

**Purchaser:** Government purchaser via NTPF initially.

**Provider:** Trusts, PCCC, GP, Medical facilities, Private Hospitals

- What are the main entitlements that patients will be provided under your funding model?

**Choice of venue within trust, choice of facility attended.**

- Please provide examples of best practice, or estimated costs of such models if available. I would leave this to the healthcare economists.

**Specific Issues:**

### **SDU/NTPF**

The NTPF should be continued as a value for money exercise and to encourage a third funding stream (public & insurance being the others). This allows a fusion of public private mix and encourages competition in any “fee per item” model that is envisaged. It also allows government to have some control in private costings within the private sector. It also could potentially realise cost savings as the cost of elective work should fall with greater demand.

### **HIQA**

HIQA, the national quality assurance mechanism should be rolled out to ALL healthcare facilities that are recipients of any type of healthcare funding. This insures that standards of healthcare are uniform and regulated. The private sector for instance are currently not policed by HIQA and as such may operate under other non-national accreditation systems or not at all. HIQA are ideally placed to provide guidelines and proper internationally recognised standards as well as outcomes. They should have a roll in any planned reform. Perhaps to insure high standards of care a system similar to the NICE guidelines in the UK should be adapted in Ireland to provide evidence based guidelines to medical practices.

<https://www.nice.org.uk/>

### **Private insurance sector**

The insurance industry continues to grow yet patients are still bewildered by the number and costings of policies on offer. The industry is an integral part of the delivery of healthcare in Ireland. There have been many new insurance providers entering into the sector in recent years which is perhaps an indication of growing confidence in the sector. New entrants are welcome as it fosters competition. With the evolution of universal healthcare a system of tax allowances should be introduced to offer those on lower incomes the opportunity to avail of health insurance at reduced rates. A co-pay system popularised by HMO/PPO type insurances in the United States is creeping into the current system.

### **Professional indemnity**

Medical indemnity, healthcare workers need to be indemnified against litigation. The fundamental legal system pertaining to this needs to be changed to mirror that of other

small nations, New Zealand for instance. The State Claims Agency is currently charged with indemnifying the healthcare public sector and although there have been calls for them to assist in the indemnification of private healthcare workers all parties seem to be reticent with engagement and costings. Private medical practitioners are as competent as public ones and as such considering the shortage of the latter private consultants should be approached to address the work shortfall in public sector consultants. A pro-rata insurance system could then be implemented where the private consultants indemnity is borne by both indemnifiers. Also if HIQA were regulating practices across private facilities it would allow the SCA better governance of indemnification.

### **Consultants contract**

Flexibility is required as in the UK/NHS. There needs to be a fluid capability for consultants to move between public/private sector work depending upon demand. The working weeks of consultants needs to be policed and regulated closely with penalties and withdrawal of access for infringements. An alternative is to set a base rate salary for sessional commitments and call and to allow a “fee per item” system as a supplement to this base salary. It is impossible to gauge a fee per item in some disciplines such as medicine and psychiatry. This may involve a reduction in private insurance fees payable to consultants, however perhaps hospitals and units are paid a set fee for a ‘bundle of care’ and the unit then decides payments to consultants.

### **Trade Unions**

The trade unions need to accept fluidity and flexibility in contracts. Everyone is entitled to fairness and pay scale equity. The disparities in pay across the healthcare sector must be corrected.

### **Experimentation**

Healthcare is a rapidly changing landscape. As with all business and science the key is that stakeholders are willing to try something different. Governing authorities must be willing to trial new technologies and strategies. Patient care must never be at risk but testing out pilot studies should be encouraged with proper initial due-diligence. Failure must be expected and should serve as a learning experience as opposed to a media showcase as has been the case in the past.

Eoin Sheehan,  
Coniker,  
Durrrow,  
Tullamore  
Co. Offaly  
Email: [eoinsheehan@aol.com](mailto:eoinsheehan@aol.com)

## Dr. Brian Turner, School of Economics, UCC

- While the Irish healthcare system has a number of well-publicised flaws, it also has a number of positive points, and recognition should be given to these. In particular, it needs to be acknowledged that the Irish system is under-resourced in terms of the number of doctors and hospital beds in the system.
- The goal of a universal single-tier health system needs to be carefully defined and realistic. It will not be possible (and may not be desirable) for all services to be covered in all settings, and the existence of a private health insurance system and a private hospital system needs to be taken into account in any redesign of the Irish health system.
- Two possible areas for focus are reserving the public hospital system for use by public patients only – so privately insured patients do not get faster access, although they may be permitted to use their insurance to purchase superior accommodation in public hospitals or they may opt to be treated in private hospitals – and extending free-at-the-point-of-use GP care to the entire population. However, both of these measures would require significant additional resources and contract renegotiations. Extending access to GPs without fees should prioritise those on lower incomes rather than particular age groups.
- In order to maintain a progressive financing mechanism, taxation or social health insurance should be used. In the absence of any strong evidence that a move to social health insurance would bring significant advantages, the current tax financed system should be maintained, as a change in the funding mechanism would entail significant costs in terms of time and resources. Whichever funding mechanism is used however, a single purchaser of care for the public health system should be retained. Careful consideration also needs to be given to incentives created by any redesign of the system.
- A national forum should be established to bring together the main stakeholders in the health system.

The Irish health system currently demonstrates a number of shortcomings, particularly in relation to over-crowding in hospital A&E departments and long waiting lists for public hospital treatment, as acknowledged by the Terms of Reference of the Committee. However, it should be noted that the system also has its positives, and these should be acknowledged.

For example, life expectancy at birth in Ireland, at 81.1 years, is higher than the OECD average of 80.5 years. Meanwhile, perceived states of health in Ireland are among the highest in the OECD, with 82 percent reporting their health as good or very good, the fifth highest proportion out of 33 countries in the survey (OECD, 2015).

Furthermore, although Ireland is ranked mid-table in comparisons of European health systems, having lost a number of places as a result of the discontinuation by the survey co-

ordinators of the use of official waiting time statistics in favour of responses from patient organisations, its score on the Outcomes sub-discipline is joint 10<sup>th</sup> out of the 35 countries in the comparison. It also scores relatively highly (joint 8<sup>th</sup> position) on Prevention and on Pharmaceuticals (joint 1<sup>st</sup>). The sub-discipline of the ranking in which Ireland particularly struggles is Accessibility, where it has the joint lowest score (Health Consumer Powerhouse, 2016).

One issue that needs to be acknowledged is that Ireland's health system is under-resourced in some areas. OECD figures show that Ireland has 2.7 doctors per 1,000 population compared with an OECD average of 3.3 (and a particular shortage of specialists), and 2.8 hospital beds per 1,000 population compared with an OECD average of 4.8 (OECD, 2015). In order to reach the OECD averages, we would need an additional 2,800 doctors and over 9,000 additional hospital beds.

By contrast, we currently have approximately 15,000 acute hospital beds, around 3,000 (or one-sixth) fewer than in 1980, despite a population increase of around one-third, and an increase in the over-65 population of around two-thirds, over the same time (CSO, 2016b; HSE, 2007; Wren, 2003). It would appear that the Irish health system never fully recovered from the cutbacks of the late 1980s and early 1990s.

In this context, it is interesting to note that, contrary to the assertion in the Committee's Terms of Reference that the Irish health system displays "poor outcomes relative to cost", a recent study showed that, taking health spending per capita, number of hospital beds per 1,000 population and number of doctors per 1,000 population as inputs, and life expectancy at birth and infant mortality rates as outputs, Ireland was one of 11 OECD health systems found to be technically efficient (Recai Cetin & Bahce, 2016).

This suggests that outcomes are quite good given the resource shortages. It should also be borne in mind that, between 2009 and 2014, the HSE's budget and workforce were cut significantly, yet it managed to maintain service levels in many areas, particularly in terms of hospital treatment (HSE, 2010, 2015).

### **Universal Healthcare**

The first task that the Committee should address is to define what is meant by universal healthcare. The Committee's Terms of Reference refer to "the need to establish a universal single tier service where patients are treated on the basis of health need rather than on ability to pay." However, it will not be possible to have such a system across the entire population for all health services; firstly because it would be prohibitively expensive for the State to provide this, and secondly because a private health insurance market and private hospital sector already exist and will therefore form part of the Irish health system into the future. Indeed, voluntary health insurance is a common feature in European health systems, so it is hard to find an example of an entirely single-tier system in Europe (Sagan & Thomson, 2016a, 2016b).

Therefore, the scope of such a system and the services to be included therein, must be specified. For example, a single-tier system in public hospitals for medically necessary (but not, for example, cosmetic) treatment might be a more achievable goal. Similarly, free-at-

the-point-of-use GP care for all might be achievable. However, these targets would require significant investment in resources, as discussed further below.

Ireland is not unusual in having a mixture of public and private funding and delivery of healthcare services. However, where it is unique is in the overlap of the private and public sectors. For example, privately insured patients may be treated in public hospitals, by consultants whose contracts allow for a mix of public and private patients, while public patients have been treated in private hospitals at the expense of the State under the National Treatment Purchase Fund. Furthermore, private health insurance is subsidised by the State, via tax relief on premiums, a lack of full economic costing for beds in public hospitals (Department of Health and Children, 2010), notwithstanding the removal of the bed designation in 2014, and the subsidisation of the training of medical professionals, some of whom go on to work in the private sector.

The 10-year plan for the Irish health system should aim to reduce these overlaps, both in funding and delivery. One potential way to do this would be to ensure that the public hospital system only treats public patients (bearing in mind that those who hold private health insurance are still entitled to treatment as public patients). In this way, those with private health insurance would no longer be able to access public hospitals more quickly than those without, as has previously been the case (CSO, 2002). Under such a scenario, those with private health insurance may be permitted to use such insurance to pay for better accommodation (e.g. a private room) but not to access treatment more quickly. However, privately insured patients would still be free to be treated in private hospitals.

However, this would require a renegotiation of the existing consultant contract, as well as additional State funding for public hospitals. The contract issue reflects the fact that some consultants currently have private practice rights in public hospitals. However, contract renegotiation should not be a barrier to increasing fairness in public hospitals. The funding issue arises from the fact that the accommodation of private patients currently provide a source of income for public hospitals. In 2015, private charges accounted for €321.54m (HSE, 2016). This money would no longer accrue to public hospitals if they were for use by public patients only (although some money may be recouped if insured patients are allowed to pay for superior accommodation). Furthermore, the State would be required to pay for the treatment of more patients than is currently the case, assuming that the capacity currently being utilised by private patients is instead utilised by public patients.

Research has found that lack of confidence in public hospital services or access to such services is a significant driver of demand for private health insurance in Ireland (HIA, 2016). Therefore, if access to the public hospital system is improved for public patients, then this would remove one of the main incentives for people to purchase private health insurance, thereby naturally reducing the two-tier nature of the hospital system.

In terms of widening the scope of free-at-the-point-of-use GP care to the entire population, it should firstly be noted that this will almost certainly result in greater numbers of visits to GPs, which will in turn require significant additional numbers of GPs if the current situation whereby appointments are usually received on the day of contact or the following day is to be maintained. In this regard, it should be noted that, in 2013, only 52% of adults in the UK, where GP services are free at the point of use, were able to get same day or next day

appointments when sick (Mossialos et al, 2016). It should also be borne in mind that an extension of GP care without fees would require contract renegotiations with GPs.

Furthermore, the current policy of expanding access without fees to GPs by age-group should be reconsidered. GP Visit Cards are not designed to improve access to GPs *per se*, as anyone can access a GP within a reasonable time-frame. Instead, they are designed to remove the financial barrier to accessing GPs, which has been shown to lead to significant numbers of people putting off seeing a GP on cost grounds (O'Reilly et al, 2007).

The people who are more likely to face a financial barrier to accessing a GP are those who are on low incomes and (at least some of) those who are likely to visit a GP more frequently. In granting GP Visit Cards to those aged under 6 and those aged 70 or over, most of the latter category has been covered. The former category – those on low incomes – should therefore be the next priority. During the press conference on the health elements of Budget 2016, the then Minister Varadkar acknowledged that extending GP Visit Cards to those aged 6-11 (subject to successful negotiation of a new GP contract) would not cost a significant amount of money because the capitation rates payable to GPs would be lower, reflecting the fact that children in that age group visit GPs the least<sup>250</sup>. Rather than extend GP Visit Cards to further cohorts who do not visit GPs often, priority should be given to raising the income threshold for GP Visit Cards.

### **Funding Model**

The main funding mechanisms for healthcare are taxation, social health insurance (SHI), private health insurance (PHI), out-of-pocket payments (OOP) and medical savings accounts. Ireland's health system is predominately taxation financed (69%), with significant contributions from private health insurance (13%) and out-of-pocket payments (15%) (CSO, 2015, 2016a).

International evidence suggests that taxation is the most progressive funding source, with SHI also being progressive, while PHI and OOP are both regressive funding sources (Evans, 2002). Progressive in this context means that those on higher incomes pay a higher proportion of their income for health services, while regressive means that those on lower incomes pay a higher proportion of their income. Therefore, a single-tier health system in Ireland would need to be funded via either taxation or social health insurance if it is to be progressive.

Surveys of European health systems show that systems financed by SHI tend to be ranked higher than those financed by taxation, although it is noted that smaller population systems with tax financing tend to do better than larger ones (Health Consumer Powerhouse, 2016). Given that Ireland has a relatively small population, this suggests that taxation financing has the potential to deliver a health system that well serves the needs of patients. However, it should also be noted that other international comparisons have shown the UK health system (which is tax financed) to have the highest rank (Davis et al, 2014).

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<sup>250</sup> A recording of this press conference can be found at [http://www.merrionstreet.ie/en/News-Room/News/Budget\\_2016.html](http://www.merrionstreet.ie/en/News-Room/News/Budget_2016.html).

Furthermore, given that Ireland's health system has developed as a predominately taxation financed one, changing to a social health insurance based system would involve significant investment in time and resources that may not necessarily lead to better outcomes. In this regard, Wagstaff (2009) found that countries that switched from taxation financing to SHI financing increased health spending per capita by 3-4% without significant impact on what he calls amenable mortality, except for breast cancer, on which SHI systems tend to perform worse than tax financed systems.

One of the most common criticisms of taxation financed systems is a lack of transparency, particularly if health services are funded from general taxation. A ring-fenced health tax is sometimes proposed to improve transparency (Evans, 2002). Social health insurance, by comparison, is predominately an employment-based funding mechanism, which leads to challenges in terms of providing funding for those who are not in employment (Normand & Busse, 2002).

In the absence of any clear evidence that a change from taxation to SHI funding would provide significant advantages, it would be more advisable to focus on the allocation of funding and the delivery of healthcare rather than the funding mechanism.

Whether taxation or SHI is chosen as the preferred funding mechanism, it would be important to ensure that there remains a single purchaser of care for the public health system. A move to multiple purchasers would inherently create incentives for competing purchasers to engage in risk selection, which would be detrimental to consumers, particularly those who are considered high-risk, i.e. older and sicker consumers. Even if a risk equalisation scheme were implemented, such incentives would not be entirely eliminated, as such schemes do not perfectly compensate for risk differentials (van de Ven et al, 2016), and research suggests that the current Irish risk equalisation scheme is no different (Keegan et al, forthcoming).

Any redesign of the system, either from the point of view of funding or allocation of funds, should involve careful consideration of any incentives created for various stakeholders. An example of such incentives can be seen in the current situation in public hospitals, whereby both hospitals and consultants are paid on a fixed basis for public patients but on a fee-for-service basis for private patients (for those consultants who have private practice entitlements under their contracts). This gives those hospitals and consultants an incentive to treat more private patients rather than public patients. Even when the money-follows-the-patient system is rolled out for public patients in public hospitals, if the remuneration levels for public patients are lower than for private patients, incentives may still remain to prioritise the latter group over the former.

Indeed, although the introduction of charges for privately insured patients in all beds in public hospitals in 2014 was designed to ensure that hospitals were fairly remunerated for the accommodation of private patients, and it would appear that this has helped to reduce the State subsidisation of private health insurance without causing significant damage to the market (Turner, 2015), an unintended consequence is that there is now a stronger incentive for public hospitals to treat more private patients as they will now be paid for such patients irrespective of what type of bed they occupy. This exemplifies the importance of giving

careful consideration to the design of any remuneration system and the incentives thereby created.

### **Model of Care**

The proposed move from the current model of care towards a more integrated model will require investment in primary and continuing care resources before patients can be transferred out of hospital-based care. Therefore, cognizance should be taken of the fact that any savings from reducing the amount of hospital-based care will only accrue after the additional investment in primary care has been made, and consequently the health budget will need to be increased in the short- to medium-term.

In terms of ensuring buy-in from stakeholders, a national forum should be established to bring together stakeholders (including representatives of patients, providers and payers) to facilitate transparent discussions on the best way forward for the Irish health system.

### **Recommendations**

- The meaning, and scope, of a universal single-tier health system needs to be clarified and a realistic definition used in order to set achievable targets.
- One possible such meaning is to have a single-tier public hospital system where privately insured patients cannot get faster access to treatment, but may use their insurance to pay for superior accommodation.
- Another is the extension to free-at-the-point-of-use GP care, but this should initially target those on lower incomes.
- Adequate resources need to be put in place to ensure that capacity is sufficient to deliver the health system that is envisaged.
- The current tax-financed model should be maintained rather than moving to social health insurance unless there is strong evidence that such a move would deliver significant improvements.
- A single purchaser of healthcare in the public system should be maintained.
- Careful consideration should be given to any incentives that may be created in any redesign of the Irish health system.
- A national forum should be established to bring together relevant stakeholders so that buy-in can be encouraged.

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## Dublin Academic Medical Centre (DAMC)

### Introduction

Health system organisation is complex and globally diverse. There is much to learn from the experience and status of systems in other jurisdictions. However, it is naïve to believe that the model employed in one country can be transposed into another easily. Health care solutions must be adapted to meet local conditions.

This paper is aimed at outlining perspectives on a number of key areas that the Future of Healthcare Committee is considering as part of its work in mapping out a blueprint for the health system in Ireland over the next decade.

### Organisation and Hospital Groups

To successfully design health systems at a macro level, there must be clarity on the underlying principles and beliefs around the nature of health, excellent knowledge of and exposure to the domain and comprehensive understanding of the inherent characteristics of complex interactive organisations. A fundamental requirement is that the outcome is complete and internally consistent.

By reference to these considerations, the Irish experience has been patchy at best. There is also a “reform fatigue” that has set into the health system as new political dispensations have attempted to bring their own vision to the health portfolio. Therefore, as the Committee looks towards the next decade in healthcare, to achieve completeness and consistency, there is an absolute need to appropriately recognise, value and provide for the existence of and dependence on a large independent sector – statutory, voluntary and private – and adequately and meaningfully encompass it in national organisation constructs.

In this respect, the debate around Hospital Groups and their retention or otherwise lacks domain understanding and context. Stand-alone acute hospitals as they exist in the Irish system are not viable – even in the case of our largest units. This position pertains, and will continue to do so, even in instances where they are part of some overarching authority within which they hold effective stand-alone functioning status. The case for constitutionally incorporating hospitals into Groups would accordingly seem irrefutable. The issue is thus not one of whether or not acute hospitals should be formed into constitutionally incorporated Groups. Rather it is what are the appropriate groupings and how should they fit into a comprehensive national macro organisation construct.

### Integration

The Committee’s recognition of the importance of integration to future health care is welcome. The challenge however, as applies in almost all health systems worldwide, is not this recognition, but securing a shared understanding of what integration means and how to achieve it.

Experience suggests that creating overarching structures with an integrating remit around existing institutions misunderstands the domain and its dynamic and simply does not work in this respect; for example, in the Irish case Health Boards / Regional Directors of Operations. Also, the homogeneous one size fits all solution approach is unlikely to be successful; that is, what might work in Donegal most likely will not fit Dublin and vice versa.

A number of characteristics common to contemporary visionary integration initiatives are however now becoming discernible. The suggested most significant of these are set out below:

- **Population Focus**

Health system focus requires to centre on keeping the population healthy – not just provision of healthcare. Related organisational provisions increasingly see the need to promote and incentivise institutional integration around this provision.

- **Institutional Relationships** Converging relationships between primary and acute care are by far the most critical to system integration and are necessary to its achievement. Initiatives such as creation of Integrated Health Campuses which encompass acute care, primary/urgent care centres, re-enablement facilities and strong links to continuing and home care are emerging as the exemplars in integration. The concept of Accountable Care Organisations which are made responsible for the health of communities or population centres is also gaining traction as an integrating force for healthcare institutions. As an example, the Ireland East Hospital Group, has recognised the critical nature of structured acute/primary care relationships. It has established an Integration department to be headed by a Director of Integration who is a practising general practitioner. The Director will be a core member of the group executive team.

- **Reimbursement**

Reimbursement and how it is conceived and structured is emerging as a key driver of integration. Systems which reimburse on an institution basis regardless of payment model (block grant, activity based etc.) do not promote or incentivise integration and are likely in certain circumstances to thwart it. Systems which reimburse around communities or population centres, usually on a capitation basis, are increasingly considered more likely to result in the delivery institutions uniting around and ensuring right place/right time access for system users.

- **Information Systems**

Comprehensively developed information systems which are built around users/patients and accessible to health professionals across the care continuum are now universally acknowledged as essential to facilitate integration.

## **Academic Medical/Health Science Centres**

Academic Medical/Health Science Centres are associations of large scale health service and academic institutions formally constituted at high levels of integrated partnership. They are generally seen to deliver significantly enhanced patient value in terms of range and scope of services provided at a scale which allows for extensive niche and sub-specialisation and highest levels of safety and quality. They are also seen to attract and retain highest level service and academic health professionals, are major centres for discovery and innovation in patient diagnosis, treatment and care, and provide much speedier access for patients to new and emergent treatments and technologies. They also add significant socio economic value at both local, community, and national levels.

Ireland is capable of sustaining at least one and possibly more large scale Academic Medical/Health Sciences Centres. Enabling structures which would facilitate development of such centres already exist at varying levels of maturity in a number of Hospital Groups working in conjunction with their respective Academic partners. It would be strongly urged that going forward, formal provision be made to establish, recognise and support such a centre(s) which would add considerable value and status to the system.

### **Conclusion:**

As stated at the outset, health systems are complex and diverse. The work of the Committee in setting out a 10 year vision for Irish healthcare is lauded, and much needed. The move away from reform of the health service in tandem with electoral cycles is very welcome. This paper endeavours to underline the critical importance of ensuring that health systems are integrated in order to deliver the best possible service to communities and population centres. It also views the organisation of acute and primary care as vital and cautions against attempting to revert to stand-alone hospitals.

Finally, it singles out Academic Medical/Health Science Centres as an exemplar of integrated partnership, which bring significant benefits to patients, healthcare professionals and the system in general.

**Thomas Lynch**  
**Chairman**  
**Dublin Academic Medical Centre (DAMC) and**  
**Ireland East Hospital Group (IEHG)**

[Dublin Academic Medical Centre](#)

## Dublin Dental Hospital

People with disabilities have more untreated oral disease, missing teeth and difficulty obtaining oral health care than the general population in Ireland. Contributing factors include a lack of resources for dental services (1), limited access to General Anaesthesia (2), a lack of appropriately designed service models (3) and inconsistent and variable targeting of “Special Needs” groups across primary dental care services (4). Health Policy in Ireland has long recognized that there is a need to provide equitable health care “to disabled and institutionalized” (5). An updated, coherent National oral health strategy is currently in development (6). This new policy should lead to evidence based service models for people with disabilities and vulnerable groups (4, 6).

The development of future healthcare policy gives an excellent opportunity to design and fund a service that will deliver equitable healthcare for people with disabilities in Ireland.

The Irish Society for Disability and Oral Health (ISDH) represents dental and other healthcare professionals in advocating for the oral health of people with disabilities. The ISDH advocates for the development of a strategy that delivers a range of accessible and available services that meet individual needs and lead to positive experience and optimal outcomes.

This will involve the development of Managed Care Networks across services and the lifespan. These networks require improved processes of care, provision of a diverse and skilled workforce, who have access to appropriate training and the development of integrated care pathways. The ISDH suggest incentivisation of preventive and restorative healthcare for people with disabilities by recognizing the realities of providing care to the spectrum of people with disabilities and direct payment by people with disabilities.

**The key recommendations of the Society are summarized in Box 1 below.**

1. When developing policy, all government policies need to be underpinned by principles of equity and health proofed, acknowledging the changing demography of the Irish population, the increasing advocacy for patient-centered care, shared decision-making and the right to cost-effective health care.
2. People with disabilities should be involved in the design and evaluation of dental services, which they use.
3. A national oral health service model with local flexibility should be developed that ensures equitable outcomes and access to a range of appropriate dental services for people with disabilities, informed by an Oral Health Needs Assessment.
4. Develop a strategy to embed integrated primary and secondary care into policy-making and service development processes, in order to place disability onto oral health agendas and oral health onto disability agendas.
5. A range of posts should be developed to create a workforce to deliver managed care networks for people with disabilities in Ireland and appropriate training in Special Care Dentistry should be available for the whole dental team.
6. Ensure that all people with a disability are offered early oral health assessment, whatever their age, as part of the wider healthcare team approach, and provided with a customized care plan that is implemented and reviewed.
7. Services should be evaluated to measure effectiveness, efficiency and patient experience

***Box 1. Key recommendations for action***

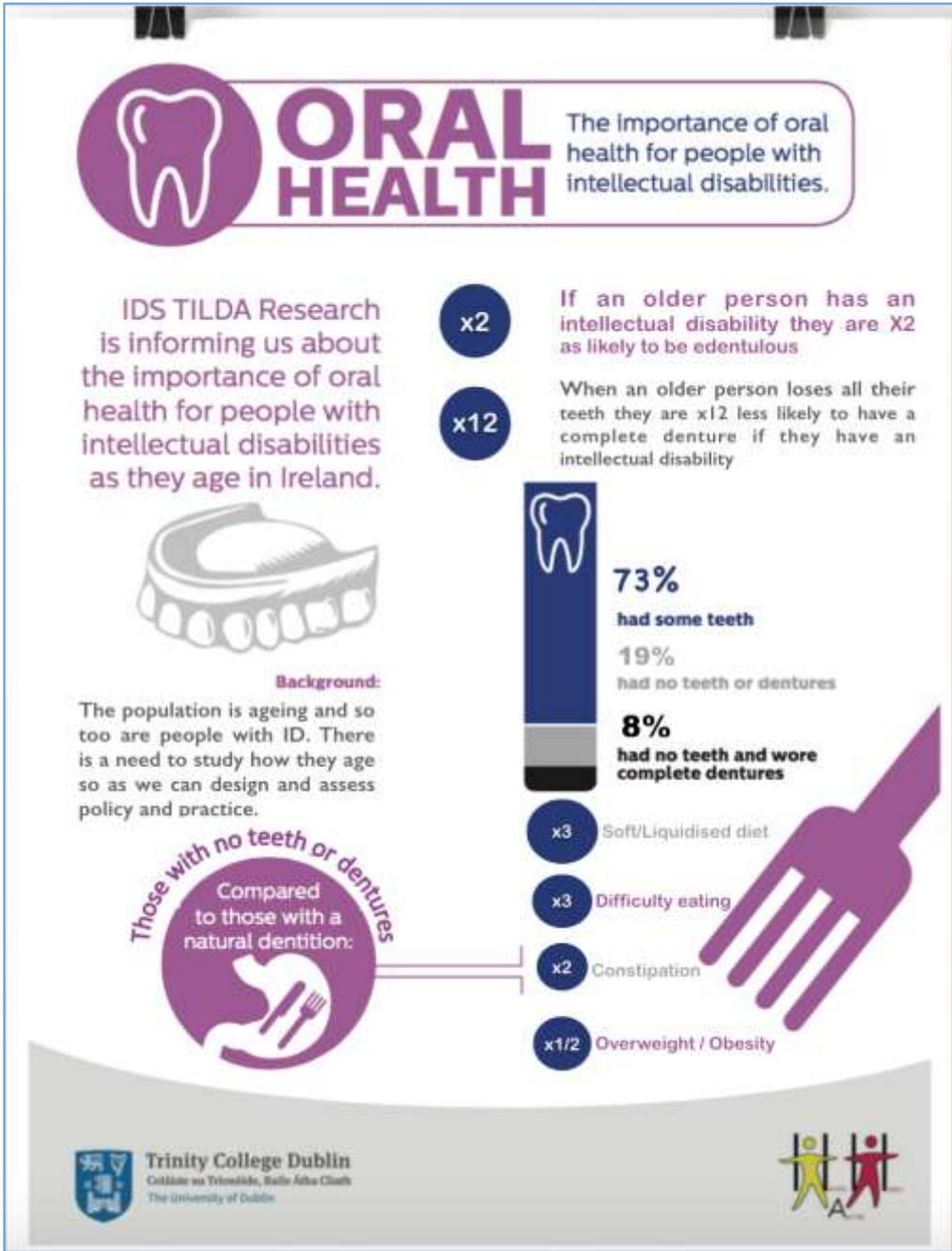
**Oral Health is important-** Poor oral health can affect how we look, feel about ourselves and enjoy our lives, grow and socialize. Oral health is so integral to general health that it is impossible to be healthy without a healthy mouth. The implications of oral disease on health can be demonstrated in the relationship between gum disease and adverse pregnancy outcomes, diabetes, cardiovascular events and stroke in susceptible subjects (7). Particularly in people with disabilities, poor oral hygiene can lead to respiratory disease, a leading cause of mortality (8). In contrast, oral health enables communication, nutrition, confidence and self esteem, among people with disabilities, promoting their participation and contribution (3).

**Oral disease is prevalent among people with disabilities** - In Ireland, the oral health of people with disabilities is poorer than that of the general public. For example, people with Intellectual Disabilities (ID) are seven times more likely to have moderate or severe gum disease than the general public(1, 9). Oral health services result in poorer outcomes for

those with disabilities because they are more likely to have their decayed teeth untreated or extracted, whereas people without ID are more likely to have these treated with fillings (1, 9). Over the lifespan, the cumulative effect of the failure to prevent and manage oral disease is total tooth loss and oral disability (10). This is twice as prevalent amongst those with disabilities than the general population. Box 2 summarises evidence from the IDS-TILDA study, which explored total tooth loss amongst older adults with ID in Ireland, based on research presented at ISDH conference, Galway, June 2016.

**Oral health services may inhibit outcomes and experience** - It is perhaps surprising that people with ID, with such poor outcomes, are found to access dental services far more regularly than those without ID, as one would assume a positive impact from frequent dental service use (11). This brings into question the benefits from accessing current services frequently. In contrast, appropriate dental care is often limited for people with disabilities. Unpublished research undertaken by the ISDH found long waiting lists for General Anaesthetic (GA) facilities nationally (Unpublished data, Irish Society of Disability and Oral Health, 2012). Reliance on GA services leads to increased waiting times, cost and treatment need (12, 13). Other barriers that contribute to access issues for people with disabilities are complex and lie mainly in addition to, rather than resulting from, the person's disability. Many access issues arise from within the structures and processes of oral health services, as they have been delivered in Ireland (1, 14-16). For example, the Public Dental Service, which is tasked with providing oral healthcare to people with disabilities (5) does so in an ad hoc manner. The proportion of Public Dental Service output, received by patients considered as having "Special Needs" varies from just 2% of overall output to 20% (4). This level of variation raises questions about the extent to which there is equitable access to services across Ireland.

***Box 2. Infographic exploring total tooth loss from the IDS-TILDA study.***



The following sections outline the issues the ISDH feel are integral to improving Future Health Care to ensure that people with disabilities achieve equitable oral health. They are organized by heading outlined by the Committee: 1 Strategy; 2 Integrated Primary and Community Care and 3 Funding Model.

**Key priorities for inclusion in a ten year plan for the health service**

It is crucial to identify priorities for oral health services for people with disabilities in Ireland. This will let those who plan, deliver, and use services in Ireland communicate the aims of services and also measure their outcomes. In Ireland, there is research, which has specifically looked at this crucial first step in healthcare delivery. A project called Project SMILE Ireland used an inclusive

emancipatory approach to agree priorities for oral health services for people with disabilities in Ireland. A national project identified and ranked a list of priorities for oral health services in Ireland (17). This evidence should be included with further consultation to achieve a National vision for these services. Box 2 outlines the priorities agreed by oral healthcare planners, providers and service users recently.

**Box 3. Priorities for oral health services for people with disabilities in Ireland**

Final Rank	Statement
1	Oral health services should raise awareness of oral health among people with disabilities, their families, carers and non-dental, health professionals
2	Oral health services should enable optimal outcomes for people with disabilities that meet individual need
3	Oral health services should be structured to enable the targeting of specific groups and deliver care based on individual need
4	Oral health services should be available and accessible
5	Oral health services should be designed using defined care pathways.
6	Oral health services should be acceptable to people with disabilities
7	Disability related training should be available to Dental Healthcare Professionals and students, appropriate to their need
8	Oral health training should be available for people, their families, carers and health professionals
9	Oral health services should be quality assured
10	Oral health services should be structured to enable frequency of care, appropriate to individual need
11	A range of Oral health services including emergency, preventive, primary and secondary care, should be available as appropriate to individual need
12	Oral healthcare should be available within an acceptable timeframe
13	Oral health services should be well resourced
14	Information and documentation should be accessible, and available in suitable formats where appropriate
15	Care pathways should be developed that allow people to choose Oral healthcare settings, appropriate to individual need
16	Oral health services for people with disabilities should be integrated both with general Oral health and non-Oral health services

**Current challenges and actions for future demographics** - The key challenge currently facing oral health services in Ireland for people with disabilities is a lack of a national service model. There is therefore a need to develop a plan to deliver equitable services. This should be developed following a National Oral Health Needs Assessment for people with disabilities. Future challenges and demographic features of Irish people with disabilities that will affect capacity and the actions required to manage these are summarized in Box 4.

**Box 4. Demographic features and actions required**

Feature	Issues	Appropriate policy response
Population with disabilities and r rights	<p>The number of people with disabilities is increasing over time. Currently, between ten and twenty per cent of the Irish population report having a disability and according to the National Disability Authority, this number is growing (18). This parallels a heightened awareness of rights for people with disabilities (Ireland became a signatory of the UN Convention on the Rights of Persons with Disabilities on the 30th March 2007). The growing population of people with disabilities and the growing recognition of their rights to equitable health, mean that there is increasing pressure on the Health Services to provide equitable, quality health care. This is operationalized by part B of the Disability Act (2005).</p>	<p>Increase in capacity to deliver oral health care to people with disabilities.</p> <p>Ensure reasonable accommodation for people with disabilities by ensuring equitable outcome and access to treatment.</p> <p>The National Disability Authority has summarized actions required in this regard, previously. Many of these suggestions are still relevant today (3).</p>
Range of ability	<p>Within the cohort with disabilities, there is a spectrum of need to receive dental care from those with no additional needs and maintain their health, to those who will have massive barriers in maintaining health and accessing services (19). A contemporary definition of people requiring Special Care Dentistry is those with “a condition, disability, or activity restriction that directly or indirectly affects their oral health”. This recognises that individuals with the same medical diagnosis can have a wide spectrum of individual needs in order to receive dental care and achieve equitable oral health. The range of need within this group has implications for the design of care delivery for this group (20).</p>	<p>Build choice and options to a range of appropriate services, so as those who can access mainstream care can avail of this and those requiring secondary and tertiary care can do so accordingly (17). Therefore care networks should be able to deliver a range of care pathways depending on the needs of the individual.</p>
Population ageing	<p>Older adults require additional time and care. Their treatment needs are likely to be complex. The prevalence of multiple and acquired disabilities such as arthritis, diabetes, dementia and Parkinsonism amongst our oldest is set to increase dramatically, leading to increases proportionally, of those living with acquired disabilities (21). The population with developmental disabilities is also ageing (22).</p> <p>Both cohorts are likely to retain their teeth for longer, meaning that oral function is challenged into older age. They may also have complex dental work to maintain and increasingly require more complex supports such as sedation, and general anaesthesia to maintain oral health and function, as they age.</p> <p>On top of this, social factors such as use of Long Term Care (LTC) facilities of the most frail introduce further complication in the delivery of appropriate care.</p>	<p>Oral health services will require a new skills mix, necessary to support this demographic.</p> <p>There will be a need to increase the availability of dentists skilled in the management of older adults (23).</p> <p>There is a need to increase the availability of and skills for dental treatment under sedation and general anaesthesia (3).</p> <p>There is a need to regulate the delivery of dental care to individuals in LTC facilities to ensure equity of care.</p>

**Integrated primary and community care** For the majority of people with disabilities, oral/dental care delivered in the community, alongside their peers, is the preferred option. This is, provided that there is early assessment and access to appropriate services where necessary. For a minority, care within and across secondary or even tertiary clinical services will be required constantly or intermittently, in a shared care model. Similarly, some people will best attend publicly funded services and others may seek private dental care. This range of need means that a suite of care pathways are required constituting preventive care, routine care in both general and public dental services, specialist care and access to supports such as IV sedation and general anaesthetic. Therefore the ISDH recommends that policy leads to development of such integrated care pathways, so as patients can navigate services seamlessly.

**A Model of good practice in integrated primary and community care** Good practice in Special Care Dentistry (SCD) dictates that there is sharing of resources to greatest effect. The concept of managed clinical networks (MCNs) promotes this with mutual sharing of expertise, so that by professionals collaboration, patients receive appropriate care in a timely way (24). Such a network has been in place in Wales since 2012. The membership of this network includes specialist and consultants in in SCD as well as other clinical disciplines, the wider oral healthcare team, managers of services as well as staff from postgraduate education centres and lay people. Such a construct enables sharing across health and other departmental boundaries for more effectual service delivery. Some of the advantages of this approach are listed in Box 5 (25).

***Box 5: Examples of outcomes from Managed Clinical networks in Wales 2012***

1. Review of workforce and services in a geographic area and identification of gaps in service provision
2. Development of dental referral pathways for adults requiring SCD, identifying the roles within the pathways from primary dental care teams through to consultants as well as more specific pathways, for example domiciliary and bariatric care pathways
3. Provision of local and regional information for patients
4. Development of training (and mentoring) of specialists and continuing professional development in SCD for the dental and wider multi-professional team
5. Establishment of MCN webpages and the mapping of information for the public and dental teams

### **Integrated care across the lifespan**

As people with disabilities transition over their lifespan, oral health services should be designed to support people at these transitions. There is good evidence from Ireland that oral/dental disease becomes prevalent after three years of age (26) and that intensive preventive programmes can contain this (27). As vulnerable children transition into adulthood, a purposeful, planned movement to adult-orientated health care systems is required. With a focus on the person, throughout a lifetime, seamless, inter-agency collaboration has the potential to have a cumulative, additive and even multiplicative impact on health outcome in older age (28).

### **Model of funding**

The majority of patients with disabilities receive dental treatment in the primary care setting, with approximately 20% requiring dental treatment under general anaesthesia, in a hospital-setting (1). Primary care dental services are provided either by general dental practitioners working in the Public Dental Service or in private dental practices, subsidized by the DTSS scheme. There are also a proportion of patients with disabilities who receive self-funded private dental care. A number of issues have been identified with current dental service provision in Ireland resulting from funding deficits. Namely these include staff shortages in the public dental services, and the removal of funding for preventive dental treatment within the DTSS framework (29). These issues are likely to have impacted detrimentally on the oral health of patients with disabilities. Additionally, for those patients requiring specialist care, outside the remit of community care, there is an unclear referral pathway in Ireland (30) resulting in inequitable access to tertiary services Nationally (31).

### **Incentivize preventive and restorative treatment with appropriate supports**

Evidence based clinical guidelines state that health promotion and preventive care must be prioritized and services should promote preventive services for health gain, away from curative and clinical services (32). Effective preventive care can potentially save money by avoiding costly medical interventions for dental treatment, such as the use of general anaesthesia (31). Currently under the DTSS system payments for dentists are only available for clinical procedures, not preventive procedures. This means that many people with

disabilities do not receive appropriate preventive dental care, which could prevent oral disease and the need for intervention. In addition, people with disabilities may require behavioural adjuncts, extra time or varying forms of sedation, at specific times or for specific procedures, in order to receive successful dental care. These adjuncts are not covered by current reimbursement schemes.

#### **A tool to weight payments based on complexity rather than diagnosis or item of treatment**

The current extension of the DTSS scheme for individuals with specific medical conditions or disabilities (HSE 2010), whilst increasing the range of care available to a vulnerable group, is based on the medical model of disability. This means that entitlement to care is based on a medical diagnosis, instead of individual need, which can increase the time taken the cost to provide treatment. In the UK context the BDA Case Mix Tool (30) was developed as a commissioning tool. Case mix tools are used throughout medical service planning to take into account the characteristics of patients within a particular setting to predict and distribute resources (33). A case mix model can aid commissioners and providers of dental services for people with disabilities to understand the challenges of caring for this patient group, in order to allocate appropriate funding. Indeed, emerging research has shown the BDA Case Mix Tool to be a reliable measure of cost of treatment for people with disabilities in UK.

#### **Summary**

This document outlines the ISDH position in advocating for people with disabilities to maintain their oral health, function and independence.

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Dr. Caoimhin Mac Giolla Phadraig,  
President of ISDH on behalf of the Irish Society for Disability and Oral Health  
Division of Child and Public Dental Health,  
Dublin Dental University Hospital,  
Lincoln Place,  
Dublin 2.  
Phone 016127337

Email [macgiolla@dental.tcd.ie](mailto:macgiolla@dental.tcd.ie)

## Dublin Neurological Institute Mater Misericordiae Hospital

*Start by doing what is necessary  
Then do what is possible  
And suddenly  
You are doing the impossible.*  
(St Francis of Assisi 1182-1226)

Neurological disorders are common in Ireland. Over 700,000 people have a neurological condition and approximately 44,000 people receive a new diagnosis of a neurological disorder every year. It is known that one in ten people that attend an Accident and Emergency Department have a neurological problem, one in seven admitted to a medical service have a neurological problem, and one in five visits to a General Practitioner have a neurological problem (e.g. headache, dizzy spells, epilepsy, multiple sclerosis, Parkinson's disease, Alzheimer's disease, stroke etc.). Neurological disorders increase with age (e.g. Alzheimer's disease, Parkinson's disease, Stroke etc.) and as the Irish population is ageing there will be an increase to 800,000 people with neurological problems within ten years. Research and innovation have led to many new treatments for neurological disorders that substantially decrease mortality, morbidity and decrease cost to the exchequer for patient care. Therefore we need to meet the challenge in Ireland and provide state of the art therapies in a cost effective manner. Unfortunately neurological disorders have been relatively underfunded in Ireland for many years with some improvement in recent times through the HSE National neurology programme, the national stroke programme and the national epilepsy programme.

The care of patients with neurological problems requires integrated care between the acute hospitals, mental health services, social care, primary care and health and well-being. This will provide a multi-disciplinary approach to the care of patients with these common disorders including Alzheimer's disease, Parkinson's disease, stroke, epilepsy, migraine, acquired brain injury, multiple sclerosis, and others. In acute hospitals close communication among different sub-specialities including clinical neurology, neurosurgery and clinical neurophysiology, neuroradiology, neuropathology, physiotherapy, speech and language therapy, occupational therapy, dietetics, neuropsychology and social services is required. This integrated care is required to deal with the fact that "neurological disorders are one of the greatest threat to public health" (WHO,2006).

The Dublin Neurological Institute at the Mater Misericordiae University Hospital (DNI) is a centre for excellence for the care of patients with neurological disease and a registered charity. We provide a multidisciplinary holistic approach where clinicians, nurses and services allied to medicine strive for excellence to improve standards of care. In Ireland there is a great need for the DNI's innovative service to improve access for diagnosis and appropriate treatments, but also to alleviate the growing pressure on Emergency Departments throughout Ireland by diagnosing and treating patients with acute neurological disorders quickly. Moreover, education and research in clinical neuroscience

are critical to good neurological care nationally. Importantly, the DNI's integrated and collaborative model of care has been incorporated into the HSE Neurology Programme Model of Care by Professor Lynch, National Lead HSE Neurology Programme.

## 2) Recommendations

1. We recommend a substantial expansion of services for patients with neurological disease in Ireland as these disorders are one of the greatest threats to public health (WHO, 2006). Improved neurological care is cost effective as it decreases morbidity and mortality and hence decreases the cost to the exchequer by decreasing disability long-term.
2. Expansion of the neurological services is required across acute hospitals covering mental health service, social care, primary care and health and well-being.
3. Initial expansion should be within the acute hospitals to aid early diagnosis and quick management. Without a diagnosis future planning of care and specific treatments is not possible.
4. Neurology has evolved from a diagnostic specialty to a treatment speciality. Indeed the next ten years will be the era of neurological disease as novel treatments will alleviate symptoms and slow or rest disease. (Thrombolysis for acute stroke, monoclonal antibody therapy for multiple sclerosis)
5. To help fund the expansion of the neurological service a public private partnership model should be adopted as this approach provides value for money ([www.neurologicalinstitute.ie](http://www.neurologicalinstitute.ie))
6. The Dublin Neurological Institute is a charity based at the Mater Hospital which raises funds to expand its service and meet the needs of patients while at the same time working closely with the public hospital. Hence it is a public private partnership that is flexible to provide excellent care.
7. The model of Dublin Neurological Institute can be expanded nationally with development of institutes in different sites of the country evolving into an *Irish Neurological Institute* with multiple neurology units across the country linked by a common web based database to provide demographic data with regard to illness and also potential teaching, research and innovation.
8. The Governance of the Dublin Neurological Institute is excellent with the Clinical Director answering to an independent board. The DNI charity meets all the new charity legislation.
9. The DNI treats patients whether public or private in the same fashion so that the care provided is based on the need rather than the insurance status of the patient. This is appropriate and should be adopted nationally.
10. The Dublin Neurological Institute expansion will improve care of patients with neurological disease in the acute setting. In addition the DNI will be a catalyst to develop education, research, innovation and equitable care of patients around the country.

11. Awareness of the brain and the mind in Ireland needs significant uplift as there is ignorance with regards to how the brain works because of poor education at primary and secondary levels in schools regarding neuroscience. This needs to be addressed.
12. The Dublin Neurological Institute can mature into an *Irish Neurological Institute* to deal with outpatient waiting lists in an efficient flexible fashion so that patients do not wait for an anxious prolonged period of time for a diagnosis and treatment. Neurological treatments can be disease modifying and thus can decrease disability and mortality in the country. The *Irish Neurological Institute* would provide a multi-disciplinary approach to patient care, linking clinical neurology, neurosurgery, neuropathology, neuropsychology, neuroradiology, clinical neurophysiology, physiotherapy, speech and language therapy, occupational therapy, dietetics and speech and social services.

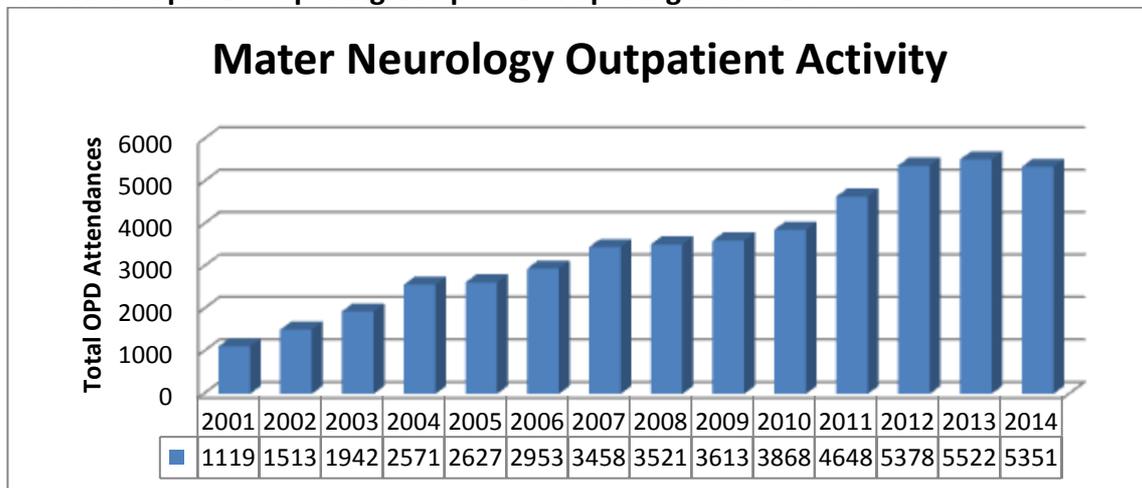
### 3) Submission

How we improve our service to our patients in the community, outpatients, day ward and inpatients is a significant challenge. The National Neurology Programme has improved neurology care by initially increasing the number of consultant neurologists to decrease the prolonged waiting lists for a neurology appointment in Ireland. This approach has been partially successful doubling the number of patients seen in outpatients by 2015 as compared to 2010. However, the number of patients referred increased. It is now recognised that many patients with neurological problems over the years were never seen by a consultant neurologist (a “tip of the iceberg” effect). Subsequently the programme has concentrated on improving both outpatient and inpatient care in acute hospitals linked to the community.

One of the National Neurology Programmes innovative approaches to improve neurology care is the Dublin Neurological Institute ([www.neurologicalinstitute.ie](http://www.neurologicalinstitute.ie)) at the Mater Misericordiae Hospital. This is a public/private partnership providing excellent care. A Mater Georgian building was renovated for the care of patients with neurological problems providing an outpatient day ward and multidisciplinary care for people attending both general clinics and specialty clinics (stroke, epilepsy, Parkinson’s disease and other movement disorders, hypertension, neuropathy neuromuscular disorders, migraine and multiple sclerosis. Furthermore the Dublin Neurological Institute provides a “one stop shop” for patients attending from around Ireland. They are not only seen by a consultant but also by a physiotherapist, speech therapist and other services as required. The DNI is a charity and raises funds through fundraising, philanthropy and other means to improve care of our patients with neurological problems but also to decrease the wait list times for people to be seen. This is done in close partnership with the Mater Misericordiae University Hospital and hence it is an ideal model for public /private partnership.

A Dublin Neurological Institute Patient Satisfaction Survey undertaken in 2012 by Dr.Allan McCarthy showed a 90% satisfaction rate amongst our patients attending neurology clinics here in 57 Eccles St.

**(1)The histogram shows the number of outpatient seen by the Department of Neurology at the MMUH pre DNI opening and post DNI opening in late 2008.**



### DNI Opening



The above graph is indicative of the impact the DNI model has had on broadening access for patients to the neurology service in the wider Mater Campus. Official MMUH yearly attendance summary statistics show a footfall of 3,915 patients attending our DNI service by year ending 2014. This is indicative of the impact this public private partnership has had on wait lists for a Neurologist referred to the Mater Hospital.

**(2) Neurology attendances January to August 2016 – year to date: 2,398**

DNI Consultant Clinic	DNI Nurse Led Clinics	DNI Staff
Headache - 490	Neuro-immunology clinic - 51	Clinical Director
Movement - 492	Family Care support clinic -8	3 Consultant Neurologists
Multiple Sclerosis- 184	Headache Nurse led -3	3 CNM II Neurology
Neurovascular -368	Parkinson’s Nurse led clinic -41	3 CNS Neurology
Hypertension - 45	Epilepsy Nurse led clinic -41	1 Physiotherapist
Neuromuscular - 66	Nurse Relaxation clinic -18	2 Research SpR
Study Clinic - 23	Physiotherapy clinic - 143	4 Administrators
Young Onset Stroke-35		1 Research Assistant
DBS -47		1 Porter / Security

The Dublin Neurological Statistics show that from January to August 2016 alone there was footfall of 2,398 patients attending a neurology clinic within our service. (MMUH monthly statistics). These multidisciplinary clinics include Nurse led clinics, Consultant Led Clinics, Physiotherapy clinics, and Day Ward admissions. The list above is symbolic of our broad multidisciplinary team here at the Dublin Neurological Institute who work cohesively to deliver excellence to our patients.

The public/private model for healthcare can work. The DNI is modelled on many of the great University teaching hospitals in the U.S (e.g. Massachusetts General Hospital, Longwood and Brigham Hospitals, Colombia Presbyterian Medical Centre and University of Pennsylvania Johns Hopkins). These are charities that raise income to develop and expand their excellent services. In Ireland the DNI model provides care to patients based on their clinical need and not because they are public or private patients. Both public and private patients should be able to access care as needed. The DNI avails of some public funding used to employ Mater employees who work at the DNI to see patients in an efficient and excellent fashion but also raises income to appoint new staff for new services as required. Thus the DNI is a flexible centre of excellence that can adjust its service based on the need of the patient. It also has a highly efficient system to deal with waiting lists and can increase the number of patients seen as demand increases. Thus it can meet the need and demand identified by the HSE neurology programme.

The DNI also provides an outreach approach. We see patients from all counties in Ireland and the DNI has been instrumental in setting up the North West Neurological Institute (NWNi) based in Sligo General Hospital. The NWNi which is modelled on the DNI to provide care of patients in the North West of Ireland. It is known that the neurological services in the North West of Ireland are limited as there has only been one consultant neurologist in this region although neurological disorders such as multiple sclerosis are very common in this area. The development of the NWNi will substantially improve the care of patients in this region and act as a catalyst to improve neurological care and education in the community.

The Dublin Neurological Institute is an excellent example of best practice and a centre of excellence for neurological care in Ireland. Its model of care (a charity and a public private partnership) is an ideal flexible model that can be expanded to improve equitable neurological care across the country. For example other neurological institutes could be developed at different regions including Cork, Limerick, Galway, Donegal, Waterford etc. so that a grid of neurological institutes would be developed linked by a common database and

use the excellent governance of the Dublin Neurological Institute across the various units. These units will act as a catalyst to improve the care of patients across the country but also to improve education, research and innovation in neurological disorders and neuroscience across the country. Furthermore, by linking these by a common web based database it will be possible to get clear demographics and data with regard to the demand for neurological care in Ireland but also provide a way and a means for research, innovation and trials that could generate substantial income from the pharmaceutical industry. In due course the Dublin Neurological Institute would evolve into the Irish Neurological Institute linking neurology units across Ireland to provide the best care of patients with neurological disease. The best care is provided when there is also an academic component to it to maintain standards now and into the future.

Professor Tim Lynch  
Clinical Director, DNI  
Adjunct Professor of Neurology, UCD  
[Tlynch@dni.ie](mailto:Tlynch@dni.ie)

The Dublin Neurological Institute  
57 Eccles Street,  
Dublin 7  
Ph: 8545258  
[www.neurologicalinstitute.ie](http://www.neurologicalinstitute.ie)

## Epilepsy Ireland

Nearly 40,000 people in Ireland live with epilepsy. Epilepsy is the most common neurological disorder according to the WHO and carries a heightened risk of co-morbidity.

Key barriers to integrated care for people with epilepsy include the limited numbers of neurologists and the centralisation of services and the limited services on the ground at community level.

Further barriers include staff shortages which have affected major specialised assessment services for people who require inpatient monitoring as well as unfilled posts within the wider system.

People with epilepsy require access to specialised care. Those with difficult to control epilepsy and those with complex psychological and behavioural needs need access to specialised neuropsychological and neuropsychiatric services which are difficult to access when the numbers of clinicians in the public system are in single figures.

Epilepsy Ireland is calling for the strategy for future of healthcare to address these issues and to resource the existing services and programmes to be able to deliver integrated care effectively.

### **Integrated care : The main barriers and challenges**

Currently the main barriers to integration of care services are limited numbers of specialists, the centralisation of existing services and weak links between primary and tertiary care.

There are significant unmet needs for psychological and behavioural assessment services, respite access and free travel. No specific transport provisions are in place for people unable to access clinics due to driving restrictions.

Data needs to be gathered on experiences of how families and individuals use services. Currently access to care is needs dependent, catchment based and community services are ad hoc.

There are no specific guidelines on screening in respect of childhood epilepsy. There is a need for a systematic approach for referral to specialised services and for results of screening to be shared among key professionals involved in the care of the child. At present there is limited access to specialised neuropsychological and neuropsychiatric services where required and there is still no dedicated national epilepsy centre for the assessment of epilepsy.

People with epilepsy have limited eligibility for community based services and disability related welfare supports. Assessment processes which focus on physical incapacity do not capture the difficulties experienced by people with episodic conditions and hidden disabilities. The only entitlement across the board is free medication otherwise everything else is conditional and hard to access. In our member survey just over a quarter had a medical card and the remainder were faced with significant cost barriers to access basic and essential services.

## **Recommendations**

### **Opportunities to improve integration include:-**

The new Transition Nurse for Epilepsy post which will focus on service development for adolescents is a significant development and which needs to be supported by extending services such as outreach clinics for paediatric epilepsy and additional epilepsy nurses within Intellectual Disability (ID) services.

Dealing with essential staff shortages in nursing posts

Dealing with shortage of specialists and specialist services

Removing medical card eligibility barriers for many community based services

Reducing frequency and volume of admissions through strengthening community supports

Continuing to invest in specialist services, neurologists, specialist nurses, neuropsychologists, neuropsychiatrists with specialisms in epilepsy

Proper assessment of the true cost of living with epilepsy.

Provision of care to include OT access, physiotherapy and better networking between community intervention teams

Additional involvement of GP's in epilepsy care

Additional mental health supports for people with epilepsy and better access to neuropsychology and neuropsychiatry

Partnership between clinicians, patients, families and carers and voluntary sector organisations

Integrated patient centred care plans to include links to clinical and community supports.

An overall strategy to identify overlap and gaps in service provision

### **Epilepsy Specific Health Needs**

Epilepsy is a chronic neurological condition with the tendency to have seizures. Seizures are electrical discharges in the brain which disrupt normal functioning. Depending on where the seizure focus is in the brain various symptoms may be observed. Some people get warnings prior to seizures but many do not. Living with the unpredictability of epilepsy is a major source of anxiety. The risk of co-morbidities is heightened for people with epilepsy.

### **Incidence and prevalence**

Worldwide incidence of epilepsy ranges between 16-51/100,000 (Banerjee, et al 2009). Age specific prevalence of epilepsy is 4.5-5/1000 in children and adolescents, 6/1000 in adults and 7/1000 in the elderly. Age specific incidence is high in children and adolescents at 70/100,000, stabilises in adults at 30/100,000 and rises sharply in older people at 100/100,000 (Forsgren et al, 2005b) European prevalence studies have found rates of active epilepsy between 2.3/1000 - 8.6/1000 averaging between 4.9/1000 - 5.1/1000.

## **Irish data**

Linehan et al, (2009) found the prevalence of epilepsy here to be 8.6/1000 and that 36,844 people over age of 5 years in Ireland have epilepsy. While there are no figures for the under 5's in Ireland epilepsy is commoner in this age group than other age bands (with the exception of over 60's) and estimates from other countries put the rate at 1 in 20 (Shorvon, 2009). Among the general population rates are 1 in 115 people having epilepsy. It is estimated about 10,000 are women of childbearing age (Liggan and Delanty, 2010). There are special issues in the care of women in pregnancy due to effects of AEDs on the foetus and other management issues.

## **Clinical Care Programme**

The National Clinical Care Programme in Epilepsy was established in 2010 as a national framework for future development of epilepsy services in Ireland. The objectives of the programme are :-

1. Improving access to expert care and information.
2. Improving quality of care across the healthcare spectrum from prevention, through managed primary care to complex surgical care for difficult epilepsy.
3. To improve value conscious care by shifting care where possible from expensive hospital based care to the community.

Much has been achieved to date with the ongoing roll out of this programme and continued investment is needed to sustain its' vital role in improving epilepsy care.

## **Epilepsy care options**

Epilepsy is treated primarily with a range of anti-epileptic drugs (AEDs). Up to 70% of people with epilepsy can potentially achieve seizure freedom with medication. The remaining 30% with refractory epilepsy may need non-drug options combined with their medication including epilepsy surgery, vagus nerve stimulator implants and the ketogenic diet. Few posts exist in Ireland for professionals with these specialisms which adds to wait lists for treatments for the most difficult cases.

Epilepsy is the most common serious neurological condition seen by GP's. Referrals are indicated in cases of first seizures, diagnostic uncertainty, poor seizure control, persistent seizures, side effects and poor tolerability of medication, co-morbid illness, pre-conception and pregnancy issues, underlying causation issues and withdrawal of AEDs. Special attention is warranted in groups such as children, the elderly, women of childbearing age, people with learning disability, those at risk of injury or SUDEP, and those needing driving guidance.

The new Advanced Nurse Practitioners are an important link between primary care and specialist services. People with epilepsy have ongoing needs for primary and specialist care, also for secondary care due to hospital admissions for seizures, seizure related injuries or other co-morbid illnesses. Access and review needs remain when seizures are controlled as epilepsy care is more than just seizures.

## **More than seizures**

Epilepsy impacts on the person right across their lifespan. For young children there is a high rate of associated learning difficulties and behaviour problems. These can persist through schooling even when seizures have resolved. Recent studies (Young Epilepsy, 2014) found that 95% of children with epilepsy had a significant difficulty in at least one area related to cognition and behaviour and that learning related difficulties were much higher than for children and teens with other chronic medical conditions. Children with epilepsy need referrals for psychological screening and assessment on a systematic basis but that this is not currently happening.

Rates of depression and anxiety are high among people with epilepsy as a group. Ongoing seizures typically prevent driving and this has a major impact on employability and independence. Many people with epilepsy are not eligible for free travel and incur substantial transport costs for medical appointments and services. Women with epilepsy of childbearing age have special requirements in pregnancy due to the effects of drugs on the foetus and with regard to baby care (the latter applies to fathers with epilepsy also). Among older people higher rates of epilepsy are well established and this cohort present specific challenges for management. Special issues include loss of independence and bone health and more complex management due to co-morbid conditions.

## **Risks in epilepsy**

Epilepsy carries significant safety risks. Even apparently minor seizures can lead to serious injuries and even death with 41.4% of people with epilepsy having injuries at home (Nyugen and Telles Zenteno, 2009).

## **Hospital admissions**

A Welsh study found epilepsy admissions to be 2.8% of total admissions (Currie, 1995) and most were admissions to paediatric neurology (53.4%). Length of stay was longer (24.8 days) than for controls (9.1 days). Canadian figures (Telles Zenteno, et al 2008) show rates of accident related hospital admissions were 3 times higher for people with epilepsy than controls. Dunne (2013) states that there is an 86% increased chance of hospital admission among people with epilepsy. A person with epilepsy has a 5% chance per year of visiting A&E (Nyugen and Telles Zenteno, 2009). Besides fractures, (the most common reason for admission, van den Broek and Beghi, 2004) people with epilepsy are 4 times more frequently hospitalised for other illnesses (24%) than controls (6%). Kirby and Sadler (1995) found incidence of seizures resulting in injury or death was 32.2/100,000 and that 15% of seizures requiring admittance resulted in injury or death.

## **Bone health and epilepsy**

Long term use of certain AEDs and particularly multiple AEDs can lead to bone demineralisation, osteopenia and osteoporosis. Seizures pose further risks to people with reduced bone density. Fractures often involve the hip, forearm, or spine, and can have adverse outcomes. Even in young people whose bones are still forming AEDs can prevent normal bone development. In adults who commence AEDs a deterioration of bone health can occur.

## **Non-fatal accidents and injuries**

The most common of these are burns, soft tissue injuries, fractures, dislocations, concussion and submersion injuries. (Nyugen and Telles Zenteno, 2009). Beghi and Caraggia (2002) found 24% of injuries were seizure related. Mild head injuries, concussions, limb contusions, orthopaedic injuries, sprains strains and internal injuries were also higher among people with epilepsy, as were burns scalds and poisonings (Telles Zenteno et al, 2008).

### **Fractures**

The risk of someone with epilepsy sustaining a fracture is twice that of the average person. Relative risks were increased for hip fractures (pooled RR : 5.25) forearm fractures (pooled RR : 2.53) spinal fractures (pooled RR : 6.16) (Westergaard et al, 1999). Similarly Souverein et al (2005) found that risk of fractures among a population of 40,000 people with epilepsy was twice that of the general population. Risk factors for fractures include recent diagnosis, male gender, age 45 years or older, generalised seizures and multiple medications. Risk factors for epilepsy patients with osteoporosis include long term AED use, multiple AEDs, frequent falls, older age, female, low body weight and early menopause.

### **Dislocations**

Posterior shoulder dislocations and bilateral posterior shoulder dislocations are often linked with convulsive seizures despite being rare in the general public. Other common dislocations involve the hip and jaw (Gosens, Poels and Rondhuis, 2000).

### **Burns**

Telles-Zenteno et al (2008) reported that people with epilepsy had a higher frequency of burns 6.9%, compared to the general population, 3.9%. and account for up to 10% of admissions to burn units. Burns were more severe in people with epilepsy with full thickness burns requiring surgery. Women with epilepsy were twice as likely to sustain burns in seizures.

### **Premature mortality**

Dunne (2013) reports the standardised mortality ratio in epilepsy is 2-3 times that of the general population. Neligan et al (2011) report that risk of premature death is more than double among people with epilepsy even where they were more than five years seizure free on or off medication. The risk remains elevated even 20 years after the first seizure.

### **Deaths directly due to epilepsy**

Status epilepticus or a prolonged seizure affects 5% of adults and is higher in children and carries a 5-20% mortality rate (Dunne 2013). Accidental deaths account for 6% of epilepsy deaths. Drowning or submersion accidents are well known risks and a significant part of these figures.

Bell et al (2011) stated the risk of drowning in people with epilepsy is raised 15-19 fold compared to the general population. Risks were found to be higher among adults than among children. The relative risk for drowning in the bath for children with epilepsy is 96 and

for drowning in a swimming pool it is 23. Overall the SMR for drowning in epilepsy is 15.6, far above the general population rate.

### **Psychiatric and psychological co morbidity**

Rates of depression and anxiety are high and psychosocial factors contribute to this as does living with a chronic and unpredictable condition with elevated co-morbidity. Previous studies report higher suicide rates in epilepsy. Kwon, Liu, and Quon, (2011) found that a high probability of suicide among those with very frequent temporal lobe seizures with no warnings who were on certain medications. Screening for suicide risk and psychiatric co-morbidity as well as close monitoring was recommended. In view of such findings there needs to be increased awareness of these risk factors among GP's and mental health professionals.

### **SUDEP**

Sudden Unexpected Death in Epilepsy (SUDEP) is a sudden unwitnessed non-traumatic death of someone with epilepsy. Heightened risk factors are frequent generalised tonic clonic seizures, multiple medications, young age at onset, being young and male, but SUDEP can affect a person with less frequent seizures, and at any age. Most SUDEPs reported in a systematic review by Thurman, Hesdorffer and French (2014) were in the 15-25 age group. Control of tonic clonic seizures is key in SUDEP prevention. SUDEP occurs more commonly, but not exclusively, in sleep. Nightly supervision has proven helpful for sleep seizures Langan, et al. (2005) can also be a barrier to independent living. Seizure detection alarm technology can be beneficial but this technology is expensive and there is no systematic funding mechanism for it.

People with epilepsy have a risk 2-3 times greater of premature death. SUDEP accounts for 4% of such deaths (Thurmann, Hesdorffer, and French 2014). Langan (1998) in a study of SUDEP cases in South Dublin and Wicklow found crude annual rates of 1.05 / 1000. A US study has found rates of SUDEP were higher than those of Sudden Infant Death Syndrome (Centre for Disease Control and Prevention, 2010). Epilepsy deaths are not always consistently recorded. Epilepsy Ireland helped set up a register of such deaths.

### **Medical needs arising from seizures and treatment**

Dental care is a concern for people who have broken or damaged their teeth during seizures as well as those whose medication impacts on oral health. Currently, only medical card holders can access limited dental services for free. Others are liable for full costs of essential dental repair work.

Foetal valproate syndrome is a condition affecting some babies of mothers who were on valproate during pregnancy. The condition can have significant and severe developmental implications. Awareness raising among professionals needs to be reinforced around this issue.

### **The cost of epilepsy**

The Epilepsy Ireland survey on Medical Costs (2014) looked at cost barriers with regard to essential services. Due to heightened injury risks and premature mortality rates, certain core

provisions must remain accessible to people with epilepsy, without unreasonable costs being a barrier.

A key recommendation was the extension of the discretionary medical card scheme to those with epilepsy who are income ineligible. It is a huge concern to us that so many experienced cost barriers to essential services. In our survey 58.64% said cost was a barrier in relation to GP care, 52.04% said it was a barrier in respect of A&E and 44.7% said it was a barrier due to other costs such as essential lifesaving emergency medication costs.

For Epilepsy Ireland a priority must be continued provision of free medication through the Long Term Illness Scheme. People on both the LTIS and medical card schemes are being asked to pay for prescribed items for the emergency treatment of epilepsy and for the prevention of side effects. This needs to be remedied urgently and those items automatically included under both these schemes.

Given the safety risks involved there needs to be a clear funding mechanism to obtain seizure detection devices which could help reduce risk of injury and associated costs to the health services.

Some accidents and deaths are potentially preventable with effective treatment, patient education, and the use of alarms where appropriate. However optimising prevention is predicated on having access to primary and specialist care, and to secondary care as appropriate, without unreasonable cost barriers.

### **Funding Model**

Any funding model for future healthcare needs to take account of the additional costs of epilepsy. Personalised budgets for person centred care are required for individuals with specific needs. Funding needs to also strengthen posts at every tier in the system from personal assistants and home support workers to additional GP's at primary care, nursing staff at community level and neurology specialist staff at tertiary level. Epilepsy Ireland as a member of the Neurological Alliance of Ireland supports their position on the need for investment in neurorehabilitation services. Any funding model needs to commit reducing wait times on public waiting lists and ensuring timely access to crucial mental health services at community level. It needs capacity to invest in increasing numbers of therapists, psychologists and ancillary staff to improve access to therapeutic

supports and assessment. The model needs to take account of further implementing strategies such as the Carers Strategy and A Vision for Change.

### **Recommended action points for change:-**

Allocate medical cards based on health related need.

Introduce a standardised funding mechanism for seizure alarms and monitoring equipment.

Invest in specialist neurological services to fill key gaps.

Invest in and improve linkage between community and secondary care services.

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*Ms. Geraldine Dunne,  
National information Officer,  
Epilepsy Ireland,  
249 Crumlin Road,  
Dublin 12.  
Tel : 01-4557500  
Email: [gdunne@epilepsy.ie](mailto:gdunne@epilepsy.ie)  
<http://www.epilepsy.ie/>*

## Equality and Rights Alliance (ERA)

The Equality and Rights Alliance (ERA) is making this submission to inform the development of ten year plan for Health Care and health policy in Ireland. ERA would like to point out the importance of Public Sector Duty and the statutory requirement for Public Bodies to implement their duty. A ten year plan for the future of healthcare should, in order to meet its Public Sector Duty, involve an equality and human rights assessment of the draft ten year plan. The plan needs to specifically state commitments to Public Sector Duty and how conditions will be created for all aspects of health service delivery to meet their Public Sector Duty.

### The Public Sector Duty

Section 42 of the Irish Human Rights and Equality Commission Act 2014 requires public bodies to have regard, in carrying out their functions, to the need to eliminate discrimination, promote equality of opportunity and treatment for staff and service users, and protect the human rights of staff and service users.

Specifically the Act requires public bodies in giving effect to this duty to:

- a. “set out in a manner that is accessible to the public in its strategic plan (howsoever described) an assessment of the human rights and equality issues it believes to be relevant to the functions and purpose of the body and the policies, plans and actions in place or proposed to be put in place to address those issues, and
- b. report in a manner that is accessible to the public on developments and achievements in that regard in its annual report (howsoever described)”.

Government Departments (except the Department of Defence and the defence forces), local authorities, the Health Service Executive, Education and Training Boards, and public bodies established under an enactment or charter or any scheme administered by Government and financed wholly or partly by Government are covered by this duty.

### A Future Healthcare plan that Gives Effect to this Public Sector Duty

It is clear that the development of a ten year Healthcare plan will be covered by the legislation and hence the need for a clear equality and human rights proofing of the ten year plan. As such it must meet the requirements of the public sector duty. In preparing the draft plan, the Committee must:

- Carry out an assessment of and document in the draft policy the human rights and equality issues relevant to their functions as policy-maker, service provider, employer and/or procurer of goods and services.
- Identify the policies, plans and actions it already has in place to address these issues and document these in the draft ten year plan.
- Identify the policies, plans and actions it proposes to put in place to address these issues and documents these in the draft plan.

The draft Strategy should, among any policies, plans and actions proposed to address the equality and human rights issues, include a commitment to:

1. Conduct an equality and human rights impact assessment of new legislation, policies, and plans to be developed during the lifetime of the ten year plan.
2. Conduct a rolling series of equality and human rights reviews of internal policies, procedures, and practices to address any equality and human rights issues for staff and service users.

### **A Statement of Strategy that Gears up for Ongoing Compliance with this Public Sector Duty**

The Equality and Human Rights Alliance has developed guidance material to support an effective implementation on an ongoing basis by public bodies: *A New Public Sector Equality and Human Rights Duty*.<sup>251</sup> This recommends a number of steps that should be taken by public bodies to implement the public sector duty. The draft ten-year plan on the Future of Health Care should commit to meeting the requirements of the public sector duty in its strategic planning on an ongoing basis.

This would require a commitment in the draft strategy to:

1. Create the conditions for its implementation by:
  - a. Establishing a working group drawn from senior management across its different functions to oversee and drive the process of implementing the duty.
  - b. Providing training to working group members and key relevant staff on equality and human rights issues on the implementation of the public sector duty.
  - c. Conduct a review of the current approach by the Committee to equality and human rights issues to establish the most strategic approach to implementing the public sector duty.
2. Develop a methodology for the assessment of equality and human rights issues by:
  - a. Gathering data and information to develop a database of the equality and human rights issues relevant to the functions of the health service delivery in Ireland covered in the plan.
  - b. Establishing an ongoing dialogue on implementing the public sector duty with organisations representing groups experiencing inequality and human rights violations.
  - c. Developing and implementing an equality and human rights impact assessment methodology to be conducted on draft legislation, policies and plans.
  - d. Developing and implementing an equality and human rights review process to assess internal policies, procedures, and practices for their impact on equality and human rights for staff and service users.

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<sup>251</sup> Available at: <http://www.eracampaign.org/uploads/A%20New%20Public%20Sector%20Duty%20March%202015.pdf>

- e. Developing a plan of action to progress work on the equality and human rights issues identified.
3. Build an approach to monitoring, evaluation, and reporting by:
- a. Establishing data systems must be established from the outset to ensure systematic data gathering in relation to the affected groups.
  - b. Establishing indicators to ensure that change in relation to equality and human rights issues is measured.

### **Equality and Rights Alliance**

The Equality and Rights Alliance (ERA) is a network of over 170 civil society organisations, trade unions and individuals with an interest in equality and human rights. It was established to seek, support, and monitor the highest standards for our equality and human rights infrastructure.

For more details see <http://www.eracampaign.org/>

## Eugene Breen, Dublin

This submission to the health debate, is a little *tongue in cheek*, but basically asks fundamental questions about social justice, ethical health care and changing the goal posts completely. We have 13 billion euro to spend on the health of a population of 4 million, any ideas? - type of scenario.

### The Health Service Long Term Plan

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Money money money – how much have you got, and how do you want to spend it? Simple! What is it being spent on now and is it possible to de-couple it and free up large dollops of cash for “the plan”? What is the best value for a euro? Who should get what?

There is free education, free air, free water (?), not free electricity or broadband, free speech, not free housing, free money for the unemployed or those that are ill or don't want to work. When does a state stop giving out free-bees, or in other words what is an unequivocal basic human right? Is 13 Billion euro (the health budget) to be equally divided among the population giving each person roughly 1000e each and let them spend it on health? This would be universal health care! But as we know, it is not a level playing pitch and some are more needy than others. Some people need 24 hour care and most people don't need any care. A country has to decide what is moral, and just, and intelligent use of resources.

Prevention and a sense of responsibility have to be key pillars in any just and smart distribution of health monies. It is obvious that health education with a view to promoting healthy lifestyles is money well spent. It is better to exercise before having a heart attack, than afterwards. It is preferable to spend money preventing illness than treating it. Responsibility. We all have to take responsibility for our health. The evidence is there. Chronic illnesses are avoidable to a large extent. Exercise, diet, weight control, avoidance of substance abuse (cigarettes, alcohol, fatty foods, drugs) are key players in the health of a population. Healthy children usually grow into healthy adults. Money spent on child health is wise. A healthy young population is a solid basis for a healthy country and economy. Mental and social health are critical foundations for a healthy society and should be well funded.

You could say “Sorry but we can't afford the kidney machine, or the 4 weeks in ITU, or the quadruple cabg. You will have to fund that yourself. The state's money is only for agreed programmes, discussed by all parties and put to the people for approval.” After all the people pay the taxes (those that work) so they should have some say in where the health (and other) money goes. They may vote for child- care, mental health, and prevention, and not for treatment of preventable chronic illness. We are free, we are not a communist state, and people can have private property and private health care. The utopia of universal health care is way out of our reach. It is like the idea of a minimal wage for everyone working or not working, which didn't even get off the ground in Switzerland, and they have more cash than we have.

At present most of the health budget goes on paying the 100,000 health care staff, and on high tech hospitals. Is this what we want to do into the future? Can we afford it? Unless one seriously taxes the population with a substantial health tax (as in France) one cannot continue to do what we are now doing. At best our state can afford basic health education, prevention strategies, child care, and mental health services to the younger part of society – those below 50 years. Those over 50 years

are expensive and need hospitals and treatments and intensive input. SO, how do you divide the money? Give half the budget for those under 50 and half for those over 50? This is a complicated situation and an expensive situation and our country cannot afford to keep everyone happy. If people can afford health care, allow them to buy it. Insurance companies and the private sector are necessary and are a right in a free country. Universal health care is not like free bread or education. There are levels of health care and we need to decide what is basic, what is affordable, and what is just and intelligent. A threshold needs to be established to cover the entire population, and after that private enterprise should occur. A complete overhaul of the health system is required. Care of the elderly is going to be the big spend in the next 50 plus years. There are no, or very limited natural social supports (families) to care for the elderly and nursing support is very costly.

A broadly based conversation needs to occur engaging the public in particular, and those paying the piper (taxpayer) as regards deciding what to do. Should we have a 34 billion euro social welfare budget for a population of 4 million? Should some of this be diverted to health? The people have a right to know where their money is going. They have a right to have up to date information on health and social welfare, and they have a right to influence spending. The real power in any outfit is with the finances. Whoever has the purse strings has the power. The people elect TDs but don't get to decide about how money is spent. They don't even know how it is being spent. The real sign of a democracy and a free independent state is that the people have a part in real decisions and are at the real decision making process – those that have to do with spending their money.

The cost of health staff and facilities, and the place for research and centres of excellence is also part of the health equation. Basic human rights to a certain level of health care, rights to fairness of distribution of money, terms and conditions for access to resources, are all involved. Is it fair to do a cabg on one person at a cost of a possible 13 mental health interventions in teenagers? Let's say both cannot occur, so who decides who gets what? These are real everyday decisions, and the system, and what has been the usual practice to date, and vested interests, are making these decisions. What can you buy for 20k? Who decides what criteria are used? This is all about ethical health care and social justice, and until a broad ranging and transparent and public debate is had on what we are doing in health (and social welfare), and what we should be doing, and why we should be doing something else - nothing will change. The 10 year plan will be another political football. It will be another 25 year Vision for Change (Mental health blueprint which is 10 years on, and mainly gathering dust). The citizen's assembly or an equivalent non-political grouping, may take the heat off politicians, and allow a new open dialogue about what the best way to spend the health budget into the future might be. We need to think newly and outside the box. Costs have gone up, life expectancies have gone up, medical information and evidence has increased, and social supports have gone down. These are not the same conditions that applied 35 years ago when we started up our present health system. It is now time to ask: "Would you do the same things all again? Would you do things differently? What can we afford and what percentage of the government budget and each household budget should be spent on health?"

A much more fundamental discussion is needed before the pointers outlined in the terms of this submission process are addressed if at all. You could conclude "If I was you I wouldn't start from there at all!"

Eugene Breen, Dublin 7

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## Extra Special Kids Group of Ireland

We wish to make the following points regarding our concerns about the proposed development of the proposed new National Children's Hospital.;

### Wrong Location

Had the parents and families of the sick children of Ireland been asked about the right location, St. James' campus would not have been chosen. But we weren't asked. The hospital will be the only hospital serving the seriously ill children from all over Ireland, 75% of whom live outside the M50.

### Access

Access is a nightmare. Speedy access to the right medical support is what our children need in a crisis, not being stuck in rush hour traffic. Minutes matter and the difficult drive be it by car or by ambulance into St. James' could limit their lives, literally. Almost all (around 90%) children are brought to hospital by car. We know that even now it can take 45 minutes to exit the St James' site at rush hour. The approach roads are single lane and congested. All our children do not travel well by car. They get distressed. If one of our children is having a seizure or requires suctioning or oxygen and we are stuck in gridlock traffic, what would we do? If their condition deteriorated, what would we do? Minutes matter, it can be the difference between life and death for our children.

Also, what about ambulances trying to access the hospital in gridlock traffic? Is it guaranteed that every ambulance transfer will go to plan and arrive to the hospital swiftly encountering no obstacles along the way? We know that emergency services are currently disrupted around the James' campus. How will they physically move gridlock traffic if the cars have nowhere to go? With regards to Garda escorts, will all ambulances require a Garda escort to the hospital to ensure no lives are lost? How many potential Garda escorts will be required daily? This is **NOT** acceptable both from an accessibility point of view but from a greater public point of view. Garda resources should be used for stopping crime and making our living environment secure and peaceful.

### Parking

Parking is not sufficient. For a 473 bed hospital, there will be just 675 public parking spaces. What happens on the day every child's parent park their car and every child's visiting relative parks their car, in addition to day clinic cars and the public/people attending the adult hospital? Where will we park? Many of our children are oxygen dependent and have wheelchairs, we carry a lot of equipment with us just to keep our children stable.

We have been told that we can prebook a parking space if we need to attend the hospital, this is absurd, what will the criteria be to park? how will we prove we need it more than another child, what system will be there to stop people that do not need a parking space booking one?

Some children in the group have had surgeons waiting on them whilst their parents searched for parking at Crumlin and Temple Street hospitals. The same will happen at James'. This is **NOT** acceptable. The political concept that parents with sick children can travel to and from St James's hospital via public transport is a fantasy.

## Safety and Security/Environment

Safety and security issues of an inner city centre site is of great concern to us. We know that it is not safe to go outside the hospital campuses at Temple Street and Crumlin hospitals alone once it gets dark. The same will apply to the St. James' campus. Believe us. Many of us parents were aware of car break-ins whilst our children were inpatients at Temple Street Hospital. In addition to this, the security guards at Temple Street had to escort nurses to their cars during the shift change car switch. The majority of the time, it is the mother who accompanies the child to the hospital and stays with their child. Getting a dinner at night time or a break from the hospital should not have to be a worrying experience. Every mother in the group has said that they will not feel safe at James'. Can our safety be guaranteed or will we be like prisoners having to stay within the hospital building itself whilst we are there, which can be for months at a time. This is **NOT** acceptable.

Nursing staff at St. James' are very distressed as their parking spaces have been removed to facilitate the construction of the new hospital. They are very upset as they do not feel safe walking around or to and from the campus. The staff at the new childrens hospital will not have any parking spaces either, they will feel the same way. Who will staff the hospital? What will happen when somebody gets hurt....staff or visitors.....or children?

## Space/Expansion

The hospital has been shoehorned into a restricted site with no room for expansion. It's been proven from existing hospitals all over the world that they double in size every 10-20 years. There will be no room for that at St. James'. We are also worried that planned services to be included on site will be moved off campus as there is simply not enough room. You don't have to be an architect, walking around the St. James' site to know that the children's hospital, along with the adult hospital and the proposed maternity hospital just won't fit in there.

The childrens hospital is supposedly meant to be tri-located with an adult hospital and a maternity hospital to apparently make it a world class facility. There is **no supporting evidence** that shows a childrens hospital should be co-located with an adult hospital. Our children are the sickest in the country and have spent hundreds of years overnight in hospital and not once were they treated by an adult doctor. Children are not small adults. Pediatric medicine is a specialty in its own right. However, a co-located maternity hospital is crucial to a childrens hospital. Tiny newborn babies will not survive if a maternity hospital is not on site and babies have to be transferred via ambulance. See letter attached which was submitted by the intensive care doctors at Crumlin childrens hospital supporting this. The planned maternity hospital (Coombe Maternity) will never obtain planning permission on the St. James' site as there is simply not enough room and the construction would also seriously disrupt the operation of both the adult and childrens hospital. In addition to this, in a fantasy world, if the maternity hospital did get planning permission, construction could not commence until the childrens hospital is open.

How or why was it chosen when it's doomed to fail? St. James' campus is a long narrow campus of 49 acres, 10 of which are owned on leasehold by Trinity College. It is difficult to see how all three hospitals will be squeezed into the remaining space and leave room for expansion which all these hospitals will inevitably need. The childrens hospital site is just 12 acres. What happens in 10 - 15 years time when the children's hospital has reached its expansion capacity of 20-30% which is all that is currently allowed for in the plans...will we need to build a new children's hospital elsewhere to cover the clinical requirements? This hospital is meant to be a world class facility that will last for the next 100 years to include all primary specialties for present and future demand? The lack of spatial opportunity (for whatever use) that this site presents is **NOT** acceptable.

The previous site at the **Mater** was originally deemed to be the most appropriate site for this hospital. Why now is the James' site the most appropriate? Surely, it's the second most appropriate site? Given the obvious change in political views one might question or indeed challenge if either site is suitable? Who is driving the policies here? It was bad enough wasting €40+ million on the Mater location which was rejected for valid environmental, physical and medical reasons, how many more millions will we waste on the St. James' site which is just as bad? The meter is running for the taxpayer. This is **NOT** acceptable.

### In Summary



We support Jonathan Irwin of the Jack & Jill Children's Foundation and many others opposed to the St. James' campus, with the option of moving the hospital location to a green field site at Connolly Hospital in Blanchardstown on the M50. We wish to make the following points regarding our support for this particular site;

- It would be **easily accessible to the entire country** by car or by ambulance. **Lives will be saved.** Hard shoulders are already provided along the M50 for emergency services, such as ambulances (i.e. grid lock traffic can be bypassed, unlike a city centre site)

- It would have the potential to provide **unlimited parking**, increased to meet future needs as they develop.
- There would be **minimal security and safety issues** as the site is over ten times bigger than James' so there will be ample green space to enjoy and facilities nearby that the families can avail of safely.
- This site would provide **sufficient space for future expansion**. It would allow for the opportunity to provide a site master plan that is flexible to meet all future needs whatever they may be. (i.e. a brown field site will NOT offer this flexibility) All future clinical criteria could be met, allowing us to construct a world class facility that will last long beyond our years. The planned maternity hospital on the site (Rotunda) could potentially be constructed at the same time as the children's hospital.
- The **cost to construct the hospital would be less** on a green field site as there would be less constraints impacting the build and construction is faster. This is a fact.

We launched a Facebook campaign on Friday, 25<sup>th</sup> September. We have received the following support:

- We have reached almost 600,000 people
- We have received 10,819 likes
- We have received 5,881 shares
- We have received 453 comments in support of our campaign.

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**Jack and Jill Children's Foundation**  
Published by Alison Shendan (9) · September 25 at 2:09pm · 🌐

Help us friends,  
We are a closed Facebook group with 150 Irish members, all mothers of very sick children. All our children have rare and complex needs and need 24 hour care. They have what the medics call 'life limiting' or 'life threatening' conditions. They have no voice or no vote in this country, but they do have a right to the best possible hospital care and we their parents, their grandparents, aunties, uncles, godmothers, brothers, sisters and friends can speak up f...

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<b>453</b> Comments	<b>225</b> On Post	<b>228</b> On Shares
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We are speaking out for our children who will be the primary users of this hospital, but we are also speaking out for all the other children of Ireland that will require the use of this facility in the future. We are more than 150 voices. We are the people of Ireland.

Hospital should be stressful because your child is ill, not because the hospital environment itself stresses you out because it's unsuitable, unsafe, inaccessible, just wrong. This hospital is meant to serve the children of Ireland for the next 100 years. If we have to endure what is being proposed for St. James', we will have failed our children and generations to come. The only thing going for this planned facility is the fact that it's a new building, but it can be a new building in the right location if the site is changed.

We would like our voices heard and to represent the sick children of Ireland.

## Signed

Michelle Forde (Cork)  
Aisling McNiffe (Kildare)  
Samantha Hogan-Villena (Dublin West)  
Lynn McDonald (Dublin South west)  
Sarah Gibson (Wicklow)  
Anthea Reidy (Clare)  
Colleen Worthington (Kerry)  
Fiona McCormack (Westmeath)  
Ashling Nibbs (Donegal)  
Maggie Butler (Tipperary)  
Kierra Adams Kelly (Galway)

For and On Behalf of

The Extra Special Kids Group of Ireland

<https://www.jackandjill.ie/the-extra-special-kids-group-says-no-to-the-st-james-site-for-the-new-national-childrens-hospital/>

## Family Carers Ireland (FCI)

### There's no Place Like Home

Family Carers Ireland (FCI) welcomes the opportunity to submit our views to the Oireachtas Committee on the Future of Healthcare in Ireland, and to set out what we believe should be the focus of our healthcare system over the next ten years. This submission is based on our experience of supporting family carers,<sup>252</sup> who provide some 6.2 million hours of unpaid care each week while saving the State over €4 billion each year in avoided health and social care costs<sup>253</sup>.

### Executive Summary

- Ireland's health service is in crisis. Overcrowding, uncontrollable waiting lists, overstretched frontline staff and the widespread culling of vital community-based supports have all contributed to this crisis. Despite the majority of care being provided in the community, we continue to pump almost 40 percent of the total health budget into hospitals, while spending €11m less on home care than we did in 2008, regardless of a 25 percent increase in the older population
- Despite endless Government reports advocating initiatives to support home-based care, and strong economic and moral arguments to do so, practice and policy remain at odds, with access to home care remaining inequitable, problematic and unreliable due to their discretionary basis.
- **FCI recommends a community-based model of care, which places care in the home at the centre of our health system and gives a statutory, demand-led entitlement to home care services for people of all ages, including access to respite. The vision set out in the National Carers' Strategy 'to respect carers as key partners in care and to support them to maintain their own health and wellbeing' is integral to this<sup>254</sup>.**
- This submission does not endorse any particular funding model, either for the health system as a whole or more specifically to support a statutory entitlement to home care. Rather, FCI feel it more appropriate to set out important measures for consideration by the Committee in weighing any financing arrangement that may be proposed in relation to the statutory provision of home care services, including the need to exclude 'room and board' components and ensure people entering into home support arrangements are left with an adequate income to meet their daily living costs.
- To operationalise a community-based model of care, Government must prioritise the enactment of home care legislation; redirect the flow of funding from acute to community-based care and pursue hospital avoidance strategies; invest in fully resourced Primary Care Centres; address staff shortages; abolish budget silo's; and adopt a whole-of-Government approach which shares the responsibility for a successful health strategy with Departments not traditionally associated with healthcare (e.g. Housing, Transport, Social Protection, Jobs).
- FCI supports the approach taken by the Committee in recognising the need for a long-term, cross-party consensus on a strategy for healthcare, and we wish to offer our

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<sup>252</sup> National Carers Strategy (2012) defines a Family Carer as 'someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty'.

<sup>253</sup> Based on Census 2011 and €12 per hour replacement care cost rate.

<sup>254</sup> National Carers' Strategy 'Recognised, Supported, Empowered' (2012): Department of Health.

continued support. There is little doubt that whatever strategy the Committee proposes, family carers will be the cornerstone. We ask that the Committee continue to engage with the caring sector to ensure the needs of carers are reflected in the final strategy.

### **1. Our Proposal – Community-based Model of Care with a Statutory Entitlement to Home Care Services, including Respite**

Ireland is facing a demographic crisis. There has been a 9 percent increase in the population since 2006. Life expectancy has increased by two and a half years since 2004, driven largely by welcome reductions in mortality rates, and the numbers of people over the age of 65 years is projected to almost double to 1million by 2031, with 136,000 of these over the age of 85 years. Our ageing population, and the recognition that with it comes a prevalence of disability, chronic conditions and a complexity of medical needs, will have serious implications for the future planning, funding and delivery of the health service. The model of care proposed by the Committee must address these serious demographic pressures and the commensurate need to create a healthcare system that:

- places the home at the heart of healthcare and creates a statutory entitlement to home care for older people, people with a disability and all those with care needs, including access to respite care;
- respects carers as key partners in care and supports their health and wellbeing;
- places medical need rather than fiscal considerations as the principle on which access is based;
- recognises primary care as a point of first contact, and a mechanism to avoid unnecessary hospital admissions;
- fully integrates primary, secondary and community care and provides the right care in the right place at the right time;
- provides uniform standards of care regardless of ability to pay or geographic location;
- ensures value for money while providing quality care;
- provides an optimal balance between formal and informal care;
- is transparent, accountable and delivers better outcomes for patients and their carers.

### **2. The Case for Community-based Model of Care with a Statutory Entitlement to Home Care Services, including Respite**

#### **- The Policy Case<sup>255</sup>:**

Government policy has long supported initiatives to maintain the care of people in their own homes. The *Care of the Aged Report*<sup>256</sup> was the first significant report for older people, which recommended that older people should be able to remain in their homes for as long as possible. Subsequently, the NCAOP published *The Years Ahead-A Policy for the Elderly*<sup>257</sup> in 1988. This emphasised the need to maintain older people at home, with a primary focus on the promotion of dignity and independence. The Irish Health Strategy *Shaping a Healthier Future* in 1994 emphasised ‘the role of GPs, public health nurses, home helps and other primary care professionals in supporting older people and their carers’. The target was that not less than 90% of those over 75 years could continue to live at home. In 2001, the *White Paper on Supporting Voluntary Activity* recommended: ‘Programmes to support

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<sup>255</sup> ‘Irish Government and Health Care Policy on Family Carers/Older People’: HSE November 2011.

<sup>256</sup> *Care of the Aged Report* (1968): Department of Health.

<sup>257</sup> *The Years Ahead-A Policy for the Elderly* (1988): NCAOP

informal caregivers including informal networks, basic training and the greater availability of short-term respite care<sup>258</sup>. In the same year, *Quality and Fairness-A Health System for You* was published with the objective that ‘appropriate care is delivered in the appropriate setting’ and included examples of people receiving services in an inappropriate setting, such as, being cared for in hospitals due to the unavailability of more appropriate facilities or community supports<sup>259</sup>. In the same year, *Primary Care-A New Direction* stated that ‘a variety of supports will be provided to older people, such as health care assistants to support patients in the home, and reduce the need for crisis hospital admissions’<sup>260</sup>. More recently *2012’s Future Health*<sup>261</sup> advocated for reforms in social care that would enable older people and people with disabilities to remain in their own homes rather than go into residential care and a Seanad report on the rights of older people recommended that home care entitlements be clarified and put on a statutory footing, similar to that of Fair Deal<sup>262</sup>.

#### - **The Economic Case**

In addition to quality of life factors, there are strong economic arguments to support a community-based model of care. With daily hospital bed rates in excess of €900, average nursing home costs at €128 and average home care costs at €76, it makes economic sense to support care in the home. In addition, international research indicates that relatively modest home services, if provided at the right time, can have a major impact on quality of life, can reduce admissions to residential care and can address capacity issues within hospitals by avoiding unnecessary admissions. FCI acknowledges however, that home care is only feasible where family members are willing and able to provide the necessary care and where the person can be cared for safely within the home.

Figure 2: Cost of Care Comparison (source: HSE National Case Mix)

	<b>Hospital</b>	<b>Nursing Home (avge.)<sup>263</sup></b>	<b>Home Care<sup>264</sup></b>
Cost per day	€909	€128	€76
Cost per year	€331,785	€46,720	€27,740

#### - **The Re-balancing Case**

The entitlement to residential care under the demand-led provisions of the NHSS (Fair Deal), alongside the discretionary basis of home care services, has in effect prioritised residential care over home-based care of older people and has forced the inappropriate placement of many older people into a nursing home, when home care services were unavailable or inadequate to meet their care needs.

#### - **The Moral Case**

The health service depends on family carers. Without the 6.2 million hours of unpaid care they provide each week, the service would collapse. The rapidly increasing demand for home care is being met by family carers rather than by the State. Logic would suggest that services to support care in the home should therefore increase in line with demand, but this has not been the case. At best, home care services are being maintained at the previous year’s level, and at worst they are being rationed to the extent that even those assessed as needing home support cannot access help until another person dies and hours can be ‘recycled’. In fact, the HSE spent less on home care in 2015 (€320m) than in 2008 (€331m), despite a 25% increase in the population aged over 65 years. During the same period however, the HSE increased spending on long-term care from €920m to

<sup>258</sup> White Paper on Supporting Voluntary Activity (2001): Department of Social, Community and Family Affairs.

<sup>259</sup> Quality and Fairness-A Health System for You (2001): Department of Health and Children, 2001.

<sup>260</sup> Primary Care-A New Direction (2001): Department of Health and Children.

<sup>261</sup> Future Health: a Strategic Framework for the Reform of the Health Service (2012): Department of Health.

<sup>262</sup> Seanad Report on The Rights of Older People published 21st June, 2012.

<sup>263</sup> Average daily cost of private and public nursing home care.

<sup>264</sup> Based on payment of Carers Allowance (€204 p.w), Carers Support Grant and Home Help for 2 hours per day at €21 p/h.

€988m. This rationing of home care is in addition to the widespread closure of respite beds, cuts to disability and mental health funding, and the withdrawal of important supports such as the Mobility Allowance and Motorised Transport schemes, all of which are forcing carers to fill the ever-increasing gap between home care demands and the limited support available.

- **The Sustainability Case**

Most informal care is provided by family members – partners, parents, adult children, siblings etc. Changes in family structure, whether from having fewer children and starting families later, increased levels of marital disruption and more complex family relationships or greater geographical separation of families, are likely to affect the future availability of informal care and calls into question the sustainability of familial care.

**2. Funding Models**

FCI does not intend to use this submission to endorse any particular funding model, either for the health system as a whole or more specifically to support a statutory entitlement to home care. Rather, we feel it more appropriate to set out important propositions for consideration by the Committee when weighing any financing arrangement that may be proposed in relation to the statutory provision of home care services. Furthermore, we acknowledge that persons seeking home care support may also have family members or friends in receipt of Carers Allowance for their care or may receive some other form of care-related State support (e.g. Housing Adaptation Grant, Carer Tax Credit, tax rebates under the Disabled Driver's and Passenger's Scheme etc). FCI also acknowledges that home is not always the most appropriate care setting, not only for environmental reasons, but also when the costs of providing care safely within the home are so high that it becomes economically unviable. Proposals we ask the Committee to consider in relation to the funding of home care services include:

- Eligibility for home care should be based on a transparent assessment of medical need and applied consistently across the country.
- People under 65 years with an assessed need should also be eligible.
- Family members should not be means-tested or expected to contribute to the cost of their loved one's care (as with NHSS).
- There should be a significant savings disregard in the assessment of means.
- Funding arrangements should be 'locked' so that people are not exposed to future price inflation.
- Any consideration of a co-payment model must exclude the family home from reckonable assets as the 'room and board' portion of care costs remains with the caree.
- Likewise any consideration of a co-payment model must leave the caree with an adequate income to cover the costs of running their household and cannot make a contribution that would leave them with a disposable income so low they are at risk of poverty.

**Example:** A 79 year old with €222 pension, €40K savings and home valued at €100K would make a contribution of €326 (€182 deferred) to his nursing home care under the current Fair Deal regime.

Table 3: Fair Deal

	Income	Liquid Assets	Principal Residence
Fair Deal	80% income	€36k/€72k disregarded single/couple. Balance@7.5% p.a	Residence @ 7.5% p.a. up to max 22.5%
Financial Assessment	€176.60	(€4000x7.5%) €5.76	€144
Weekly Contribution	€326.36 (€182.36 deferred loan)		

If the same gentleman applied for a package of home care support the same funding model could not apply. If we replace the 80 percent contribution used in Fair Deal with a hypothetical 20 percent of weekly income, it would mean the pensioner would make a €50 contribution to his weekly care costs.

Table 4: Home Care Support

	Income	Liquid Assets	Principal Residence
Home Care Support	20% income	€36k/€72k disregarded single/couple. Balance@7.5% p.a	Not applicable as Room and Board provided by caree
Financial Assessment	€44.40	(€4000x7.5%) €5.76	€0
Weekly Contribution	€50.16		

## Key Recommendations

### For Government

- **Create a statutory entitlement to home care:** The ‘even playing field’ promised by Fair Deal has resulted in even greater disparity by instituting guaranteed access to full funding for residential care while retaining the discretionary nature of home care services. Without legislation to underpin access to home care, provision will remain inequitable, problematic and unreliable. It is critical that Government enact legislation that will give a statutory, demand-led entitlement to home care and place care in the home on an equal footing with nursing home care. In the interim, commit to the amendment of the NHSS to include an alternative package of home supports, where the costs are equal to, or less than the contribution that would be provided for residential care under Fair Deal.
- **Reorient funding from acute care towards community-based care:** The HSE spent €5.4billion on acute care in 2015, almost 39 percent of the total health budget of €13.9billion. A further €988 million was spent on residential care, through the NHSS. Government must gradually reorient health spending away from a hospital-centric model, where care is provided at the most expensive level, towards primary and community care, that delivers the best health outcomes and the best value for money. Such a dramatic shift cannot be achieved in the short-term. Rather, efforts must first focus on reducing patients’ use of hospital services, for example by carrying out minor surgery in primary care centres, allowing GPs to have direct access to a range of diagnostic tests and investigations. We must also instigate behavioural changes – in

the way GPs refer patients, in how patients themselves make informed decisions about their care and in establishing patients' trust in the primary care system.

- **Establish fully functioning Primary Care Centres:** Primary Care Centres are intended to be the first point of contact within the health service, providing a 'one-stop shop' for everything that a patient may need and representing the most local element of healthcare provision. The *Primary Care – A New Direction* Health Strategy stated that primary care was seen as the appropriate setting for the treatment of between 90 and 95 percent of healthcare needs and highlighted the potential for primary care to reduce hospitalisations and facilitate earlier hospital discharge. This plan suggested that 400-600 primary care centres would be required nationally. To date there are 44 functioning Primary Care Centres across the country, with an additional 14 being planned through Ireland's first health-related Public Private Partnership. While the target set by the Primary Care Strategy may appear optimistic, the creation of an adequate number of fully functioning Primary Care Centres, with the full complement of multidisciplinary staff is an essential component in the creation of a community-based model of care.
- **Hospital avoidance strategies:** The health strategy must actively pursue efforts to avoid unnecessary hospital admissions. Initiatives such as those previously mentioned including access to community-based diagnostic testing, and minor surgery will help achieve this, however primary and geriatric care within nursing homes must also be reformed if hospital admissions are to be avoided. For example intravenous cannulations are not permitted in many nursing homes despite the presence of trained nurses, meaning hospital admission becomes necessary. More seriously, anecdotal evidence suggests that the fear of a HIQA investigation following the death of an older person while in a nursing home, can result in patients being unnecessarily admitted to hospital when they are close to death to avoid such an investigation.
- **Abolish Health Budget Silos:** Patient journeys cannot be considered in the silos of acute, primary or social care, but rather as an integrated, interdependent system. In this way, parochialism and the myopia of focusing on individual budgets will be removed, and replaced with a more holistic view of patients care. An activity-based funding model, rather than one based on historical budgets, should be deployed across the health service and not only confined to acute hospitals.
- **Adopt a Whole-of-Government Approach:** The health strategy must unite Government and ensure absolute cohesion, irrespective of changing Ministers or Governments. In a similar way, Departments not traditionally associated with healthcare must play their part. The reorientation of healthcare towards community-based care will involve the Department of Housing as it requires investment in accessible environments, and schemes to support the adaptation of homes for the elderly and disabled; it will involve the Department of Social Protection as more carers will require financial assistance; it will involve the Department of Jobs and the Department of Education as it will be necessary to have a skilled workforce to support a growing home care market; and it will involve the Department of Transport to support the mobility of people being cared for within their local communities who need reliable access to supports and services.
- **Address staff shortages:** Action must be taken to address staff shortages in key medical specialties such as general practice and psychiatry as well as amongst allied health professions. Work incentives and student bursaries must be created to encourage doctors and specialist clinicians to remain in Ireland. Likewise, efficiencies could be created by the reconfiguration of staff structures. For example, freeing up nurses by using trained healthcare assistants to deliver low-level nursing tasks.

- **Promote employment in the home care sector:** In 2009 the Irish home care market was worth €340million, with projections suggesting it could be worth as much as €568million by 2021. Preparing for the elder boom and the projected increase in the prevalence of disability and chronic conditions, and promoting quality employment within the sector is a significant challenge for Ireland over the coming years. Failing to do so will have implications for labour supply and the delivery of the health strategy.

#### **Other Considerations for the Committee**

- Use the resources available to the Committee to estimate the cost of providing a statutory entitlement to home care services for people of all ages and ensure funding is ring-fenced for its implementation.
- Legislation giving an entitlement to home care will stand or fall on the funding model chosen. The considerations in relation to the criteria underpinning the chosen funding model (section 2 above) will be critical.
- GPs, Public Health Nurses and other social care staff are already overworked and under-resourced. It will be critical to secure their support in the roll-out of a community-based health strategy.
- Being able to identify a patient uniquely is essential in the provision of high quality, integrated healthcare. The Health Identifiers Bill 2013 and the impending introduction of a health identifiers will be a critical building block in the health reform programme.
- Examine the role assistive technology, telecare and reablement supports can play in helping people remain at home.
- The support of family carers will be critical to the implementation of any health strategy and as such it is important that their views are listened to during the consultation process. Family Carers Ireland would welcome the opportunity to attend a hearing of the Committee

#### **In Conclusion**

FCI supports the approach taken by the Committee in recognising the need for a long-term, cross-party consensus on a health strategy. There can be little doubt that whatever strategy the Committee proposes, family carers will be the cornerstone of its implementation and success. To this end, we ask that the Committee continue to engage with the caring sector to ensure the needs of carers are considered in your deliberations and reflected in the final strategy. Finally, on behalf of Family Carers Ireland I wish the Committee every success in your work and look forward to an improved healthcare system as a result of your efforts.

**John Dunne**  
Chief Executive  
Family Carers Ireland

<https://familycarers.ie/help-and-advice/carer-groups/>

## Family Therapy Association of Ireland (FTAI)

The Family Therapy Association of Ireland (FTAI) is the representative body of Family Therapists in Ireland. FTAI is a member of the Irish Council for Psychotherapy (ICP) and through it is affiliated to the European Association for Psychotherapy (EAP). Family Therapists operate to the highest European Standards and advocate for these to be accepted in Ireland for the development of the profession of Psychotherapy and for the Protection of the public.

In this submission on the Future of Healthcare, we in FTAI advocate for a movement toward a universal health service. We believe that, in particular, Mental Health Services in Ireland need to be expanded and made more accessible to the public that is currently the case. We argue the widespread availability of Psychotherapy free of cost at the point of entry would have many benefits for health service providers and users. Among these would be:

- It would give power to the public to take greater ownership of their Mental Health needs by having greater control over access to services
- It would have a significant cost benefit by reducing entry to the Primary Health System
- It would thereby ease pressure on the Primary Health System
- It would ease pressure on the GP system
- The model of psychotherapy provision within the NHS system in England can provide considerable learning for how we might proceed in this direction

In order to achieve this positive benefit and incur these savings, it is vital that the profession of Psychotherapy be brought under statutory regulation as soon as possible to give both service users and the Oireachtas confidence in developing, funding and using this service.

We ask that the Committee give these matters consideration.

### **Introduction**

The Family Therapy Association of Ireland (FTAI) is the representative body for Systemic Family Therapists in Ireland. FTAI recognizes the need to develop a comprehensive approach towards healthcare planning in Ireland. FTAI holds that this approach should be based on what is identified as best practice internationally, and that this identification of best practice should be evidence based.

Family therapists follow a model known as the Systemic Model. The basis of Systemic Therapy is a core belief that our lives consist of us being involved in a series of interlocking systems, personal relationships, family, work, the community, and that power issues are often at the core of these relationships. In many of these systems, we find ourselves locked

in a hierarchical power structure in which we have or can exert little power; or certainly less than we need to for our own good.

A core part of our work is a belief that coming to an understanding of the role of power relationships in our lives and freeing ourselves from them or learning to work productively with and within them can greatly improve the quality of a person's life. Ultimately, a systemic approach asks us to look at these power relationships and see if it is possible to move to a more collaborative system of power relationships.

Given the hierarchical state of the medical system, power issues are at the centre of any user's experience of the system. This can be for many a wholly negative experience. FTAI proposes changes to the system which will make some services more freely available that at present, and simplify access in the future over what is available now. FTAI proposes that were this to be done for many local services in the area of Community Based Mental Health, then life quality and access to services would increase for many people *even if the fundamental hope of the committee to perhaps replace the current model were not met.*

As a part of review of healthcare systems over the next 10 years; FTAI proposes a number of changes within the mental health services.

### **Strategy**

FTAI accepts that Ireland has long had a two tier health system, and that this two tier system has, for reasons that are beyond the scope of this submission, enjoyed much popular support. However, one of the elements of our changing society over the past fifty years has been the development and deepening of the concept of equality. The recent marriage referendum is perhaps the best example of this. But applying a deeper concept of equality to healthcare is leading to a change in the popular view of our health system. Whereas previously, it could be argued that having the two tier system was a matter of *acknowledging peoples' right to choose*; it is now being viewed *as an equality and justice issue*. Given that private health care is increasingly unaffordable for the majority of people, pressure on government to create a viable one tier system is likely to grow. The question arises as to how to bring this change about. Much of our experience of involvement in the health system is in the area of Psychotherapy and Mental Health, and it is to the creation of a one tier access to Mental Health services that we shall now turn.

It is a core view within Systemic Therapy that major change is often too difficult to achieve; and practically the best way to proceed may be through a planned sequence of minor changes which, it is hoped, may snowball in time to a major change. The reason for stating this is that despite much change over the years about the need to challenge the two-tier system, change is still far away.

### **FTAI proposes a strategy change in how mental health services are accessed in this country.**

We propose a move from the current over-medicalized system where a psychiatrist or psychologist carries out an assessment on a member of the public to determine what level of service they require, to a self-referral system where the public decide what level of service they require and access it accordingly. While many who present with complex

mental health issues require a range of interventions ranging from psychiatric to pharmacological approaches, many who present with issue such as anxiety or depression or family-based issues do not look for or require such levels of resource. What they want is highly-trained, experienced and regulated psychotherapists who can help them to achieve goals of their own selection.

Currently for people presenting with mental health issues, there are a number of pathways to treatment (1). Principally the service user approaches their GP who refers them onto a Community Mental Health Services, and an assessment follows. While on paper this appears to be a sensible way to proceed with checks and balances built into the system, we assert selecting the alternative option, which involves facilitating the person to identify their own needs, will be both cheaper and more patient-friendly and will have a number of measureable advantages.

There is copious evidence that giving power back to communities and to individuals to be involved in their own treatment design is positive benefit for self-efficacy and for life in general (4).

We propose this be done in the area of Psychotherapy and Counselling. Currently, the National Counselling Service is mainly working in a vitally important but restricted field. We propose consideration be given to the establishment of a National Psychotherapy service designed to help people in their daily lives. Currently the absence of such a service leaves people with little opportunity to seek professional support for their issues without paying.

Certain power relationships are unavoidable. We believe this is the case for example in Hospital in-treatment. We understand the development of the medical model of treatment. However, there has been long been a recognition of an over reliance on a model which is often too cumbersome and expensive and not suitable for all situations. In this submission to the Committee, we suggest that while there is much emphasis on making a new health system, with new structures, we have been having these conversations for many years without making the necessary progress. We question the presence of the medical model in so many areas of mental health care, where it may not be the most appropriate model to use.

### **Roadblocks to Treatment; The lack of Statutory Regulation of Psychotherapy**

People looking to engage psychotherapeutic services encounter many roadblocks to the treatment they want. One is the lack of statutory regulation of Psychotherapy and Counselling. Because the state has not yet regulated these professions and identified and imposed standards of qualifications and training, it is difficult for the general public to be clear on what standards they should seek or require from a therapist. Only a small number of psychotherapists in Ireland are trained to the standards which are accepted across Europe by the European Council for Psychotherapy (EAP). It is vital that the Committee recognize that if we are to embrace principals of justice and equality in the delivery of Mental Health services, we must embrace the Europe-wide understandings of what are acceptable levels of qualification and training for psychotherapy services.

### **Roadblocks to Treatment; Cost**

Our members speak anecdotally of a number of roadblocks our service users experience in negotiating the system. Psychotherapy in Ireland has been largely a private matter, and cost has become a major factor in availability; with the public often not able to access the service they need for economic reasons. This means that for many in Ireland, there is a clear two tier system of psychotherapy services. Research from the UK suggests that adults in the bottom fifth of the population by wealth are more likely to develop a mental illness than the rest of the population (2); but these are the very people who cannot afford to pay for psychotherapy. Their only option is to go untreated or to go an over-stretched mental health system, causing a knock-on effect to waiting lists. Were the option of self-referral to a service more available, this knock-on effect might be prevented from happening.

There are clear links between poverty, exclusion and the development and persistence of mental health issues (3). While it is beyond the remit of the committee to alter the economic forecast of the country, recommending the provision of an adequately-resourced Psychotherapy service and Family Therapy supports would help to provide an important type of safety net for people struggling to cope with the effects of the current recession.

Amongst other factor our members speak of are that when services are made available, it is often on a time-limited or session-limited basis. The number of these sessions on offer is often below what is needed for a successful intervention. Our argument is increasing the number of sessions on offer gives a better result and eases strain on the Primary Mental Health System and so should be considered.

We also find that waiting times for assessment, and for follow-up to assessment, are too long.

We are further concerned that a decision on the type of service to be offered is not made by the service user, but is often imposed. This can happen, for example, when a particular modality is nominated as the approach rather than the service user choosing their modality which best suits them, or when a group work approach is taken rather than an individual treatment approach.

### **The impact of proposed changes on current staff in Primary Health Care**

We do not see this as a major issue because the creation of a psychotherapy service is not a competition to a current system but a compliment. It is a core part of all psychotherapy practice codes that a case is referred to another service if that is more appropriate (5) so at this point it could be referred into the mental health team to begin their assessment. The team could then accept the case, or refer it back to psychotherapy services. This could serve as a check for the service user.

We also believe that a greater availability of talk therapy would considerably reduce the pressure on an overstretched GP system, where doctors find that given the time pressure on doctor appointments that many patients would benefit from an available talk therapy option.

### **The Search for a Best Practice Model**

The easiest model for consideration in terms of best practice for making psychotherapy services more widely available already operates on the Island of Ireland. It is, of course, the NHS model (6). Access within the NHS is by approaching your GP or by self-referral. This is a simple, cost effective approach, it would require two elements: an expansion of the National Counselling Service beyond its current remit and funding, and an agreement to recruit suitably qualified and trained psychotherapists. In terms of establishing a working relationship in this area between the HSE and the NHS, it is worth noting that when the HSE was looking to develop material on psychotherapy services that it turned directly to the NHS (7). It seems reasonable to believe that if the Committee were to recommend the development and expansion of psychotherapy services, that the HSE would respond positively to this request.

### **Funding**

We acknowledge that there would be costs attached to the development of such a service, but expenditure can bring measurable benefits. There is ample evidence from studies going back 40 years that individuals, couples and families who participate in psychotherapy fare better in terms of managing their issues in the short to long term than approximately 75% of people who do not participate in psychotherapy (8).

There is also evidence that people who use psychotherapeutic services use fewer medical services, including hospital services, and so incur reduced medical costs to the Exchequer. This is known as a **Medical Cost Offset**. In research conducted over a 30 year period, it was demonstrated that in 90% of cases surveyed, the cost offset was actually greater than the cost of the psychotherapy provided. In other words, making psychotherapy services such as Family Therapy readily available results in a significant cost saving the Primary Health Budget to such an extent that it becomes self-financing (9). As was said a long time ago:

*“An ounce of prevention is worth a pound of cure.”*

In summary, we ask the Committee to consider the following points when reporting back to the Oireachtas:

1. The need to prioritize the statutory regulation of Psychotherapy in order to protect the public and to ensure the highest European standards of treatment operate in Ireland
2. The need to develop the profession of Psychotherapy in order to make Psychotherapy widely available to the public on a national basis
3. The need to simplify access to these Psychotherapeutic services in order to alleviate the pressure on the Primary Health Care system
4. That making high-quality Psychotherapy available to the public has a substantial medical cost offset

Thank you on behalf of our members for considering this Submission.

Yours Sincerely,

Peter Caffrey  
Chairperson  
Family Therapy Association of Ireland  
Email: chairpersonftai@gmail.com

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<http://www.familytherapyireland.com/>

## **Federation of Ophthalmic and Dispensing Opticians (FODO) & Association of Optometrists Ireland (AOI)**

### **The joint submission of the Federation of (Ophthalmic and Dispensing) Opticians (FODO) Ireland and the Association of Optometrists Ireland (AOI) to the Oireachtas Committee on the Future of Healthcare**

The World Health Organisation (WHO) defines optometry as “a healthcare profession that is autonomous, educated, and regulated (licensed/registered), and optometrists are the primary healthcare practitioners of the eye and visual system who provide comprehensive eye and vision care, which includes refraction and dispensing, detection/diagnosis and management of disease in the eye, and the rehabilitation of conditions of the visual system.”<sup>265</sup>

The demographic profile of Ireland is changing rapidly and with this, the health needs of the Irish people are also shifting. However, it is clear that the current system of healthcare provision, developed for past conditions, is failing to cope with present realities.

For the provision of eye care, there is an urgent need for a reallocation of resources and redistribution of clinical interventions, in particular for primary care. To make services efficient, interventions more effective, and outcomes for patients more successful, Ireland must have a primary care system that enables the complete suite of healthcare professionals to play their part. The primary care system must also have direct linkages to the secondary care system to facilitate efficient patient discharge, management and treatment.

With ever increasing waiting lists, over-reliance by GPs on referrals to specialists and the increasing prevalence of eye conditions, eye care in Ireland is unnecessarily overburdened. Community optical practices located across the country and staffed by qualified and trained optometrists with the clinical knowledge and experience to make diagnoses and treat certain eye conditions are not being used to do so, at both a massive cost to the Exchequer and to the detriment of patients. Given that the populations most likely to be affected by eye conditions are also those that are likely to grow significantly in the next ten years, it is imperative that the current model of provision is reformed and sooner rather than later.

A fully funded model of primary eye care services delivered in community optical practices is the best solution to meet growing patient need and the key to ensuring that Ireland delivers world class eye care to all its citizens. There is a strong body of evidence from other jurisdictions, such as Scotland, that this model is the most cost efficient mode of delivery with the best clinical outcomes for patients.

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<sup>265</sup> <http://www.worldoptometry.org/en/about-wco/who-is-an-optometrist/>

### **Key Recommendations for the Committee:**

- Removal of legislative barriers to the delivery of primary care in the community by allied health professionals. This would also include:
  - Changes to allow direct referral from optometrists and other clinicians to A&E and other hospital departments. Community optical practices should also be enabled to refer patients directly to secondary services and tertiary services.
  - Legislation should be amended to allow those with benefit under the social welfare schemes access to COSSMT and other secondary care clinics.
  - Allowing children to be seen and screened other than under the current limitations of the Healthcare Act 1970
  - Allowing the PPS number to be used as a unique identifier by all clinicians and IT systems improved to allow layered access to records for information and upload.
  - Prescribing rights for suitably qualified primary care clinicians.
  
- The development of a clear cut national guideline for procedures in all primary care schemes so that access is equitable and consistent in all areas.
  
- Better use should be made of primary care practitioners within hospital settings to free up expensive hospital resource. As part of this, provision should be made for in-hospital clinical training for optometrists. This would help foster a mutual understanding of capabilities and roles within the health service.
  
- Develop protocols and reporting structures to allow patients who can be, to be managed in the community by other clinicians. This would reduce patient travel time and expense, increase access and reduce costs. Allowing patients to control appointments and access also reduces the incidence of non-attendance.
  
- Primary eye care should, wherever possible, be delivered by optometrists working in community optical practice.
  
- Children's eye examinations should be undertaken by optometrists as part of a HSE contract following failure at the junior infant school screening or where required opportunistically required for older children whilst still in primary school
  
- A formalised pathway for management of dry eye and red eye conditions should be developed by the HSE, whereby patients are examined and treated in community optical practices in the first instance, based on the Scottish and other UK models.

- Investment in a robust IT system for all HSE providers to use – primary care professionals, general medical practices and hospitals, in order to facilitate greater information sharing and maintain high levels of security on patient data.
- An Optometric Advisor to the HSE and Department of Health should be appointed in order to promote and oversee best practice in the delivery of primary eye care.
- Primary Care Reimbursement Service (PCRS) should be used to provide payments to optical practices for all primary eye care services delivered by them, in order to provide statistics and data on the cost nationally and users of all services.

### **Transforming eye care services in Ireland**

The promotion and provision of world-class eye care should be an essential component of Ireland’s health strategy. A much expanded role for community optical practices in the delivery of primary eye care, working alongside other primary care providers, HSE community ophthalmologists and the ophthalmology departments of local hospitals, is crucial to creating a system of eye care that provides clinical excellence in a cost effective way with timely interventions and treatment that will reduce sight loss and improve outcomes for patients. It is our view that the current system of primary eye care provision by the Health Service Executive (HSE) is deeply flawed and inefficient, resulting in ever-increasing waiting lists and wasted resource. The current system does not effectively utilise the clinical knowledge, training and experience of optometrists and dispensing opticians working in community practices throughout the country, much to the detriment of patients. At present the role of optometrists and dispensing opticians in community practice is largely limited to carrying out eye examinations and the provision of spectacles or contact lenses.

Optometrists can do much of the work (at a greatly reduced cost) that is currently allocated to the community ophthalmic physicians (COPs). According to the National Eye Care Plan 2014, there are only 22 whole time equivalents COPs employed by the HSE<sup>266</sup>. In a country with 4.76 million people, this equates to one COP per 216,000 people. This has inevitably resulted in excessive waiting times for treatment and growing levels of unmet need for patients with eye problems, with an adverse impact on sight loss prevention. It has also resulted in our highly qualified COPs and ophthalmic surgeons being utilized for clinics where their skill set is being under utilised.

We ask the Committee to recognise in their strategy that community optometrists, working in over 350 practices around Ireland, should be explicitly identified as the first point of reference for any citizen with an eye care problem and empowered to deliver a broad range of primary eye care services. As Ireland’s older population increases over the next 10 years, the prevalence of sight threatening conditions such as age-related macular degeneration

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<sup>266</sup> National Eye Care Plan, 2014, p.12 - 14

(AMD), cataract, ocular hypertension, diabetes and glaucoma will also rise. We ask the Committee to recommend in their strategy that the HSE engage with community optical practices to develop a framework for the roll out of primary eye care services in order to meet the growing eye health needs of the population..

### **Doing more for less – The economic benefits of optometrists as primary eye care providers**

From a cost-efficiency perspective, it is irrational for the HSE to rely on expensive medical professionals to provide primary eye care when optometrists can deliver the same quality of service, with no risk to patient safety or quality of outcomes, at a lesser cost.

All optometrists in practice in Ireland must be registered with CORU, the health professions regulator, and will have undergone in depth academic study of eye health (a 4 year B.Sc. degree is the minimum requirement) and supervised clinical training prior to registration. Optometrists and dispensing opticians are required to undertake continuing professional development (CPD) and all optometrists and dispensing opticians possess professional indemnity insurance cover. Almost all community optical practices have contracts with the HSE and the Department for Social Protection to deliver eye examinations under the Optical Treatments Benefits Scheme.

A reformed model of primary eye care provision delivered in community optical practices would save the HSE a significant amount of money. It would also reduce the burden on GPs and substantially reduce waiting times for hospital eye services (HES), and provide patients with a swifter and more convenient service. The three areas outlined below exemplify how a reformed model could both improve eye care services and better meet patient needs in a more cost-effective way.

#### ***Children's eye care***

The current waiting lists for children's eye-care can be solved immediately and cost effectively by referring children from the existing Primary School Children Optical Scheme to their local optometrist, rather than HSE Community Clinics which, in some areas, have waiting lists of up to six months for urgent cases and up to four years for non-prioritised patients. More complex cases would then be referred to the multidisciplinary team or hospital.

The benefits of introducing such a scheme include:

- Elimination of children's waiting lists
- Earlier diagnosis and treatment leading to better clinical outcomes
- Freeing up of specialist ophthalmology for complex cases
- By extension– reduction of adult waiting lists
- Easy to audit and generate statistics for future planning.
- Better educational and social outcomes for children with visual impairment

On the basis of a HSE Community Clinic examination costing €100 per visit and at the current level of 100,000+ children's annual examinations, we estimate an annual cost saving in excess of €6 million can be achieved by directing children's eye care to community optometrists.

### ***Adult Eye Care***

The principles of treatment delivery outlined in the previous section can also be applied to adult eye care. Community optometrists are best equipped to provide a triage service to streamline each individual patient into the appropriate, most cost-effective care pathway. In practice this would enable optometrists to follow established evidence based protocols and guidelines to monitor pathology, treat routine conditions, appropriately refer complex or urgent cases and then follow up and monitor stable and discharged cases.

This model can be applied, in a condition appropriate manner, to each of the major eye diseases including cataract, glaucoma, AMD and diabetic retinopathy. By implementing this approach we estimate that the HSE would save at least €15 million per annum.

### ***Dry/Red eye scheme and non-chronic eye problems***

Optometrists are trained to differentially diagnose the various conditions that fall under the umbrella label of 'red eye'. They possess and are trained in the use of the range of diagnostic equipment necessary for accurate diagnosis and treatment, which most GP clinics will not. Currently, emergency eye care services for red eye problems in Ireland are provided locally by optometrists on an ad-hoc basis. The service is only available to those who wish to pay privately rather than attend their GP, effectively reinforcing the two tier provision of healthcare by limiting the poorest in society, who rely on access to healthcare through the medical card/GP payment card system, to seek treatment from their already overburdened GPs.

The Scottish Government has provided for the treatment of red eye by community optometrists, freeing up GP services and reducing onward referral to hospital services. NHS England have piloted a very successful red eye scheme in Manchester with a view to rolling it out nationally and, since 2014, a red eye pilot scheme has been in place in Dungannon and Armagh with positive results.

We ask that the Committee recommend that a formalised system for the management of dry/red eye (including minor eye care emergencies and infection) by community optical practices be put in place using the successful models from the UK as a basis for planning and implementation. We estimate that a significant saving of several million Euros would arise from reduced GP appointments and unnecessary referrals to secondary/tertiary care.

### ***Case Study – Scotland’s successful reform of primary eye care.***

The Scottish Government, in particular, have been highly successful in restructuring the delivery of primary eye care services by devolving provision to community optical practices. In Scotland, all patients with eye problems go to an optometrist for evaluation, triage and if necessary, referral. A 24 hour telephone hotline service operates for those patients who require an urgent appointment. In most cases GPs no longer see patients with eye health problems and walk-in eye casualty centres have been closed.

Referrals from community optometrists are direct to secondary/tertiary care, and the patient sees the appropriate specialist on their first visit. Electronic referral will be introduced in the near future.

All of these activities are within the core competencies of optometrists. This system has reduced the number of referrals to hospitals and the savings to secondary/tertiary care have been calculated conservatively at £55m per year.

The scope of practice of optometrists in Scotland will extend further in the coming years with the discharge of patients with stable glaucoma, diabetic retinopathy and macular degeneration for monitoring by optometrists in the community. 25% of optometrists in Scotland are qualified or currently in training to undertake relevant prescribing.

### **Barriers to progress**

The successful transition of primary eye care provision to community optical practices will require systemic and in some instances, legislative change. We have outlined below, the main areas of potential difficulty that may arise in transforming primary eye care services to a model based on delivery by community optical practices.

### ***Information sharing and IT connectivity***

In order to ensure that primary eye care in the community contributes to an integrated model of primary care provision as a whole, protocols and clinical pathways must be developed to enable optometrists with responsibility for the management of a patient’s eye care to share relevant clinical information with other primary care professionals involved with a patient’s care and vice versa.

To safeguard the confidentiality of patient data and safely and efficiently facilitate the sharing of patient information across primary and secondary/tertiary care, a robust IT system integrated with general medical practices and hospital systems would need to be developed and rolled out. The issue of efficient IT systems operating across the health service is one that the Committee will undoubtedly be required to address in its proposals for a long term strategy. We believe that any comprehensive review and redevelopment of IT systems should include the provision and use of these systems by the suite of health

professionals who deliver primary care, which would include community optical practices. Integration and investment at the outset will save a lot of further costs downstream.

### ***Referral and Prescribing***

For community optical practices to be able to provide primary eye care services, they will need to have direct referral capabilities for patients that they examine. Currently optometrists, on identifying referable ocular pathology, must direct their patient with a medical card via the GP, for secondary or tertiary care. This referral system is circuitous and inefficient. Direct referral pathways should be developed for all primary care providers, including optical practices, to the secondary/tertiary care system in order to eliminate this unnecessary and inefficient burden.

As part of any redesign of services that would expand the role of community optometrists, it would be essential that appropriate prescribing rights be afforded to appropriately qualified optometrists for the relevant medications and preparations required to treat the eye problems that patients present with. The Committee should look again to the progressive policies in Scotland where registered optometrists with a prescribing qualification have been able to prescribe and treat conditions using ophthalmic medications since 2013. To introduce this may require amendments to the relevant Acts but may also be possibly introduced by Statutory Instrument under the Irish Medicines Board Act 1995.

### ***Contracts and Commissioning***

If community optical practices are to take on new roles beyond sight testing, new contractual frameworks will need to be agreed and put in place.

Safe and consistent practice should be a requirement of, and be managed through contract specifications. It will be essential that all contracts are proportionate to the risks involved. In the case of primary eye care, these risks are recognised to be low. Optical practices comprise a mix of large, small and independent providers. The majority of optometrists and dispensing opticians are employed under limited company models and it should be these companies that hold the contracts.

We ask that the Committee recommend that the HSE propose a national framework for primary eye care services in community optical practices. In developing this, we would ask that the HSE consult and work with both FODO and the AOI, as the representative professional bodies for the sector.

The Primary Care Reimbursement Service (PCRS) is already used by most community optical practices providing eye examinations under the Community Ophthalmic Services Scheme (COSS). We believe it would be most efficient that any future payments for primary eye care treatments delivered by community optical practices be managed by this same service,

similar to the medical card/GP visit card payments to general medical practices with GMS contracts.

### **System Change – UK Case Study (Minor Eye Conditions Service – MECS)**

Across the UK, Minor Eye Conditions Services (MECS) have been commissioned to allow community optical practices provide treatment for minor eye conditions. The service is currently available across all of Scotland and is being rolled out across England, Wales and Northern Ireland. Under the scheme, community optical practices accept referrals from GPs, pharmacists, and other professionals for patients with sight problems that are beyond the scope of the NHS sight examination. Walk-in patients with eye problems are also treated under the scheme.

A MECS examination provides a timely assessment of the needs of a patient presenting with an eye condition. This is undertaken by a registered optometrist within suitably equipped premises who will manage the patient appropriately and safely. Management will be maintained within the primary care setting for as many patients as possible, avoiding unnecessary referrals to hospital services. Where referral to secondary/tertiary care is necessary, e.g. for emergencies such as possible detached retina, urgencies such as suspected wet AMD and routine further investigations, community optometrists can refer with appropriate urgency including calling the consultant ahead in cases of emergency.<sup>267</sup>

It has been shown that 78% of these patients can be effectively treated outside of hospital<sup>268</sup>. In some cases such as NHS Grampian this has enabled all minor and urgent work to be transferred to primary care, significantly freeing up hospital resources<sup>269</sup>. In a 2014 study of 6 areas implementing the MECS scheme, 92% of patients said they were likely or extremely likely to recommend the service to their friends and family.

At an average cost of £54 per patient, the MECS scheme provides savings of up to 40% over the previous system where all patients would be referred to secondary/tertiary care.

### **Primary Eye care Services Review Group (PESRG)**

As the principle eye care provider in Ireland we would welcome the publication and more importantly the implementation of the Ophthalmic Pathway report (Appendix III) as agreed. This is the way forward for eyecare in Ireland.

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<sup>267</sup> Local Optical Committee Support Unit (LOCSU). <http://www.locsu.co.uk/community-services-pathways/primary-eyecare-assessment-and-referral-pears/>

<sup>268</sup> Minor Eye Conditions Service (MECS) Pathway. LOCSU. 2015. [http://www.locsu.co.uk/uploads/community\\_services\\_pathways\\_2015/locsu\\_mecs\\_pathway\\_rev\\_may\\_2015\\_v2.pdf](http://www.locsu.co.uk/uploads/community_services_pathways_2015/locsu_mecs_pathway_rev_may_2015_v2.pdf)

<sup>269</sup> Delivering Better Health, Better Care Through Continuous Improvement: Lessons from the National Programmes. NHS Scotland. 2008. <http://www.gov.scot/Resource/Doc/212120/0056427.pdf>

In 2014, the HSE established the Primary Eye care Services Review Group (PESRG) to appraise the current system of primary eye care provision and set out proposals to revamp and improve the way in which primary eye care is delivered.

Neither optometrists nor dispensing opticians were invited to be part of the committee but were invited to make submissions. The AOI and FODO submissions to the Review Group (Appendix I and Appendix II) are attached. In our submissions, we called for an expansion in the role of community optical practices in primary eye care and set out clear arguments for reform of both the delivery of primary eye care and the administration and eligibility criteria of the COSS. We highlighted some specific examples of the need for reform both of the system protocols and administrative structure.

As of the date of this submission, the report of the review group has not been published and we have not yet received any indication as to what the contents or proposals outlined in the report will be. However, it is clear that any recommendations or proposals the report makes to restructure the delivery of primary eye care to community optical practices would be bolstered by this Committee's report and proposals for healthcare in Ireland over the next ten years.

We ask that the Committee to make explicit their support, based on the principles and rationale outlined in this submission, for an enhanced primary eye care service that will fully utilise the skills and resources of community optical practices in its delivery.

<http://www.fodo.com/>

<http://www.optometrists.ie/>

## Galway Community Perinatal Mental Health Working Group

Prepared by the Galway Community Perinatal Mental Health Working Group and Perinatal Mental Health Group University Hospital Galway

Contributing Members: Dr Malie Coyne, Clinical Psychologist, HSE West; Deirdre Naughton, Clinical Skills Facilitator, Galway University Hospital, HSE West; Siobhan O'Connor, Staff Midwife Galway University Hospital; and Nicole McGuigan, Galway Parent Network.

Contact details – Dr. Malie Coyne, Clinical Psychologist [marie-claire.coyne@hse.ie](mailto:marie-claire.coyne@hse.ie)

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This submission is focused upon the lifelong significance of perinatal mental health for both adults and infants. In Galway the Galway Community Perinatal Mental Health Working Group and Perinatal Mental Health Group University Hospital Galway are both seeking to remedy the serious lack of awareness and support that exists within the health service and the community in order to improve outcomes for families. We recognise that the current government strategies are moving towards acknowledging the significance of childhood but are falling short of adequately addressing the critical perinatal period and the mental health of both the mother and baby at that time, which lays the foundation for lifelong wellbeing for the infant. Our recommendations cover policy creation, service provision, care processes, pathway development, and staffing issues.

### **Submission**

The proposed new 10 year health strategy provides an inimitable opportunity to modernise the health system in light of significant research into the foundations of good health. It is now undeniable that the time period stretching from before birth until the age of three is of lifelong significance, which is an enormous cultural and societal shift from historical attitudes when it was often considered to be the least significant. Consequently, it is imperative that the Health Services provided in Ireland are re-focused to ensure that this period is given significant priority as the foundation of good health over the lifespan.

Our submission is focused upon the significance of perinatal mental health care, which we define aligned with international sources (National Institute for Health and Care Excellence NICE, 2007) as from conception until the child is aged one. Although perinatal mental health focuses on the mother, it is intricately interwoven with infant mental health, such

that the care of the mother is the care of the infant by proxy. The Maternal Mental Health Alliance 'Everyone's business' campaign (2014) identifies the negative impact on the woman, her children and her family when mental ill health is not identified and/or untreated in the perinatal period. The financial cost benefit analysis shows that the cost of early intervention and appropriate treatment ensures a larger economic benefit to society than when untreated (Bauer et al., 2014). Martin and Carr (2006) estimate that 15% of under 5's in Ireland meet the criteria for at least one psychological disorder. There is no infant (and therefore in most cases adult) mental health without maternal mental health. As such we see these recommendations, although focussed on care of the mother and care-giving adults, as recommendations that prioritise making an investment into the future wellbeing of all people in Ireland.

*"Outside of (Dublin) there is no routine assessment of or screening for major mental health problems in pregnant women at a time of markedly increased risk and at a time where appropriate advice and intervention can have such vital benefits not only for the mother herself but for her bond with her new baby whose long-term development depends so much on her wellbeing,"* (Consultant perinatal psychiatrist at Holles Street Dr Anthony McCarthy in Shannon, 2013).

Current policies and strategies, such as Better Outcomes Brighter Futures, Creating a Better Future Together - National Maternity Strategy (2016-2026), The Nurture Programme - Infant Health and Wellbeing (2015-2018), Healthy Ireland, and the foundational goals of the Area-Based Childhood Programme (2013-2017) are all drawing the focus of Irish policy towards this crucial period. There has been recognition in Ireland of the lifelong significance of perinatal mental health in *The Case for Prevention and Early Intervention*, published by The Prevention and Early Intervention Network (Harvey, 2014), and yet no focussed strategy has been developed. It is understood that it is a challenging area given it doesn't fit neatly into one area of government policy. It intersects physical health, mental health, early years, child and family services, social work, child protection, community development and welfare. Consequently by priority we recommend this area be looked at specifically and a focussed Perinatal Mental Health strategy developed in Ireland as it has been in other countries. Relationship building with formal services such as health, semi-formal services in the community, and informal supports such as family, is an essential component of mental health for perinatal women in order for them to have social support to alleviate stress at

this time of transition. Good relationships not only benefit the infant indirectly through support for their mother's wellbeing but also directly through expanding the network of healthy people to develop attachment towards and model themselves upon at this crucial time of learning. Thus healthy social relationships have multiple positive outcomes. Below we discuss specific recommendations to facilitate these including Continuity of Care and HSE staff training and staffing levels as well as the creation of more supports in the community.

### **Section Three; Recommendations**

In order to provide adequate services to families during the perinatal period we recommend the following:

#### **Development of a Perinatal Mental Health strategy.**

Numerous countries including New Zealand, Australia and Northern Ireland have developed a specific National Perinatal Mental Health Strategy. Ireland needs a strategy upon which local policy in all 19 maternity units can be based, comprising of a clear pathway of screening, identification, referral and treatment for perinatal mental health issues. This needs to cover prevention and health promotion, community facilitation of social support antenatally and postnatally, mental health screening in health services in both antenatal and postnatal care, clear identification of care pathways for people identified with mental health concerns and people diagnosed utilising both community and statutory services, support options for perinatal women to access, debriefing service for traumatic birth and bereavement, stigma free evidence based treatment for diagnosed women, ongoing community supports during recovery, and prevention support in future pregnancies. All staff who work with perinatal women need training in the promotion of perinatal and infant mental health as well as care pathways.

Ring-fenced funding needs to be allocated for training and the development of regional and local care pathways so that staff doing these screenings and all people who work with perinatal mothers in statutory services or otherwise can safely refer an identified perinatal woman into a targeted service.

There need to be a process to gather accurate statistics introduced to fully comprehend the extent of the need in Ireland and ensure adequate resources are put in place to address it.

This strategy would need to be developed in conjunction with service users by doing satisfaction research around people's experiences of the maternity services in Ireland.

### **Facilitate continuity of care for perinatal families**

The aforementioned significance of relationship building for perinatal families includes the very important relationships of perinatal women with their health providers. Continuity of care, where a perinatal mother/family access services from the same service providers throughout the period of health need, is a key factor in preventing perinatal mental health concerns. Continuity of care can be improved for this target group by utilising service structures that currently exist and expanding upon them.

Midwives assigned caseloads and identified as a lead professional for women with or without pre-existing mental ill health can establish trusting relationships, care continuity, early intervention and act as liaison within a multidisciplinary team when referral is required. Case loading in midwifery is limited in current practice in Ireland, those in the low risk category referred within the hospital setting to midwifery care can achieve continuity in the antenatal period but may be restricted in the intrapartum and postpartum period dependent on deviations and birth outcomes.

PHN's are a key community based support for postnatal mothers. Expanding their remit and staffing levels to cover more postnatal visits over a longer period, at least one antenatal visit in the mother-to-be's *home*, signposting to postnatal support groups for all perinatal mothers, liaison with Tusla and HSE social work services, and potentially other roles for this period. Further training for all PHN's on perinatal and infant mental health and evidence based parenting of babies. This will allow for better continuity of care for perinatal mothers and better integration of services. It could be considered to give these PHN's a separate role to general PHN's to facilitate the development of specialist knowledge.

### **Perinatal health services and staffing**

We recommend postnatal care and support services to extend to one year post-delivery from the current six weeks.

Midwifery led units can provide better experiences for mothers and midwives.

We recommend every hospital maternity unit to expand their services from physical maternity to care to include specialised staff and services focussing on perinatal mental health and wellbeing in child friendly environments. This would be staffed by mental health

midwives, social workers, evidence-based antenatal education practitioners, counsellors or mental health workers for debriefing after traumatic births and bereavements, and lactation consultants. Ideally specialised Public Health Nurses could also be based in the maternity services units. These will enable multi-disciplinary practice focused on the holistic wellbeing of mother and family, and decrease stigma of service use for families; normalising the challenges of this period and encouraging help seeking. Many successful parenting supports stem from centres where multiple governmental and NGO providers can be based in one location, ideally along with universal service providers such as child care centres, schools or a location for well-baby checks, in an ideal inter-agency working model. The Eurochild report on successful programmes in Europe holds up several of these models as inspiring practices (Eurochild, 2012).

We recommend services be based upon progressive universalism, with the above services available to ALL mothers, and further specialised support services available progressively through levels of concern such as Home Visiting schemes and Parents as Teachers programmes. Ireland already has two Home Visiting schemes, Lifestart and Preparing for Life (McClenaghan, 2012, PFL Evaluation Team, UCD Geary Institute, 2013). Noelle Cotter, 2013, has written an excellent evaluation of the successes of these programmes for the Irish Institute of Public Health. These programmes can be provided through community organisations and/or in conjunction with trained Tusla staff.

### **Training for all HSE staff who work with perinatal women and GP's**

All staff who work with perinatal women need training. Early identification of problems is essential to minimise the impact of perinatal mental health concerns on mother, infant and family. Further, staff can exacerbate, accelerate or trigger perinatal mental health concerns using disempowering practices and language and training on informed consent processes and patient-led practices would be essential in reducing the role of HSE staff in contributing to perinatal mental health concerns.

Midwives have a crucial role in identifying women in need of mental health support. Specialist mental health midwives are an excellent way to ensure individual needs are met.

They provide coordinated care and support for individuals, they working with the local multidisciplinary team to create adequate local care pathways in perinatal mental health, supporting training across the wider workforce and championing perinatal mental health within maternity care.

GP's need to be trained and resourced in services for perinatal mental health that are not exclusively medications. Currently it is common for GP's to omit the two week postnatal check up that all mothers are entitled to. We believe this already available and funded service should be used and reframed to be a mental health and wellbeing check for the mother, with a specific focus of the visit on the Whooley questions and/or the Edinburgh Postnatal Depression Inventory. GP's need training on supporting breastfeeding<sup>270</sup> and access to a current database of medications that can be safely prescribed to breastfeeding mothers. Much of the information they use in this regard is not current and is over-cautious, causing mothers to stop breastfeeding unnecessarily. This is to their own and their infants detriment physically and mentally.

Currently an online networking support for specialised mental health midwives, primary care providers, health and social care professionals interested in perinatal mental health to collaborate with knowledge sharing evidence based practice and resources is recommended by the Royal College of Midwives. Their 2014 paper '*Report on a survey of Heads of Midwifery on Specialist Maternal Mental Health Midwives*' provided research on methods to train and support those with an interest in maternal mental health and promote effectiveness in practice.

### **Integration of statutory health services with community health services**

Pathways of care must include *preventative* community resources available to all perinatal mothers as well as those in need of non-stigmatised social support for early stage or low level concerns. Good practice includes evidence based localised antenatal classes -

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<sup>270</sup> Breastfeeding is strongly linked to maternal mental health (Bora et al., 2015) and supporting the breastfeeding of new mothers not only improves physical outcomes but also the mental health outcomes for mother and infant. Current breastfeeding strategies fall short of targets due to the lack of resourcing to support new mothers individually in achieving breastfeeding, and the challenges of normalising breastfeeding in Irish culture.

potentially organised by Public Health Nurses to deliver continuity of care and seek to normalise the attending of these classes as standard practice for all antenatal mothers, facilitated parent toddler groups, strategies for peer communication and information sharing in postnatal wards, public and targeted campaigns regarding normal baby behaviour and needs, increasing lactation support in the community and statutory locations. Current effective models in increasing social support of mothers in the community include Community Mothers (various locations) and Networking Mothers (Galway), these supports do not need to be led by formal services as peer to peer supports have been found to be effective and much lower cost.

We also see it as essential to have adequate services in community to *treat* perinatal mental health disorders by staff who are trained to address these in an evidence based way. Current community psychology services providers in Galway are seeking training to serve this group with evidence based tools, and this training needs to extend to all clinical staff working with perinatal mental health. This can go hand in hand with the development of the Early Years or Infant Mental Health Services for the under 3s.

**Tomorrow's voters, taxpayers and leaders are being born to parents who are struggling with little support and changes in the care of those children and the support of their parents needs to be forthcoming in order for these newborns not to become tomorrow's prisoners, patients and suicide statistics. Theory, research and experience will condemn many of them to such fates without a holistic support plan for their parents, infancies and childhoods, facilitating good attachment and care to create strong healthy adults.**

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## Galway City Early Years Committee

Prepared by Evelyn Fanning, Health Promotion Officer; Dr. Malie Coyne, Clinical Psychologist & Marie Mulkerrin, Acting Senior Dietitian, HSE West, on behalf of Galway City Early Years Sub-Committee Contact details – Evelyn Fanning, Sub-Committee Chairperson [Evelyn.Fanning@hse.ie](mailto:Evelyn.Fanning@hse.ie)

Galway City Early Years Committee recommends that the proposed new 10 year Health Strategy includes the development and implementation of an early year's health and wellbeing plan for 0-3s as one of its priorities. This will help to give every child in Ireland the best start in life. A wide range of research now shows that the early years are a key determinant of health. Giving every child the best start in life is crucial to reducing health inequalities across the life course. The foundations for virtually every aspect of human development – physical, intellectual, nutritional and emotional – are laid in early childhood. What happens during these early years (starting in the womb) has lifelong effects on many aspects of health and well-being – from obesity, heart disease and infant mental health, to educational achievement and economic status (Marmot Review 2010)<sup>271</sup>

Research indicates that conception to age 3 is a crucial period in creating solid psychological and neurological foundations to optimise lifelong social, emotional and physical health, and educational & economic achievement. The earliest experiences, starting in the womb, shape a baby's brain, with 80% of brain development taking place by age 3. Hence, the first 3 years provide health professionals with a critical window of opportunity to affect change in a child's life due to the plasticity of their brain and the scope to work on parent-child relationships.

How we treat 0-3 year-olds shapes their lives, and ultimately our society. Loving and secure relationships with parents, together with the quality of the home learning environment, foster a child's emotional wellbeing. The capacity to form and maintain positive relationships with others; brain & language development; and ability to learn and relate to others are embedded in the earliest months of life. Poor support at this stage, particularly a failure to prevent abuse or neglect, can have a lifelong adverse impact.

The nutrition a baby receives in the first 3 years of their life will determine their future health, cognitive abilities, and physical development. The Barker Hypothesis and first 1000 days highlight the importance of early nutrition in fetal programming and long term health (Barker et al 1993, 1995)<sup>272</sup>. Good nutrition in pregnancy, exclusive breastfeeding for the first 6 months, appropriate weaning, and a healthy balanced toddler diet provide the building blocks for optimum physical and cognitive development. Breast milk is unique for a baby's nutritional requirements as it helps protect babies from infection and illnesses. Long-term conditions such as obesity, coeliac disease, cardiovascular disease and type 1 diabetes are less common in babies who were breastfed.

Childhood obesity is a huge contributor to chronic disease, and a huge drain on health care costs. 22% of Irish children aged 5-12 are overweight/obese (IUNA 2005)<sup>273</sup> Obese children are more likely to become obese adults which has adverse health consequences later in life. Early

interventions focusing on prevention, screening, and education should be invested into evidence based programmes to promote physical activity and nutrition in children ages 0-3, which will lead to a reduction in obesity and chronic disease.

Families have the most influence on their children and family based programmes are vital in supporting parents. Adequate levels of income, material and psychological support & advice for parents across the social gradient are critical. Good early parent-child relationships are associated with stronger cognitive skills in young children and enhanced work skills in school. Good quality early childhood education has enduring effects on health and other outcomes. These outcomes are particularly strong for those from disadvantaged backgrounds.

Investment in early years is vital to reducing health inequalities and needs to be sustained. Returns on investment in early childhood are higher than in adolescence yet current spending is higher in later childhood years and needs to be rebalanced towards the early years. Early interventions during pregnancy and ongoing support in early years are critical to the long-term health of the child and other long-term outcomes.

### **Key Priorities for inclusion in a ten year plan for the health service**

The proposed new 10 year health strategy provides a unique opportunity to help give every child in Ireland the best start in life. There is a growing body of evidence which demonstrates that early intervention can reduce health inequalities and promote health in adulthood.

#### **Current policies and strategies**

A number of national strategies, policy documents and initiatives have been developed which confirm a cross governmental and partnership approach across all sectors for improved health and wellbeing and an increased focus on prevention which provides the rationale for this submission.

- **Healthy Ireland** – A Framework for Improved Health and Wellbeing (2013-2025) acknowledges that “Child health, wellbeing, learning and development are inextricably linked, and the most effective time to intervene in terms of reducing inequalities and improving health and wellbeing outcomes is before birth and in early childhood. Giving every child the best start in life involves providing for their emotional and physical development, the acquisition of cognitive, linguistic and social skills and building their resilience which will support them through life. Intervention in the early years has been shown to be a good investment, as it provides a greater rate of return than that for later intervention”
- **Ireland’s Better Outcomes Brighter Futures:** the National Policy Framework for Children and Young People (2014-2020) states that “investment in early years care and education reaps significant dividends throughout a child’s life and to society as a result of better outcomes”. Furthermore, this framework promotes a shift in policy toward earlier intervention and aims to ensure the provision of quality Early Years services and interventions, aimed at promoting best outcomes for children and disrupting the emergence of poor outcomes.
- **HSE Healthy Ireland in the Health Services National Implementation Plan** (2015-2017) identifies Healthy Childhood as one of the health and wellbeing priority policy programmes.
- **The Nurture Programme** - Infant Health and Wellbeing (2015-2018) is designed to improve the information and professional supports that we provide to parents during pregnancy and the first three years of their baby’s life.

- **Creating a Better Future Together - National Maternity Strategy (2016-2026)** identifies health and wellbeing as one of its priorities to ensure that babies get the best start in life and families are empowered and supported to improve their own health and wellbeing.
- **Siolta and Aistear** - In relation to Early Education and Care, both Siolta (National Quality Framework for Early Childhood Education, 2006) and Aistear (Early Childhood Curriculum Framework, 2009) identify health and wellbeing as one of its standards and themes.
- The **Area-Based Childhood Programme (2013-2017)** has been developed to address the impact of child poverty and improve child outcomes in 13 areas of disadvantage and to mainstream the learning from the programme to services throughout the country. The focus of the ABC programme includes child health and development, children's learning, parenting and integrated service delivery.
- **Programme of Action for Children ([www.pacirl.ie](http://www.pacirl.ie))** – In relation to child health surveillance, Best Health for Children (October 2005) contains recommendations for child health surveillance in Ireland in eight key areas, which were incorporated into the ongoing regional and national training programmes for Doctors and Nurses. This national training programme for doctors and nurses working in child health surveillance began in January 2004.
- The **PIMHSIG Perinatal and Infant Mental Health: Position Paper & Recommendations** (January 2016) - represents the position of the Psychological Society of Ireland (PSI) and the Perinatal and Infant Mental Health Special Interest Group (PIMHSIG) that psychological services are a vital element of multidisciplinary service provision in the areas of perinatal and infant mental health. The PSI PIMHSIG seeks to address the lack of appropriate services in Ireland by promoting awareness of perinatal and infant psychology and to inform policy and service development at a national level.

### **Supporting Parents and Families**

Supporting parents and families is key to enabling every child to have the best start in life. The nature of day-to-day relationship between the child and primary care giver is crucial. Parental mental health (before and after birth) is a key determinant of the quality of that relationship. Pregnancy is a particularly important period during which the physical and mental wellbeing of the mother can have lifelong impacts on the child. For example, during pregnancy, such factors as maternal stress, diet and alcohol or drug misuse can place a child's future development at risk.

Supporting Mother's through nutrition in pregnancy and in the first few months following birth, is vital to enhance a child's physical and intellectual development. Nutritional intake in pregnancy has the potential to influence the growth and development of the baby. Specific nutrients play a key role in fetal development during each trimester, and also contribute to the risk of chronic diseases for the infant in adulthood (Koletzko B et al 2012) . Breastfeeding is good not only for the baby, but also to the mother, to society and the environment. Creating the right environment to promote and support breastfeeding is crucial. The Baby Friendly Hospital Initiative provides a robust evidence based framework to develop a whole system approach to supporting breastfeeding. It is recommended that women exclusively breastfeed their babies for the first six months of life, and after that, alongside appropriate complementary foods, for as long as they wish to do so. It is vital that Mothers are educated and supported around breastfeeding. Supporting families around weaning, and toddler diets can help reduce risk of obesity and chronic disease, and promote a physical and cognitive development for healthy lives. Parent's find it

difficult to recognise that their child's weight affects health. Irish research indicated a significant portion of 6 month old infants are eating foods high in saturated fat, salt and refined sugars (Tarrant et al, 2010).

Sensitive attuned parenting is the foundation of attachment. If a parent or carer is responsive to a baby's signals and 'takes turns' in communicating with them from birth onwards, babies develop a secure attachment to the carer. A secure attachment ensures a child will feel secure and reassured their needs will be met. This promotes emotional self-regulation and resilience into adulthood. Preventing and intervening early to address attachment issues will have an impact on ability to form trusting relationships, resilience and physical, mental and socioeconomic outcomes in later life.

Mental health issues can impact on a mother's ability to bond with her baby and be sensitive and attuned to the baby's emotions and needs. This can affect the baby's ability to develop a secure attachment. Many women are, however, 'falling through the cracks' and not getting the help they need for mental health problems during and after pregnancy. The Centre for Mental Health in the UK <sup>274</sup> and the Royal College of GPs highlighted that the biggest barrier to providing better support to women experiencing poor mental health in the perinatal period is the low level of identification of need. NICE has produced guidance on postnatal depression which can help health professionals recognise the signs of mental health problems and to select the appropriate treatment.

A commonly held belief, that children will outgrow early mental health difficulties has been comprehensively and consistently contradicted by research. Research has shown that infants raised in environments characterised by compromised parenting (resulting from mental illness and co-morbid drug and alcohol use), significant health issues in infancy (including prematurity, physical disability or intellectual impairment), social issues (including family violence) and inter-generational issues (including parents' own experience of less-than-optimal parenting), have poorer social and emotional developmental trajectories that continue into adulthood and are more likely to be in receipt of services, including primary care, child and adolescent psychiatry and disabilities services. Conversely, research also indicates that the first symptoms of psychological and emotional difficulties, which tend to manifest as behavioural problems in the preceding two to four years, are highly responsive to early therapeutic interventions resulting in an amelioration and reduction in symptoms (RANZCP, 2010).

Often children will not be seen in primary care services (e.g. Psychology) until they are aged 3 and above, which is not early enough, given that research points to a critical window of opportunity that exists in the first three years of life where the rapid brain growth and formation of pathways will not be repeated again in later years. Barbara Western, PSI member and PIMHSIG Communications and PR Officer, explains that: "It is verging on unethical to wait until a child is 5 or 6 years old before they, or their family, can access much needed psychological support and interventions." Ms Western added that: "Research and international best practice in the area of perinatal and infant mental health strongly shows that the earlier the intervention, the better the long term outcomes of health and well being for women, children and their families. It is profoundly disturbing that there are currently no dedicated and integrated perinatal and infant mental health services across Ireland. This really must change."

One of the most effective ways of tackling the mental health "epidemic" now and for future generations is to focus on improving mental health from the very beginning, given how significant this period is "in laying the psychological foundation for later life". Infant mental health is everyone's business. The research and facts stand for themselves, preventing mental health issues from birth is important and makes sense on all levels.

High quality assessment, early years' intervention and support are vital to giving children the best start in life and to tackling the underlying causes of ill health and poor wellbeing throughout people's lives. Interventions from health professionals in areas including: Infant and child nutrition, breastfeeding, physical activity and play, mental health and well being, safety and accident prevention, early learning and development, as well as expert advice in relation to tobacco, alcohol and drugs are critical to achieving good health. Intensive home visiting is effective in improving maternal and child health.

### **Training and Development**

GPs, midwives, nurses and other professionals who work with children and their families are key to better health in the early years. The provision of appropriate training and professional development of these and other professionals is key in providing a level of support that promotes sensitively responsive, loving, nurturing parenting. The importance of promoting infant mental health and assessing young children's social and emotional development is critical. Introductory and in-service training courses on child development in pregnancy and early infancy help all practitioners develop awareness of how the first three years of life are critical to a child's development. The importance of considering the emotional, social, nutritional and health needs of the whole family is key, including the importance of the couple relationship, because these form the context within which the young child is developing. The provision of on-going training which includes high quality modules on attachment, specialist pathways, parental and infant mental health, nutrition during pregnancy & from birth, drug and alcohol use, domestic violence, relationships and links to pregnancy birth and beyond should form a core part of the standardised curriculum and ongoing professional development of staff.

A number of international strategy documents have stated (e.g. ZERO TO THREE, 2012) that the perinatal period (i.e. the period from conception to twelve months postpartum) provides a unique opportunity for the promotion and prevention of perinatal mental health difficulties, in addition to the early intervention of mental health challenges with which parents and infants present (i.e. infant mental health). There is a significant gap within our current health system regarding the routine training of health professionals, identification of perinatal and infant mental health difficulties and clearly defined pathways of care.

### **The provision of high quality early years' settings – childminding, crèche, pre-schools**

Research indicates that the quality of early years' services and the settings that younger children and their families experience can have a significant impact on their outcomes. The quality of settings very much depends on the quality of training and development support available to, and undertaken by, those staff working in them. It is important to encouraging early years' settings providing quality care for children under age 3 to have at least one member of staff with additional competence in infant mental health. There is a need to explore how best to use existing guidance, research and examples of effective practice in ways that are more practicable and accessible for practitioners and to ensure appropriate emphasis is given to the promotion of infant mental health. A good quality workforce makes a difference to health outcomes however the childcare workforce remains low paid and low status.

### **Implementing evidence based practice**

Promoting the implementation of evidence of effectiveness of interventions for 0-3s and their families is key to giving every child the best start in life. Adequate communication and dissemination of evidence based practice is required to enable a continuous building of the evidence base. Staff should be given dedicated time to write up/publish interventions and record outcomes, which can then be used to contribute to further research. This will enable children aged 0-3 to have the opportunity to access expert advice and programmes from a range of health care disciplines.

## **Integrated Primary and Community Care**

### **Integration**

Galway Early Years subcommittee is a good example of interagency cooperation. However this needs to be adequately resourced and supported to enable this model maximise its potential. It is worth considering an examination of evidence and development of integrated action plans across the life course to promote health and wellbeing for all. e.g. 0-3, 3-6, 6-12, 12-18, 18-25 etc. This would enable interagency groups to be established with a focus on a specific age profile and involving all stakeholders working with that age group focusing on a common agenda. The key barriers to achieving best model of care include: funding, insufficient staffing, and poorly resourced community facilities. There is a clear need to integrate pre and postnatal policy and services.

## **Funding Model**

### **Economic case for investing in early years**

There is a strong economic argument to invest in early years. In an econometric analysis, Professor James Heckman<sup>275</sup> argues that structures (including knowledge and skills) are based on foundations and the stronger the foundations the more solid the structure, with the highest returns at age 0-3. He also points out that in both promoting economic efficiency and reducing lifetime inequality, early years' interventions provide policy makers with a rare ability to spend money in a way which simultaneously delivers substantial social and economic benefits. Scandinavian countries, such as Sweden and Norway, which have adopted whole country approaches to investment in early years' prevention, have achieved not only financial returns but better health for the whole population. The benefits span lower infant mortality through to reduced heart, liver and lung disease in middle-age. Investing in early years services can improve babies' and children's health outcomes including: early cognitive and non-cognitive development, social development, children's readiness for school and later educational outcomes.

Perinatal and infant mental health difficulties are considered to be among the most preventable and treatable of all mental illnesses. The lack of appropriate services in Ireland means that women and their families are not being given access to timely interventions that provide significantly positive long term outcomes for their health and well being. Recent research from the UK estimates that the overall costs of untreated perinatal and infant mental health difficulties is over £8 billion GBP (€10.2 billion), with over 70% of these costs relating to adverse impacts on children. In addition to the financial costs of untreated perinatal and infant mental health difficulties, there are other far reaching social costs including ongoing intergenerational mental health difficulties; marital and familial breakdown; and unemployment.

### **Investing in Prevention**

Providing ring fence funding for prevention and rewarding services for implementing evidence based approaches to promote health and wellbeing in early years is necessary. We need to move away from viewing success as the number of operation done to seeing success as reducing the numbers needing treatment in the first place. The way that budgets are allocated to health care influences what is done. We need incentives to choose early intervention and prevention rather than treatment. An interesting paper "Making Irish Health Care better for Less"<sup>276</sup> by Joe Fowler as part of the HSE Leadership Master class in 2015 provides some insights into how we can improve Irish Health Care systems.

### **Section 3 – Recommendations**

Develop an early year's health and wellbeing plan as part of a 10 year health strategy to help give every child in Ireland the best start. This could be modelled on Galway City Early Years Health and Wellbeing plan. The early years health and wellbeing plan should incorporate the following elements:

- a. Prioritise investment in early years health and wellbeing for children aged 0-3 years including greater investment of resources into services and investment into staffing specific to 0-3s in areas such as Public Health Nursing, Psychology, Physical activity, Dietetics, etc
- b. Give every child the best start in life by supporting parents through offering intervention from health professionals in areas including: infant and child nutrition, nutrition screening, breastfeeding, physical activity and play, mental health and wellbeing, safety and accident prevention, early learning and development as well as expert advice in relation to tobacco, alcohol and drugs.
- c. Invest and resource models of good practice in promoting health and wellbeing in early years e.g. Galway City Early Years Health and Wellbeing Plan <http://www.galwayhealthycities.ie/uploadedfiles/FINAL-Galway-City-Early-Years-Health-and-Wellbeing-Plan.pdf>
- d. Prioritise early intervention and prevention and the identification of needs and provision of appropriate supports for those most at risk under age 3 particularly the needs of those expectant parents and very young children who are most at risk of poor outcomes.
- e. Address issues relating to access to services to ensure that services are available to all and where required additional supports for those who need it
- f. Prioritise training and development for those working in early years services to ensure that services are aware of the importance of the first 3 years in a child's life and evidence in relation to how best to intervene e.g. breastfeeding, nutrition, parent and infant mental health, active play
- g. Develop mechanisms for improved use of data, research and evidence to promote health and wellbeing in early years
- h. Strengthen the economic case for investing in early years
- i. Support parents during pregnancy and first three years in particular using evidence based approaches
- j. Advocate for the provision of high quality early years settings e.g. childminders, crèche, preschools
- k. Ring fence funding for prevention and reward services for implementing evidence based approaches to promote health and wellbeing in early years.

1. The Special Interest Group in Perinatal and Infant Mental Health of the Psychological Society of Ireland are calling on the government to establish a review group to consider best practice models used in other countries. Other recommendations include the benefit of a national perinatal and infant mental health strategy; universal screening for parents and infants; clear pathways of care; resourcing existing services; specialist perinatal services; raising awareness amongst the public, staff and policy makers on the importance of infant mental health; evidence based-practice and the collaboration of multiple sectors including health and education (PIMHSIG, 2016).

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## Genetic & Rare Disorders Organisation (GRDO)

### **Over 400,000 Irish people are living with a genetic or rare disorder**

The current lack of services has a significant impact on these families. There is a 1224 month waiting time for genetic counselling and genetic testing which has serious implications for appropriate care for these individuals and their families.

GRDO are calling for the 10 year Strategy for Healthcare to make genetic and rare conditions a priority within the health system.

World-wide, genetics is bringing about a revolution in healthcare, making Personalised Medicine a reality for many. A modern Medical Genetics service should be at the heart of any strategy for the future of healthcare in Ireland. Substantial investment is required to bring the current services up to international standards.

The Government already has a National Plan for Rare Diseases<sup>1</sup>, published in 2014, but this plan needs to be implemented as part of the ten year strategy for health care and health policy.

The recommendations of the National Genetics & Genomic Medicine Network Strategy Group should be incorporated into the 10 year Health Strategy Regulation and transparency in relation to the gathering and use of family history information is essential to prevent the creation of a genetic underclass, to promote research and improve outcomes for people impacted by genetic conditions.

Respite care provisions must take into account the special circumstances and needs of families affected by rare and genetic disorders.

The financial burden associated with living with a genetic and rare disorder needs to be properly assessed and reflected within the medical card system

The long term illness scheme excludes many disabling genetic and rare disorders and must be reformed and expanded. The system for evaluating, funding and prescribing orphan drugs must be overhauled to provide equity, efficiency and transparency.

### **Recommendations**

#### **Implementation of the National Rare Disease Plan**

The Government already has a National Plan for Rare Diseases<sup>1</sup>, published in 2014, but this plan needs to be implemented as part of the ten year strategy for health care and health policy.

Specifically, the strategy must:

- Ensure that rare diseases are adequately coded and classified;

- Enhance research in the field of rare diseases;
- Identify centres of expertise and foster their participation in European Reference Networks;
- Immediate resourcing and support for potential Centres of Expertise to function as Multidisciplinary Team units to include Clinical Genetics and the other large Clinical programmes (e.g metabolic, rare complex rheumatology, rare cardiology, rare neurology), and support for research in these areas.
- Support the pooling of expertise at European level;
- Share assessments on the clinical added value of orphan drugs;
- Foster patient empowerment by involving patients and their representatives at all stages of the decision-making process;
- Ensure the sustainability of infrastructures developed for rare diseases.
- Ensure that people with rare diseases receive timely access to the best possible evidence based, patient-centred and family-centred screening (as appropriate), diagnosis, treatment and care through all stages of their lives.
- Ensure that the needs and experiences of people with rare disease are recognised, understood and addressed within all aspects of the Irish health system, including policy, services and research/information systems.

The European Council (2009) made a Recommendation on ‘Action in the field of rare diseases’ (2009/C 15/02). It proposed that Member States develop a national rare disease plan by 2013 (National Rare Disease Plan for Ireland 2014 – 2018) and, in particular, the Council called for concerted action at EU and national level in order to support:

- **Equity:** Patients resident in Ireland should receive the best possible evidence-based diagnosis and care irrespective of the rarity of their condition and the location of optimal care services. Equality in accordance with prevailing health and other legislation should underpin the provision of care.
- **Collaboration:** Cross-sectoral, cross-border and international cooperation are integral for Ireland to deliver on the vision for rare disease patients and a core activity of all policy actions.
- **Family-centredness:** Implementation of policy actions should be built around the development of coordinated packages of care for patients and their carers.
- **Sustainability:** A strategic approach to improving the situation of rare disease patients and carers should be sustainable. Policy actions should be implemented in a way that planning, delivering and monitoring rare disease issues become core work of the health system.
- **Transparency:** Progress with the implementation of the policy actions should be transparent to all stakeholders.

The current Programme for Government includes a commitment to implement the National rare Disease Plan.

## **Evidence of Need: Underinvestment and Underdevelopment of Services for People with Genetic and Rare Disorders**

The precise number of people in Ireland with a rare disease is unknown. This lack of basic epidemiology on most rare diseases can contribute to a lack of recognition and hinder the development of appropriate services and policy. For example, basic estimates of the numbers of patients affected by a particular rare disease are required to inform appropriate health and social service commissioning and workforce planning. Data from health service information systems is required in order that the health service can develop and agree clear guidelines for services to meet the needs of rare disease patients and to assess how Irish health services are performing relative to international standards.

### **Genetics Services in Ireland**

Genetics Services in Ireland are hugely underfunded and understaffed and the waiting time for an appointment can be between 12 – 24 months. Published data show that Ireland has the lowest number of Clinical Geneticists of any of 14 EU countries surveyed<sup>2</sup>. By UK and based on population standards, Ireland should have 16 to 20 Clinical Geneticists and up to 40 qualified Genetic Counsellors. There are currently 4 Clinical Geneticists and 5.2 Genetic Counsellors employed in the Department of Clinical Genetics at Our Lady's Children's Hospital, Crumlin. Numbers of laboratory staff are similarly below European norms and there has been a chronic lack of investment in necessary laboratory equipment.

In 2015, the HSE established the National Genetics & Genomic Medicine Network Strategy Group, chaired by Professor Owen Smith OBE to develop a National Genetics and Genomic Network Strategy for HSE and Department of Health consideration. The recommendations made by this strategy group were submitted in December 2015 to the HSE but are still "under consideration" by the HSE Acute Hospital Division and have not been published.

GRDO received a briefing on the recommendations, which include that the Government should:

- Nominate posts within the Department of Health and the HSE to take direct responsibility for the provision of a national equitable genetic service
- Assign dedicated funds from the health budget to ensure the provision of an appropriately resourced national genetic service which is sustainable in the long term

So that the HSE may:

- Provide for a resourced national genetic service which is sustainable in the long term
- Adopt relevant new advances and technologies in treatments, genetic testing and genomic sequencing to improve outcomes for patients and avail of health efficiencies

- Ensure that relevant genetic testing is considered an integral part of health service provision and that genetic testing will be equitably accessible to those in need
- Implement systems to ensure that key information and genetic counselling is provided in compliance with international best practice guidelines to those undergoing genetic testing
- Develop protocols for delivering genetic test results and provision of information to those impacted
- Liaise with relevant health specialities including neurology, cancer, cardiology etc. to develop protocols for delivering a genetic diagnosis and follow up information and support for the patient and impacted family members
- Provide genetic education to healthcare professionals and policy makers
- Guarantee appropriate professional qualifications, accreditations and quality standards are adhered to by genetic service providers to the Irish healthcare system
- Recognise the importance of self-referral for predictive testing for family members impacted by a genetic condition. People receiving an unfavourable test result should be offered structured follow on support and information on support groups, potential clinical trials and research studies
- Recognise the crucial role that the human genome will play in future diagnosis and personalised treatment

We recommend that this report be published and its recommendations implemented without further delay.

### **Family History**

Information on family medical history can be just as powerful and predictive as any genetic test, and this information should be included under the definition of “Genetic Information” for regulatory and data protection purposes. Regulation and transparency in relation to the gathering and use of family history information is essential to prevent the creation of a genetic underclass, to promote research and improve outcomes for patients for people impacted by genetic conditions.

### **Respite**

One size does not fit all and appropriate respite provisions, taking into account the disability and age of the person is vital. Respite care is short-term care that helps a family take a break from the daily routine and stress. Respite care can occur in the person’s/family home or in a variety of out-of-home settings, and can occur for any length of time depending on the needs of the family and available resources. In the case of genetic disorders, it is not

uncommon for more than one member of a family to be affected by the condition. Where more than one person in the family is affected by the disability it is fundamental for the survival of the family unit that the parents/carers receive regular respite. It is important to note, that respite is not exclusively for children and some people with a disability will require respite over their full lifespan.

***Note: Patient Organisations are very often providing respite for their members and should be consulted when determining what constitutes suitable respite.***

### **Personal Assistant Service**

Personal Assistants (PA) enable people with disabilities to live as independently as possible in their local community. PA's provide assistance with the activities of daily living, including traveling to work, studying or participating in social life.

A clear understanding of Personal Assistant service needs to be developed and promoted in line with the Government's aim of providing services and supports for people with disabilities which will empower them to live independent lives, provide them with greater independence in accessing the services they choose, and enhance their ability to tailor the supports required to meet their needs and plan their lives

Due to medical intervention people are living longer with complex disabilities and providing PA's for personal care is not sufficient. People with Genetic and Rare Disorders are entitled to live a full life with supports that enable them to participate in activities of daily living.

#### **1. Reform of the Medical Card System and Long Term Illness Scheme**

- Access to a range of healthcare services in the community is dependent on having a medical card.
- The financial burden associated with living with a genetic and rare disorder needs to be properly assessed and reflected within the medical card system
- The long term illness scheme excludes many disabling genetic and rare disorders

#### **2. Orphan Drugs**

- The HSE should develop a Working Group to bring forward appropriate decision criteria for the reimbursement of orphan medicines and technologies. The approach should include an assessment system similar to that for cancer therapies established under the National Cancer Control Programme and link with the CAVOMP at European level.
- The HSE should undertake a preliminary economic evaluation of current activity and costs for orphan medicine and technologies for rare disease patients across all hospitals and settings.

- Applications for the use of orphan medicines and technologies in hospitals be dealt with in the context of a national budget, rather than through individual hospital budgets, and that the HSE take account of this.
- The HSE should develop a publicly available annual report documenting the use of both existing and new-to-market orphan medicines and technologies in Ireland and a summary of applications received and decisions relating to those applications.
- The existing horizon-scanning between pharmaceutical companies and the HSE, including clinical value assessment authorities, should continue and be enhanced so as to improve information available regarding orphan medicines in the pipeline and the future needs for these medicines.
- The capacity to prescribe all orphan medicines and technologies for ultrarare conditions should be limited to specialist teams designated through the Centres of Expertise.
- The HSE should apply a set of guidelines on the prescribing of orphan medicines and technologies in Ireland. The HSE should evaluate clinical outcomes regarding use of orphan medicines.
- Clinicians should provide data necessary to the monitoring of prescription patterns and pharmacovigilance, so as to ensure patient safety and high-quality healthcare.
- Early dialogue between the HSE and companies who are running clinical trials in Ireland with Irish patients where license approval is imminent.
- Sponsors could be offered an incentive to run trials in Ireland increasing access to innovation for Irish patients.

### **3. Rare Disease & Disability**

- The Government has recently stated its commitment to ratify the UN Convention on the Rights of People with Disabilities (CRPD) by Christmas 2016. In keeping with this, the state is obliged to provide uniform and equitable services to all citizens, including those with a disability. People with rare diseases are often living with progressive disability, with is in a constant state of decline. Their care as such needs to be re-evaluated and assessed on an ongoing basis and as such provisions need to be made for their future healthcare needs.
- Patients need to have care plans in place which allow for the provision of these facilities and services in a timely manner. Such care plans should be evidence based and conform to models of best practice for their specific condition/disease. The establishment of epidemiological data on these patients together with centres of expertise allow for these care plans to be formulated.

- Therefore under the conditions of this convention, people with rare diseases need to have access to the same provisions of care that people with more common conditions have.

## References

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## About GRDO

The Genetic and Rare Disorders Organisation (GRDO) is a non-governmental organisation acting as a national alliance for voluntary groups representing the views and concerns of people affected by or at risk of developing genetic or other rare disorders.

The mission of the Genetic and Rare Disorders Organisation is to provide a strong voice for voluntary groups representing people with or at risk of developing genetic or other rare disorders in order to achieve better support and services.

The Genetic and Rare Disorders Organisation acts as a watchdog in relation to legislation concerning disability to ensure that the rights of people with genetic or other rare conditions are protected.

GRDO was incorporated in 1988 and its first achievement was to successfully lobby for a dedicated national centre for medical genetics which was established at Our Lady's Hospital Crumlin in 1994.

The objectives of the GRDO are:

- To voice and promote views of the member organisations on issues of common concern.
- To be a strong and united voice that will increase public awareness of genetic and other rare disorders.
- To promote further development of genetic services in Ireland .

- To lobby for the availability of adequate care services in Ireland .
- To promote equality of educational and employment opportunities.
- To facilitate the exchange of information between member organisations
- To represent the needs of its member organisation to the statutory and other bodies.
- To establish a liaison with geneticists and other relevant specialists nationally and internationally to help GRDO achieve its aims and objectives.
- To encourage scientific research in the area of genetics and other rare disorders

Genetic and Rare Disorders Organisation (GRDO)  
Carmichael Centre  
North Brunswick Street  
Dublin 7, D07 RHA8

Barbara@ataxia.ie, www.grdo.ie

<http://www.grdo.ie/>

## Geraldine McCabe, Co. Monaghan

The purpose of our submission is to address the issue that there are currently only two brokerage firms with Ireland making it difficult for families to access individual funding in more rural areas of Ireland. Currently families of children with a disability are not being proportionally represented on all health boards meaning decisions are being made on behalf of this population without expert knowledge.

I believe that information surrounding individual funding is not easily accessible. There needs to be more awareness and transparency on individual funding and the process needs to be clearly advertised. Giving access to individual funding for clients promotes a more holistic client centred approach to the way we care for this population. Allowing people with intellectual disabilities to shape their own care plan, this promotes best practice allowing the client to be in the centre of everything the HSE provides for them.

“The biggest single problem, and the biggest single delay has been trying to get the funding, and that comes in under a couple of headings. One is decoupling funding from a block grant...” (Staff member interviewed as part of evaluative research (Fleming et al., 2015))

Many studies have been carried out within Ireland showing that individualised funding aims to provide people with a disability more control over their lives, thus enhancing quality of life. This also improves inclusion within our communities for this population.

The money allocated to that individual can determine what services are needed for that particular individual. This can also improve employment rates for the HSE. Allowing more control over where the funding is spent.

I propose that we adopt New Zealand's approach to individualised funding. IF is available throughout New Zealand for eligible people who have either a Home or Community Support Services or Respite allocation. IF gives disabled people more choice in how they are supported. The process is clearly advertised and very transparent. Something I believe would benefit Ireland and enhance the quality of care that is provided by the HSE.

I believe that we should be representing people with intellectual disabilities in Ireland by introducing parents/siblings/carers/the client themselves onto all major HSE boards that are in charge of major decision making for this population. It is a belief that this would increase the knowledge of expertise and allow the HSE to make better formed decisions on behalf of this population. I propose that we adopt the NHS in England's process of introducing non-for-profit organisations who have the specialist knowledge in this area, to work in partnership with the HSE. The NHS use IMROC to improve services within their mental health sector. Their mission is to bring together the very best in professional expertise and the lived experiences. They work to the principles of co-production in all that they do, nurturing the strengths of every individual in whatever capacity they are able to offer them. They bring cutting edge experience that is developed through pushing the boundaries of innovation at the frontline of care, combining both evidence and practice in ways that really work.. IMROC focuses on three key areas of work:

- bespoke consultancy – collaborating with clients to understand how they can help deliver sustainable improvement in inclusive and evidence-based ways.
- learning and development – providing training and other learning opportunities.
- advancing the field – extending the evidence base through research, and the spread of innovation and knowledge.

I propose that if we were to adopt this method of practice the HSE would significantly improve the services that are provided for adults and children with intellectual disabilities living in Ireland.

When a child with an intellectual disabilities, turns 18 in Ireland there is significant drop in services offered to them. Particularly in the area of employment, thus giving the impression that Ireland does not value the skills this population have. There is a general lack of support for adults with intellectual disability to access further education.

**Recommendations for action by Government**

- Access to individual funding to be more accessible.
- At least 50% of parents/siblings/carers to be sitting on all major boards to share their expertise.
- Hold HSE more accountable for lack of services provided for over 18s- call for more client satisfaction surveys to be completed to help address gap in services
- Raise awareness and increase support for adults with intellectual disabilities to access further education/training course to help recognise the potential this population have.

Geraldine McCabe  
Co. Monaghan

## Green Party/Comhaontas Glas

The Green Party/Comhaontas Glas believe in a systematic approach to universal healthcare, built around patient empowerment and preventative methods, supported by information technology, accessed on the basis of medical need, and executed in an economically, equitably and ecologically manner, with the support of motivated health care practitioners and efficient and effective management systems at all levels.

We recognise that challenges exist in maintaining an ecology that sustains life and that health care must be delivered in an effective, compassionate and caring manner, but this does not mean that health care services should be allowed to be ecologically disruptive.

Our current health services are a system of unequal access both geographically and socially, arbitrary barriers to access and preferential access for those with influence, powerful advocates or leverage through private health insurance.

Although many of the things that are most important for health are beyond the control of the individual, all citizens have a responsibility to do what they can to protect their own health and the health of others. Also all citizens have a duty to share the financial and social costs of ensuring that everyone has a fair chance to enjoy the best possible health.

We outline below our view on how health care can be delivered in a way that is less costly and places the patient at the centre of their own care.

### Key Concepts:

#### The patient at the centre of their own health care

The Green Party/Comhaontas Glas believes that a ‘patient-centred’<sup>277</sup> approach to healthcare is consistent with the party’s founding principle that decision making should be made at the lowest possible level. Every effort should be made to ensure that patients and their carers are empowered to make decisions regarding their own health at all levels within the system, and that information systems and care pathways should be redesigned to facilitate the open and transparent transfer of information to those making such decisions.

Structural changes to make healthcare more patient-centred include; legislating for public participation and accountability through reporting, involving local communities in decision making, establishing a public body responsible for promoting public participation and establishing an independent patient representative organisation which has the powers to seek redress for patients.<sup>278</sup>

#### Evidence-based Health policy will deliver value for money

To be effective healthcare professionals should use research evidence along with clinical expertise and patient preference<sup>279</sup>. The Green Party/Comhaontas Glas believes in evidence-based medicine and we expect the best available research findings (the evidence) to be used when decisions are being made about healthcare.

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<sup>277</sup> Don Berwick, What ‘Patient-Centred’ should mean: Confessions of an Extremist, Health Affairs 2009, DOI 10.1377/hlthaff.28.4.w555

<sup>278</sup> Appendix 8, from Prospectus/Watson Wyatt, Audit of Structures & Functions in the Health System, Govt, Publications, Dublin, 2003

<sup>279</sup> Agency for Healthcare Research and Quality (ARHQ) <http://effectivehealthcare.arhq.gov>

### Monitoring and Measuring health outcomes as well as outputs

Health Performance Measurement (HPM) is a necessary part of ensuring that the health system is accountable to its citizens. We should ensure that the choice of indicators used in performance measurement reflects the priorities of patients. The Green Party/Comhaontas Glas support emphasising the measurement and incentivisation of outcomes in health service, in preference to structures and processes.

Promotion and protection of health can be seen as a continuous quality improvement process. To achieve continuous improvement we need to agree on goals, identify the status quo and forecast how changes in policy and practice can bring about improvements that we can see and measure. Health information that is meaningful and collected in a standardised way should also be published in a timely manner. The WHO's 'Framework and Standards for Country Health Information Systems'<sup>280</sup> provides a useful framework for review of Ireland's health information systems..

Ultimately improvements in the healthcare system - both in quality and resource allocation - should be based on clinical assessments and accurate data collection, rather than political decisions.

Risk Management in community and hospital services should be developed in communication with patients. Surveillance systems and audit of outcomes are important measures and should employ uniform methods and standards for collecting and analysing information, and be published. The obligation to collect and publish relevant information must be an obligation on both private healthcare providers and the public health service.

Liability costs from medical claims could be reduced by:

- Investing in patient safety to ensure that a cost-effective infrastructure is put in place to reduce adverse events in medicine. Hospitals must be incentivised to have a patient safety officer and a medication safety pharmacist in place, where the cost/benefit can be shown.
- Funding organisations such as the Irish Society for Quality and Safety in Healthcare.
- Legislating for mediation as a first resort for disputes involving malpractice.
- Emphasising patient empowerment in all clinical decisions and ensuring that a robust advocacy system is in place for patients or families.
- The introduction of no-fault compensation for failures in healthcare that result in adverse outcomes. Adverse outcomes should be thoroughly investigated and findings published to ensure that lessons are learned and services are improved.
- New structures to address the ongoing needs of patients who suffer as a result of adverse outcomes rather than one-off payments.

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<sup>280</sup> World Health Organisation, Health Metrics network, Framework and Standards for Country Health Information Systems, Second edition, available from URL: [www.who.int/healthmetrics/documents/hmn\\_framework200803.pdf](http://www.who.int/healthmetrics/documents/hmn_framework200803.pdf)

### **Reducing Waste in healthcare**

It has been estimated, that of every \$5 spent on healthcare in the United States of America, \$1 is wasted.<sup>281</sup> If this was applied in Ireland, the cost would be in excess of €2.5 billion, based on what the taxpayer pays, but greater when private or insurance funding is taken into account. The waste is a result of unnecessary care, fraud and abuse, administrative inefficiency, medical mistakes and preventable conditions.

Lean technologies and processes should be incorporated into all aspects of the healthcare system. We need to measure the extent of waste in healthcare in Ireland and a fund to finance the implementation of efficient practices if they can be shown to deliver a potential savings of 2:1 or greater.

Healthcare services are intensive users of energy, materials and chemicals and service providers should take account the environmental impact of the work they do and have programmes in place to ensure that their environmental impact is reasonable in the context of their contribution to health. We support the WHO's 7 steps for reducing waste in healthcare systems<sup>282</sup>, including better planning for carbon-neutral living.<sup>283</sup>

### **Increased use of Information Technology**

The adoption of the best currently available information technology is vital to the health of our patients. The importance of using the best currently available information technology systems in the provision of properly functioning, modern healthcare cannot be understated, particularly in a situation where a sizeable number of health care users are suffering from chronic illnesses, and practitioners may be unaware of their medical history and other treatments that may have been used in the past.

### **Electronic Health**

We support implementation of the eHealth Strategy<sup>284</sup> and believe that patients should have access to their summary-care records and be able to make comments where information is incomplete or inaccurate.

Community health professionals, including general practitioners and community pharmacies should be supported in following the progress of patients within the hospital system, and feeding information into that process to inform hospital-based professionals and assist them in empowering the patient to make critical decisions about treatments. This should include input into multidisciplinary team meetings around difficult decisions related to complex interventions and appropriate management of care.

### **Open Source and practitioner coded solutions**

Information technology solutions used in the Irish healthcare system should be, in as far as practicable, based on open-source<sup>285</sup> software, suitable for practitioner coding, and interoperable to HL7 or best-available standards.

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<sup>281</sup> Berwick DM, Hackbarth AD. Eliminating Waste in US Health Care. JAMA. 2012;307(14):1513-1516. doi:10.1001/jama.2012.362.

<sup>282</sup> Healthy Hospitals Healthy Planet. Addressing climate change in health care settings, WHO 2009, available from URL: [http://www.who.int/globalchange/publications/healthcare\\_settings/en/index.html](http://www.who.int/globalchange/publications/healthcare_settings/en/index.html)

<sup>283</sup> Institute of Public Health in Ireland, Climate Change and Health : A platform for action, 2010, available from [http://www.publichealth.ie/files/file/Climate\\_change\\_and\\_health.pdf](http://www.publichealth.ie/files/file/Climate_change_and_health.pdf)

<sup>284</sup> <http://www.hse.ie/eng/about/Who/OoCIO/ehealthstrategy.pdf>

Open source software has many advantages for providers and patients, including interoperability, speed of problem resolution, flexibility and more frequent updates.

Allowing healthcare practitioners to code their own solutions was an integral part of the improvements brought about in the US Veterans Health system, as the practitioners involved were able to design an ICT infrastructure tailored to their needs. A model similar to the NHS ‘Hack Day’<sup>286</sup> should be considered, allowing software developers to get involved in designing solutions to technology problems within the healthcare setting.

### **Structure of the Healthcare System**

#### **Healthcare based around the patient in their own home**

*Our health service should, have the patient is at the centre of all care, be delivered as close to the patient’s home and family as possible - which given the spatial distribution of the population, is likely to involve some mobile or electronic service delivery.*

#### **Patient-centred health care**

*We believe in a service where health professionals act as advisers and enablers to the public in helping them achieve optimal health rather than acting as gatekeepers and commissioners of that health.*

We envisage paramedical services, delivered by ambulance staff arranged in regions based on practical response times rather than political boundaries as being the ‘first responders’. Patients can be referred community pharmacies, community health drop-in centres, general practices, hospitals or other services as appropriate.

We also support the introduction of a 24 hour triage and health concerns telephone and website service which helps to direct patients into appropriate streams of care.

#### **Community Health Drop-In Centres & Minor Injury Clinics**

Community health drop-in centres and minor injury clinics with extended opening hours, similar to the ‘polyclinics’ found in European countries should be provided regionally, based on the distribution of the population.

These community health centres should be the focal points for self-help and community-based initiatives and should provide primary healthcare, health education and health promotion, midwifery, obstetrics, family planning, counselling and psychiatry. Staff should be organised into multi-disciplinary teams and the public should have direct access to specialist and general nurses, dieticians, physiotherapy, occupational therapy, speech & language and other health and social care services. They should also provide walk-in facilities for patients with minor injuries and illnesses.

Primary care teams should be supported in delivering the highest level of care in the community. Access to investigations and the transfer of laboratory samples by patients should be planned to avail of local transport networks, making transfers more efficient and reducing wasteful journeys by the patient.

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<sup>285</sup> Open source software is software whose source code is available for modification or enhancement by anyone. ‘Source code’ is the part of software that most computer users don’t ever see; it’s the code computer programmers can manipulate to change how a program or application works. Open Source.com: *What is Open Source?* Available from URL: <http://opensource.com/resources/what-open-source>

<sup>286</sup> <http://nhshackday.com/>

## General Practice

The emphasis in general practice needs to switch from the construction of primary-care buildings to the development of efficient teams of healthcare professionals and robust referral pathways.

Primary-care teams should be encouraged to collect relevant information to support local auditing of processes and outcomes and consideration should be given to a forum where the community is updated on team performance, which is set against standard criteria.

General practitioners (GPs) need a clear incentive to take responsibility for a wider range of primary-care services. General practice should also be incentivised to expand their expertise by employing a broader range of health professionals, including nursing and allied health professionals, such as physiotherapists, occupational therapists, dieticians, and pharmacists.

A bank of locum doctors needs to be developed to provide cover to rural doctors for annual leave, training and unexpected illness. This would lessen a rural GP's reliance on agency staff, thereby reducing costs and the risk of burnout caused by overwork.

We support the work of the Irish College of General Practitioners (ICGP) and the development of accredited training and recognition of 'General Practitioners with a Special Interest' (GPwSI)<sup>287</sup>

## Community Pharmacy

Schemes for the reimbursement of medications need simplifying and should be provided by a community pharmacy on a single transparent system. All current schemes should be amalgamated into a single medication reimbursement scheme, with a sliding scale system of co-payments depending on patient status and class of medication. Reimbursement prices should be paid electronically and based on actual invoiced cost in order to reduce the incentive to consolidate multiple pharmacies.

Repeat prescriptions for chronic and preventative illnesses should be managed in community pharmacy in collaboration, and with the oversight of the local general practice, which should be subject to audit.

## Public Health Nursing

Along with patient empowerment, a comprehensive public health nursing service can support the aims of preventative healthcare. We support the aims and findings of the North/South report on public health nursing<sup>288</sup> and would support a detailed review this document to ensure that it is put in to practice.

## Governance

In order to make healthcare more patient-centred, we need more public participation, accountability and decision making by local communities. We support the establishment of an independent patients' representative organisation as a public body responsible for

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<sup>287</sup> Royal College of General Practitioners in the UK, GP with a Special Interest (GPwSI) accreditation available from URL: <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/gp-with-a-special-interest-gpws-i-accreditation.aspx>

<sup>288</sup> Nursing for Public Health: Realising the Vision 2005, <http://health.gov.ie/wp-content/uploads/2014/03/Nursing-for-Public-Health-Realising-the-Vision.pdf>

promoting this participation. This organisation would have powers to seek redress for patients<sup>289</sup> and would be similar to initiatives in the NHS in Scotland.<sup>290</sup>

Boards of hospitals, hospital groups and local community care commissioners should include patient representatives and local primary care professionals as members, to advocate directly for patients. Local people should decide what and how services are provided and these services should have complete flexibility to meet needs in line with minimum standards.

Policy should address issues that are critical to the well-being of vulnerable population groups and be based on evidence of what works. Technical expertise must be balanced with public and community participation in agreeing priorities and developing and implementing policies. We need local and regional consultative processes that give people with a role in making decisions about their health.

It is possible to reform the HSE and it should be dissolved. There is a need to explore a new Community Health Organisation (CHO) model further and creating a series of commissioning groups to manage hospital groups. The hospital groups would, be responsible for finding solutions to local needs, be able to direct funding into the most cost effective providers, and enable transfer of service provision at the lowest level of complexity.

### **Public Information on Health Care Services and screening**

A public information campaign similar to the British Medical Journals ‘Too Much Medicine’, could benefit the service by highlighting to the public the threat posed by over-diagnosis to human health and the waste of resources involved in unnecessary care.<sup>291</sup>

### **Funding of Healthcare Provision**

*With the right measures in place, we can deliver healthcare that is accessible to all and good value for money. This section addresses the following three aspects of health care finance:*

#### **How is healthcare to be funded?**

*The fairest and most progressive way to achieve a single-tier health system based on need rather than the ability to pay is by funding from general taxation for the following reasons:*

1. It is the most progressive – as those with the greatest ability to pay share more of the burden.
2. It is the most cost-effective - OECD data shows that countries with a social insurance model, or a private/social insurance hybrid pay significantly more per capita for their healthcare<sup>292</sup>.
3. Healthcare is not a perfect market commodity, and better healthcare results from collaboration and not competition<sup>293</sup>.

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<sup>289</sup> Appendix 8, from Prospectus/Watson Wyatt, Audit of Structures & Functions in the Health System, Govt, Publications, Dublin, 2003

<sup>290</sup> NHS Scotland, Better Together, Scotlands Scotland’s Patient Experience Programme, 2008 <http://www.gov.scot/resource/doc/247026/0069783.pdf> when we’re in government? If so, why can we say what we’d implement now?

<sup>291</sup> British Medical Journal, Too Much Medicine [website] available from URL: <http://www.bmj.com/too-much-medicine>

<sup>292</sup> OECD (2014), "Total expenditure on health per capita", Health: Key Tables from OECD, No. 2. DOI: <http://dx.doi.org/10.1787/hlthxp-cap-table-2014-1-en>

4. The introduction of mandatory health insurance will be another burden on those on lower-incomes who do not qualify for subsidisation<sup>294</sup>.
5. The two-tier nature of our current system leads to inefficient use of resources, and causes hardship to patients.
6. Research has shown that the health service in the world with the best outcomes and the most cost-effective performance - American Veterans Health System<sup>295</sup> - is directly funded by general taxation.

### How healthcare providers are to be paid:

#### Multi-Annual Budgeting

The health service is a demand-led service and experiences regular and often unpredictable surges in demand. The demands of budgeting within the current annual allocation of funding ends at what is often the busiest time of the year for healthcare services, frequently resulting in short term, cost-saving measures being introduced which are unsustainable in the long term.

Multi-annual budgeting reduces the need for short-term saving measures and is better suited to the long-term financial planning required for better healthcare.

#### Activity Based Costing and Full Economic Cost-Benefit Analysis

All financial units within the health services should provide activity-based costs and budgets, indicating exactly how resources were used, in order to receive funding for their activities. All requests for new funding - both capital and operational - should be subject to this, and a programme of reviewing existing programmes should be undertaken.

#### Hybrid Capitation Models

Arrangements such as weighted-capitation<sup>296</sup> and blended-capitation<sup>297</sup> could be used to pay for healthcare services in hospital and the community. These allow health services to use incentives to move care to those who need it most, and reward healthcare practitioners and providers who achieve the best outcomes for their patients.

Weighted capitation would apply to providers looking after patients in areas of deprivation or in sparsely-populated rural areas, and can be adjusted as part of long-term planning. It also allows for targeted schemes to deal with specific problems that might occur from time to time.

Blended capitation would apply to, for example, GP practices that achieve and maintain a reduction in hospital admissions for their cohort of nursing home patients

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<sup>293</sup> Chapt 3 Market Failure in Healthcare: Justifying the visible hand, from Donaldson & Gerard, Economics of Health Care Financing, The Visible Hand, 2<sup>nd</sup> Edition, Palgrave, London, 2005.

<sup>294</sup> Martin Wall & Fiach Kelly, Irish Times, Monday 29<sup>th</sup> June 2015, Universal health insurance could cost up to €3,000 for adult, available from <http://www.irishtimes.com/news/politics/universal-health-insurance-could-cost-up-to-3-000-for-adult-1.2265824>

<sup>295</sup> Phillip Longman, Best Care Anywhere, 3<sup>rd</sup> Edition, Bernett-Koehler, San Francisco, 2012.

<sup>296</sup> This is a formula used to project future health costs. It starts with projections for a resident population, and then weights them as appropriate for the cost of care by age group for relative need over and above that accounted for by age, and takes into account unavoidable geographical variations in the cost of providing services. It is used to determine Health Authorities' target share of available resources.

<sup>297</sup> In blended capitation some ancillary services are fee-per item

These incentives should be decided on a regional or local-level in response to health outcome targets which should be set by the Department of Health, in consultation with the public on an annual or multi-annual basis.

### **Patient Charges for Healthcare**

Small charges could be introduced for all medical services, to be paid at point-of-use of those services, subject to a person's medical need and their ability to pay.

These charges, sometimes known as co-payments are a way of sharing the cost of medical services between the tax-payer and the patient in a way which ensures that people use these services appropriately, and do not opt for more expensive treatments unless necessary.

Charges should be established based on an economic evaluation of factors likely to ensure appropriate levels of use of healthcare services and in consultation with patient groups. Some examples of suggested payments could be:

- A prescribed medication co-payment to 50¢ (currently €2.50)
- A €15 GP visit co-payment for all persons over 18 or out of full-time education
- A €20 charge for attending an out-of-hours service.
- A €25 charge for a specialist consultation with a consultant, clinical nurse specialist or advanced nurse practitioner in a hospital
- A €50 charge for a minor procedure in a hospital where that procedure is available from a general practitioner.

These charges should be tailored to help achieve health targets and manage demand, and reviewed on an annual or multi-annual basis at a regional or national level,

### **Regulating the prescribing and distribution of drugs and medicines**

Medications are a major cost driver in Irish Healthcare. Procurement groups should be set up regionally to negotiate and agree on prices for medications. These groups will be affiliated with local hospital and primary care groups and will use EU procurement best practices to ensure that optimum prices and products are obtained. Contracts should be regional to reduce the risk of monopolies and stock shortages. These procurement groups should also identify 'preferred medication' where there is a difference in the cost, but not the efficacy, of the medication. These procurement groups should be run in conjunction with hospital Pharmacy & Therapeutics (P&T) Committees, which should be composed of doctors, healthcare professionals, pharmacists, patient group representatives, economists, and a legally trained chairperson. These groups and P&T committees should be supported by robust evidence-based medicine research carried out by properly staffed medicines information services. The pricing arm of such committees should then decide on a fair price for the health organisation or hospital to pay the manufacturer for the drug.

## Health Insurance Authority

A significant number of people in Ireland have private health insurance ('PHI') which helps meet the costs of the medical care that they or their families may require. The Health Insurance Authority ('the Authority') is the body that regulates the private health insurance market in Ireland. Open market health insurance undertakings are also regulated by the Central Bank of Ireland in respect of their consumer protection, financial and prudential obligations.

As public and private healthcare provision are intertwined in our current healthcare system, the Authority is of the view that the existence and functioning of the private health insurance market is a matter which the Oireachtas Committee on the Future of Healthcare should take into account in its deliberations in formulating a ten year vision for the health service, and how this might be implemented and funded. Consumers of health insurance rely on the services being provided by both public and private hospitals, and public hospitals rely on income from insurers to help fund their budgets.

This submission provides an outline of the role of the Authority, and the structure and operation of the PHI market in Ireland. The Authority can provide the Committee with additional information about the PHI market and would be pleased to do so, if requested. Indeed, one of the principal functions of the Authority is it to advise the Minister for Health on matters relating to health insurance. In formulating this advice, the Authority undertakes research and data collection on the market.

### **About the Health Insurance Authority**

The Authority was established by Ministerial Order on 1 February 2001 under the Health Insurance Act, 1994 and operates in accordance with the provision of this Act and the Health Insurance (Amendment) Acts, which are collectively referred to as 'the Health Insurance Acts'.

The Principal Objective of the Health Insurance Acts is set out in legislation as follows:

*"The principal objective of the Act is to ensure that, in the interest of the common good and across the health insurance market, access to health insurance cover is available to consumers of health services with no differentiation made between them (whether effected by risk equalisation credits or stamp duty measures or other measures, or any combination thereof), in particular as regards the costs of health services, based in whole or in part on the health risk status, age or sex of, or frequency of provision of health services to, any such consumers or any class of such consumers, and taking into particular account for the purposes of that objective:*

- a) The fact that the health needs of consumers of health services increase as they become less healthy, including as they approach and enter old age,*
- b) The desirability of ensuring, in the interest of societal and intergenerational solidarity, and regardless of the health risk status or age of, or frequency of provision of health services to, any particular generation (or part thereof), that the burden of the costs of health services be shared by insured persons by providing for a cost subsidy between the more healthy and the less healthy, including between the young and the old, and, without prejudice to the generality of that objective, in particular that the less healthy, including the old, have access to health insurance cover by means of risk equalisation credits,*

- c) *The manner in which the health insurance market operates in respect of health insurance contracts, both in relation to individual registered undertakings and across the market, and*
- d) *The importance of discouraging registered undertakings (health insurers) from engaging in practises, or offering health insurance contracts, whether by segmentation of the health insurance market (by whatever means) or otherwise, which have as their objective or effect the favouring of the coverage by the undertakings of health insurance risk of the more healthy, including the young, over the coverage of the health insurance risk of the less healthy, including the old.”*

The principal objective of the Health Insurance Acts establishes the basis for the operation of the private health insurance market in Ireland. This basis is referred to as ‘community rating’ which essentially means that those taking out private health insurance should not pay more in premiums due to their age, gender, or current or expected future health status. Community rating implies a level of inter-generational solidarity whereby the insurance premiums collected on younger, healthier lives help meet the higher claims expected on older, less healthy lives. Consumers of health insurance products also have certain rights within the community rating market, including open enrolment, lifetime cover and the right to switch provider without penalty at the same level of insurance cover.

### **Functions of the Authority**

The principal functions of the Authority, as set out in the Health Insurance Acts, are as follows:

- To monitor the health insurance market and to advise the Minister (either at his or her request or on its own initiative) on matters relating to health insurance;
- To monitor the operation of the Health Insurance Acts and, where appropriate, to issue enforcement notices to enforce compliance with the Acts;
- To carry out certain functions in relation to health insurance stamp duty and risk equalisation credits and in relation to the risk equalisation scheme;
- To take such action as it considers appropriate to increase the awareness of members of the public of their rights as consumers of health insurance and of health insurance services available to them; and
- To maintain “The Register of Health Benefits Undertakings” (“the Register”) and “The Register of Health Insurance Contracts”.

### **Assisting Consumers**

A principal function of the Authority is to assist consumers by increasing awareness of their rights and entitlements in the community rated private health insurance market and in providing information about health insurance products to assist consumers in making informed choices in selecting products that best meet their needs.

The Authority assists consumers by answering queries regarding health insurance. In 2015 the volume of queries received by the Authority decreased by 11% to 7,083 contacts (2014: 8000).

Topics that were most frequently raised with the Authority were:

- Requests for comparisons between health insurance products;
- Cancellation policies of insurers;

- Rights in relation to switching insurers;
- General queries regarding health insurance products and waiting periods;
- The cost of private health insurance;
- Service standards of insurers; and
- Requests for the Authority’s information publications.

Total consumer contacts to the Authority during 2015 were approximately 435,000, most of which were through the Authority’s website [www.hia.ie](http://www.hia.ie). The Authority’s website contains the most comprehensive health insurance product comparison tool available which provides consumers with access to information on all the products available on the market and assists them in selecting and comparing features and pricing.

### **Composition of the Authority**

The Authority comprises of five members who are appointed by the Minister for Health for terms of up to five years. The current members are:

- Ms. Sheelagh Malin – appointed 6 May, 2010; re-appointed 1 February, 2016 and appointed Chairperson of the Authority, August 2016
- Mr. Ian Britchfield – appointed 20 June, 2016
- Mr. Sean Coyle – appointed 1 February, 2016
- Dr. Fiona Kiernan – appointed 1 February, 2016
- Mr. James A. McNamara – appointed 1 February, 2016

The Authority’s executive team is led by its Chief Executive and Registrar, Mr. Don Gallagher.

## **The Private Health Insurance Market in Ireland**

### **Regulatory Structure of the Market**

The private health insurance regulatory system is based on the key principles of community rating, open enrolment, lifetime cover and minimum benefit. It aims to ensure that private health insurance does not cost more for those who need it most. The system is unfunded, meaning that there is no fund built up over the lifetime of an insured person to cover their expected claims cost. Instead, the money contributed by insured people is pooled by each insurer and the cost of claims in any given year taken from the pools.

The level of risk that a particular consumer poses to an insurer should not affect the premium paid. Everybody is charged the same premium for a particular plan, irrespective of age, gender or likely future state of their health subject to certain exceptions in respect of children under 18 years of age, discounts for members of group schemes, young adults and age-related lifetime community rating (or LCR’) loadings which began on 1 May 2015.

Open enrolment and lifetime cover mean that, except in very limited circumstances specified in legislation, health insurers must accept all applicants for health insurance and all consumers are guaranteed the right to renew their policies regardless of their age or health status.

Under the Minimum Benefit Regulations, all insurance products that provide cover for inpatient hospital treatment must provide a certain minimum level of benefits. It is considered necessary to regulate the minimum level of benefits because of the complex and specialist nature of private health insurance products which without regulation could result in consumers being provided with

products that do not provide a sufficiently comprehensive level of cover. The Minimum Benefit Regulations do not incorporate any primary care benefits currently, although this is a matter that has been consulted on.

Risk equalisation is a process that aims to address differences in insurers claim costs that arise due to variations in the health status of their members. Risk equalisation involves payments to or from insurers related to the risk profile of their membership. Risk equalisation is a common mechanism in countries with community rated health insurance markets.

### Size of the Market

The private health insurance market is the largest non-life insurance market in Ireland. Total premium income in 2015 was €2.45 billion, with 2.126 million persons insured at the end of March 2016, or 45.9% of the population. At its peak in December 2008, almost 2.3 million people had private health insurance which equated to 50.9% of the population.

During the economic recession of 2008 to 2012, the private health insurance market suffered a significant decline in the total number of insured persons, reaching its lowest point during the third quarter of 2014. At the end of December 2014 the total number of insured persons stood at 2.025 million, or approximately 43.9% of the population. This decline, including a decline in the numbers of younger persons with private health insurance, combined with continuing increases in the costs of healthcare, meant that the costs of all claims in the market were being borne by a declining total number of insured persons. This contributed to a number of years of significant, double digit, increases in private health insurance premiums.

It also highlights that broad participation in the market by people taking out and maintaining their private health insurance cover, and particularly at younger ages, is important in helping to ensure the continued affordability of premiums and the sustainability of the community rated private health insurance market.

The market has been in a recovering phase since, with an increase of 97,000 in the number insured persons at the end of 2015 when compared with December 2014.

**Table 1 - Insured Persons**

Year ended	Total insured persons (‘000s)	Private Health Insurance Coverage as a % of Population
December 2001	1,871	48.2%
December 2002	1,941	49.2%
December 2003	1,999	49.8%
December 2004	2,054	50.2%
December 2005	2,115	50.4%

December 2006	2,174	50.3%
December 2007	2,245	50.5%
December 2008	2,297	50.9%
December 2009	2,260	49.7%
December 2010	2,228	48.8%
December 2011	2,163	47.2%
December 2012	2,099	45.7%
December 2013	2,049	44.6%
December 2014	2,025	43.9%
December 2015	2,122	45.8%

### Average premiums

The average gross premium paid in 2015 was €1,173. This represented a decline of 2% on €1,200 in 2014. Average premiums increased by 4% in 2014 and 10% in 2013. The factors underlying the decline in 2015 included -

- the introduction of low cost private health insurance products with a limited range of benefits during the run up to introduction of LCR
- recovery in the total numbers insured, and
- introduction of young adult discounts.

Gross premiums charged to consumers are reduced by income tax relief of 20% up to a maximum of €200 per adult covered under the policy, and a maximum of €100 per child.

Those over age 60 pay, on average, premiums that are 31% higher than the premiums paid by those aged under 60 years; however, this is due to older insured persons opting for higher cost PHI products that confer higher levels of cover.

### Claims

Gross claims under private health insurance policies paid in 2015 amounted to €1.979 billion. The claim payments of insurers to public hospitals in 2015 were approximately €600 million. According to the CSO system of health accounts data, in 2014 (which is the most recent data available) 12.7% of all current healthcare spending was financed by voluntary health insurance schemes.

Average claims paid per insured person increased by 6.5% in 2015 following an increase of 3% in 2014. Factors underlying this increase included changes to charges for patients with private health insurance cover in public hospitals.

The average rate of increase in claims between 2008 and 2012 was 12.6%. The consumer price and health sector inflation was near zero during 2014 and 2015.

The average claims paid by insurers tend to increase with age –

**Figure 1**

**Claims included in Returns per Insured Person in 2015**



Average benefits per insured person were €1,125.

The total number of private health insurance products being marketed grew to 360 as at 31 December 2015 (355 at the end of 2014).

**Market participants**

There are currently four open membership undertakings operated in the private health insurance market, namely VHI Healthcare, Laya Healthcare, Aviva Health and GloHealth. On March 9<sup>th</sup> 2016, the Irish Life Group announced agreements to acquire Aviva Health and take full ownership of GloHealth. This transaction completed on the 2<sup>nd</sup> of August 2016 with the establishment of Irish Life Health.

In December 2015, VHI Healthcare’s market share was 51%, Laya Healthcare 26%, Aviva Health 14% and GloHealth 5%. There also a number of Restricted Membership Undertakings, such as the ESB Staff Medical Insurance Scheme and the Garda and Prison Officer Schemes. Together, these and other Restricted Membership Schemes have a combined market share of 4%.

Market shares vary significantly by the ages of the insured. For example, at the end of 2015, VHI Healthcare insured 69% (72% at the end of 2014) of those aged 70-79 years. However, the high proportions of the oldest age cohorts insured by VHI Healthcare were gradually declining.

**Table 2 - Market Shares**

December	Aviva Health*	Laya Healthcare**	Vhi Healthcare	GloHealth %	Restricted Membership Undertakings***
	%	%	%		%

2001	-	13%	82%	-	5%
2002	-	15%	80%	-	5%
2003	-	17%	78%	-	5%
2004	-	19%	76%	-	5%
2005	1%	21%	74%	-	4%
2006	3%	21%	72%	-	4%
2007	5%	21%	70%	-	4%
2008	8%	22%	67%	-	4%
2009	10%	23%	63%	-	4%
2010	14%	21%	62%	-	4%
2011	18%	21%	57%	-	4%
2012	17%	22%	56%	1%	4%
2013	15%	23%	54%	4%	4%
2014	15%	23%	53%	5%	4%
2015	14%	26%	51%	5%	4%

*\*In respect of 2007 and earlier years the data relates to VIVAS Health*

*\*\*In respect of 2012, the data is a sum of the market shares of Quinn Insurance Ltd. (Under Administration) and Elips Insurance Ltd. Previous years relate to Quinn Healthcare or (2006 and earlier) BUPA Ireland*

*\*\*\*These mainly consist of the Garda, ESB and Prison Officer Schemes*

## **Risk Equalisation**

The Authority administers a scheme of risk equalisation for the Open Membership Undertakings. The scheme is designed to support community rating in the private health insurance market by effecting net transfers from those insurers with lower costs of claims to those insurers with higher costs of claims without overcompensating any insurer. In general, insurers with a higher proportion of older customers will have higher costs of claims when compared with insurers with younger customers.

The Authority administers a Risk Equalisation Fund which accumulates inflows from stamp duty applied to all health insurance policies. Different rates of stamp duty are applied to contracts based on whether they are in respect of 'advanced' or 'non-advanced' contracts, and whether the contract applies to an insured person who is 18 years or older, or 17 years and under.

**Table 3 – Stamp Duty on health insurance contracts**

Stamp Duty from 1 March 2016 to 28 February 2017		
Age Band	Non-advanced contracts	Advanced contracts
17 and under	€67	€134
18 and over	€202	€403

Payments are made to insurers from the Risk Equalisation Fund as age credits and hospital bed utilisation credits based claims submitted by insurers to the Authority. The rates of credits currently applying are –

**Table 4 – Risk Equalisation Credits**

Age Band	Bed Utilisation Credit	Non-advanced contracts		Advanced contracts	
		Men	Women	Men	Women
	Overnight/Day				
64 and under	€90/€30	€0	€0	€0	€0
65-69	€90/€30	€575	€375	€1,125	€800
70-74	€90/€30	€900	€675	€1,800	€1,300
75-79	€90/€30	€1,175	€850	€2,550	€1,900
80-84	€90/€30	€1,550	€1,100	€3,375	€2,375
85 and over	€90/€30	€1,775	€1,250	€4,150	€2,775

In the 12 months to 31 December 2015, the Fund received total stamp duty receipts of €638.5 million. In the same period, Risk equalisation premiums credits (i.e. age credits) and bed utilisation credits paid to insurers amounted to €608.2 million. The Fund recorded a surplus for the year of €30.2 million.

Further information on the operation of the Risk Equalisation Scheme, and the Authority's analysis and conclusions on the returns submitted to it by insurers are provided in the report: '*Report of the Authority to the Minister for Health on the evaluation and analysis of returns from 1 July 2014 to 30 June 2015 including advice on risk equalisation credits*' (September 2015; redacted). This report is available from the HIA website and a link to it is provided later in this submission.

### Recent regulatory developments

The regulation of the private health insurance market has evolved as the market has continued to develop. Recent regulatory changes include -

**Lifetime Community Rating** - Lifetime Community Rating (or 'LCR') was introduced with effect from 1 May 2015. To encourage those considering taking out private health insurance cover to do so at a younger age, LCR introduces an age-related loading of 2% per year of age over 34 years when a person first takes out private health insurance. This loading continues to apply to health insurance premiums paid by the person who incurred them on a permanent basis. The Authority has reported that 5,000 insured persons paid a total of €711,000 in LCR loadings in 2015.

There are a number of exceptions to the application of LCR loadings, including for persons immigrating or returning to Ireland having worked abroad, and for those that may have been unemployed for a period.

**Young Adult Discount rates** - A sliding scale of discount rates is applicable to health insurance premiums for those aged 18-25 years. With effect from 1 May 2015, insurers choosing to apply these rates must apply the full range of discounts provided for rather than selective application of certain discounts and not others.

**Waiting periods** - with effect from 1 May 2015, the waiting periods for pre-existing conditions for older ages taking out insurance or switching plans has been reduced to the same duration as that applying to younger ages.

**Adopted children** - with effect from 1 May, 2015 full private health insurance cover is available immediately for adopted children.

## **Research**

The Authority undertakes research, conducted internally and commissioned, in fulfilling its principal functions, including in formulating its advice to the Minister for Health at his request, or of its own volition. Areas recently examined include consumer research on the private health insurance market and consumer attitudes towards private health insurance conducted by Millward Brown, and a study to cost a basket of healthcare services in the context of government's consideration of a system of universal health insurance (or 'UHI'). This work was undertaken by KPMG.

## **The private health insurance market and consumer attitudes towards private health insurance**

The Authority has commissioned consumer research on health insurance biannually since 2002. It completed the seventh round of this research in late 2015. A nationally representative sample of 1,832 interviews were conducted face-to-face in late 2015, mirroring the timing of research previously undertaken on behalf of the Authority.

Specific questions were asked of policy and non-policy holders, including a group of questions asked of the entire population.

Findings included:

- The key reason given for having Health Insurance is that the cost of medical treatment and accommodation is high. There is also a strong belief among a substantial minority of PHI holders (27%) that public services are of an inadequate standard, and that there is a lack of access to such services (18%). Another reason that was given by 17% was that they were offered PHI as part of their employment.

- In terms of attitudes towards PHI, there is a broad consensus across the population as a whole that having PHI means you can “skip queues” (58% believe this to be the case, albeit down seven points since 2013). In addition, a majority (56%) agree that “having PHI means always getting a better level of healthcare service”, and that “PHI is a necessity, not a luxury” (56%).
- The proportion of the population who report having Private Health Insurance (PHI) rose in the latest survey after falling from 2009 to 2013. HIA data show that 45.8% of the population had PHI in December 2015.
- While 41% of the population are classified in the ABC1 socio-demographic category, 62% of PHI holders are.
- Younger adults are under-represented among PHI holders. 30% of the adult population are under 35, yet just 21% of adults with PHI are.
- While 50% of the adult population are married, 70% of adult PHI holders are. 35% of adult PHI holders have dependent children.
- Those with VHI policies tend to be older, whilst those with policies from Aviva and GloHealth tend to be of a younger demographic.
- Ten percent of the population report having PHI in the past, but no longer have it.
- The average length of time holding a PHI policy remains steady at 19 years, and there is much loyalty within the marketplace – the average number of years policy holders have been with their current PHI provider is 14 years.
- Policy Holders’ overall satisfaction with their current PHI provider has increased, with over half (56%) giving a rating of at least eight out of ten. Satisfaction ratings with all aspects of Health Insurance have risen. There has been a substantial increase in satisfaction with the level of outpatient/non hospital cover on plans.
- There has been a sharp decrease in the proportion who feel that premium increases are inappropriate, and are not justified by the cost of treatments or services.
- Those aged 55+ are consistently most satisfied – possibly because they are more likely to be claiming from their PHI.
- Satisfaction with the level of understanding of health insurance cover has increased significantly (up nine points to 85%).
- Nearly 1 in 4 have switched health insurer at some time with a quarter of those having switched more than once. The main reason for switching is cost saving (65%).

### **Costing of a basket of healthcare services**

The Authority participated in a project to cost a ‘basket of services’ in relation to a Universal Health Insurance (“UHI”) system. A report presented to the Minister costed an adult premium in UHI at between €2,228 and €3,232 per annum, depending on the basket of services that would be a mandatory standard in UHI. This study was commissioned by the Authority from KPMG.

<http://www.hia.ie/>

## Further Information

The following documents may be of assistance to the Committee in its deliberations –

**Table 5 – Further Information**

Document	Date	Link
HIA Annual Report and Accounts 2015	July 2016	<a href="http://www.hia.ie/sites/default/files/HIA%202015%20Annual%20Report%20English.pdf">http://www.hia.ie/sites/default/files/HIA%202015%20Annual%20Report%20English.pdf</a>
HIA Corporate Strategy	March 2016	<a href="http://www.hia.ie/sites/default/files/HIA-Strategy-Plan-2016-2018.pdf">http://www.hia.ie/sites/default/files/HIA-Strategy-Plan-2016-2018.pdf</a>
HIA Newsletter	May 2016	<a href="http://www.hia.ie/sites/default/files/HIA_May_2016_Newsletter.pdf">http://www.hia.ie/sites/default/files/HIA_May_2016_Newsletter.pdf</a>
Report of the Authority to the Minister for Health on the evaluation and analysis of returns from 1 July 2014 to 30 June 2015 including advice on risk equalisation credits (redacted)	September 2015	<a href="http://health.gov.ie/blog/publications/report-to-the-minister-for-health-from-the-health-insurance-authority-redacted-on-an-evaluation-and-analysis-of-returns-for-1-july-2012-to-30-june-2013-including-advice-on-risk-equalisation-credits-2/">http://health.gov.ie/blog/publications/report-to-the-minister-for-health-from-the-health-insurance-authority-redacted-on-an-evaluation-and-analysis-of-returns-for-1-july-2012-to-30-june-2013-including-advice-on-risk-equalisation-credits-2/</a>
My Rights, My Choices – Private Health Insurance Consumer Rights		<a href="http://www.hia.ie/publication/consumer-rights">http://www.hia.ie/publication/consumer-rights</a>
A review of private health insurance in Ireland Millward Brown		<a href="http://www.hia.ie/sites/default/files/Final%20Report%20Health%20Insurance%20Authority%202015%2004%2003%2016_0.pdf">http://www.hia.ie/sites/default/files/Final%20Report%20Health%20Insurance%20Authority%202015%2004%2003%2016_0.pdf</a>
Health Insurance Comparison tool		<a href="http://www.hia.ie/ci/health-insurance-comparison">http://www.hia.ie/ci/health-insurance-comparison</a>
UHI Premia Costing Report (KPMG)	September 2015	<a href="http://www.hia.ie/sites/default/files/UHI_Template_Issued_22_09_15_1.pdf">http://www.hia.ie/sites/default/files/UHI_Template_Issued_22_09_15_1.pdf</a>

## Health Reform Alliance

The Health Reform Alliance brings voices from across the health, social care, charity and academic sectors together to call for Government reform of Ireland's health and social care system.

The current members are the Adelaide Health Foundation, Age Action, the Asthma Society of Ireland, Irish Cancer Society, Irish Heart Foundation and Samaritans. Alliance members share a common belief that reform is needed to create a more equitable system. We have developed a consensus on the values which should underpin reform and to advocate for systems, services and policies that could best deliver it.

The five key principles set out by the Health Reform Alliance for reform of our health and social care systems are:

- The health and social care system treats everyone equally.
- The health and social care system is focused on the needs of all social groups in society.
- People have an entitlement to health and social care, free at the point of access.
- The different elements of the health and social care system work together and are connected.
- The health and social care system is a universal, publicly funded system.

The Alliance seeks to ensure the best possible health outcomes for the people we represent who rely on our health and social care systems. We wish to ensure that their voices are heard in the conversation on health reform.

The Alliance welcomes the establishment of the Oireachtas Future of Healthcare Committee as a sign of broad cross-party commitment to reform Ireland's health and social care system. This committee - with a remit to support the Oireachtas adopting a 10-year plan for healthcare - has an important opportunity to end the two-tier health system and move towards a health and social care system based on need and not on ability to pay, where people have equal access to quality care.

This submission addresses the questions posed by the committee in its request for submissions. It begins with a summary of the recommendations, followed by a detailed response to the questions posed.

## Recommendations

- Begin by focussing on the outcome to be achieved - the healthcare system to be delivered by 2026 and the level of universality which the system will deliver
- Health and social care systems must be integrated so that they can respond to the changing needs of the population
- Key steps in achieving integration of care for the committee to consider include:
  - Start improving the integration of care by strengthening and investing in primary care
  - Promote parity between physical and mental health
  - Shift historic behavioural and cultural attitudes in health and allied services
  - Budget pooling or special ring-fenced funding for integrated services
  - Incentives for providing comprehensive, coordinated and continuous care for prevention and management of chronic diseases
  - Put in place a well-resourced integrated Information and Communication Technology system
- Examine the approaches to integrating care taken by the UK, USA, Germany, Denmark, and Scotland
- Examine publicly funded health systems based on progressive taxation or social insurance as the most effective and financially sustainable ways to provide universal access to health and social care based on need and not on ability to pay.
- Explore the merits of using our current tax-based system to provide universal access by extending free access to primary care to cover the whole population
- Explore the introduction of a single waiting list for elective treatments for public and private patients in public hospitals to address unequal access to hospital care
- The committee's decisions in relation to the proposed funding model should be informed by the Economic and Social Research Institute's (ESRI) research on the costs of reforming the health system based on different funding models and the Trinity College Pathways Project

## Strategy

### What are the key priorities for inclusion in a ten-year plan for the health service?

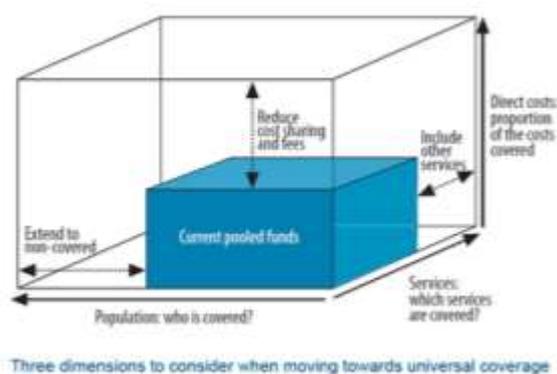
We urge the committee to begin by focussing on the outcome to be achieved - the healthcare system to be delivered by 2026. To date, discourse has focused largely on funding models, comparing one country against another. Much less time has been given to what should be a primary concern - what we expect the healthcare system to achieve.

The role of the committee is to plan for 'a universal single tier service'. By achieving this goal people will be liberated from the two-tier system. The first step must be a clear definition of universality for the Irish system.

The World Health Organisation has identified three dimensions or policy choices which countries must make when reforming their health services towards universal coverage<sup>i</sup>. These dimensions are shown below.

#### **Pooled funds can be used to:**

- **extend coverage to those individuals who previously were not covered**
- **extend coverage to services that previously were not covered or**
- **reduce the direct payments needed for each service**



The Alliance believes that all citizens<sup>298</sup> should be covered.

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<sup>298</sup> The term 'citizen' is used here instead of patient or service user. This reflects our position that reform of the health and social care system is important to all those who live in Ireland, whether they are currently sick and using the system, or may need to do so in the future. However, we are aware that the term citizen has limitations, especially for new communities in Ireland. We use the term citizen here in its widest sense, not limited to a person's legal status. We understand the term in line with the concept of inclusive citizenship, which means having the rights and opportunities for active participation in society, a condition that transcends nationalistic, ethnic, racial and ideological chauvinism (Ejorh, 2006).

The services that are covered should include curative, rehabilitative, long-term nursing, ancillary and prevention services as well as medical goods. The services provided must be of good quality and should routinely be measured against agreed quality indicators

In relation to the costs covered, we believe that essential health and social care services should be free at the point of access.

A universal system will require a commitment by all to pay into the system so that we can receive equal care for equal need. While we won't be able to provide all forms of care to all people at once, whatever care is available will be provided in an equitable manner, without discrimination. Such a system – organised through any funding model – must share the burden of illness collectively, where healthy people subsidise the sick and high-income earners subsidise low earners.

What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?

Unlike the majority of Europe, Ireland never developed universal access to health services. Our system is regrettably unique - a tax-based system<sup>ii</sup> that fails to provide universal access to primary care and which has always had significant user charges.

Taxes paid for 77% of health expenditure in 2013.<sup>iii</sup> Yet in our primarily tax-funded health system, people with private health insurance have quicker access to healthcare compared to fellow taxpayers without insurance. Policy debates often emphasise lack of health insurance as the 'problem' in our system. This overlooks the fact that the vast majority of spending on healthcare comes from taxation, with insurance covering less than 10% of health costs<sup>iv</sup>. Further, the reason many hold health insurance is because they don't believe they will receive adequate healthcare without it<sup>v</sup>. We urge the committee to focus their attention on the tax-funded, public system and how the system can be used to end the two-tier health system.

Every day, our organisations hear from people facing difficulties accessing the care they need. We support people who can't access a hospital bed or a homecare worker; who are subject to different eligibility criteria depending on their location; who are 'too late' to access nursing home care subject to a yearly budget cap; and families who are forced to navigate the disjuncture between hospital and community care. We are acutely aware of how the confusing mix of public and private healthcare means people are treated differently whether they have insurance, or a medical card.

The lack of integration between health and social care means that every day people fall between the cracks in both systems.

We are now seeing the legacy of austerity measures and major reductions in the health budget – shrinking access to health care, hospital overcrowding and continual increases in the charges patients must pay. Following the economic crisis, and as a reaction to economic downturn, the health budget was slashed by almost a quarter between 2009 and 2013<sup>vi</sup>.

This has resulted in, amongst other things:

- a 10% reduction in the number of frontline health staff<sup>vii</sup>
- 10% reduction in the number of public hospital beds
- 13% less home-help hours<sup>viii</sup>
- A 14% reduction in the number of nurses working the community in the period from 2009-2013<sup>ix</sup>

The health system is struggling to cope with these losses in manpower and beds. During this period, the number of people aged 65 and over increased by almost 14%. At the same time as access to healthcare has been declining, people are being asked to pay more towards their care. As very large cuts were made to the health budget in recent years, costs have increasingly been transferred onto citizens through user charges. Patients now have to pay increased inpatient day charges, emergency attendance charges, prescription charges, as well as face the much higher threshold for the drugs repayment scheme. During the “austerity era”, these new charges have amounted to at least €100 per person per year<sup>x</sup> across the whole population. It is likely that it is the sickest and the oldest in society who are shouldering the majority of these charges.

What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?

According to the latest available census data, 532,000 people aged 65 and over were living in Ireland in 2011<sup>xi</sup>. The number is predicted to rise to 1.4 million in 2046. The fact that people are living longer is to be welcomed. However, older people are more likely to live with multiple chronic conditions requiring either health or social care, or very often both. Cancer incidence is due to double by 2040 to 56,000 cases a year<sup>xii</sup> and the proportion of adults with chronic disease will reach 40% by 2020<sup>xiii</sup>.

Our systems must be designed to provide health and social care which helps people maintain the highest possible level of wellbeing.

The preference of many older people is to remain living at home for as long as possible, receiving care when it is needed in this setting but the resources and supports required to facilitate this vary from one part of the country to another<sup>299</sup>.

In order to meet the needs of our ageing population, social care must be integrated with our health system so that people can be treated in the most appropriate setting.

### **Integrated Primary and Community Care**

#### What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?

The World Health Organisation defines integration as “the organisation and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money.”

Integration of our health and social systems has the potential to provide better, more cost-effective care, and ensure continuity of care.

In 2013, the Department of Health commissioned the Health Research Board (HRB) to undertake a review of the international evidence in relation to mechanisms and structures used to integrate general health services with social care.

The HRB review<sup>xiv</sup> outlines six processes to integrate social care and general health systems - systemic, organisational, clinical, normative, financial and informational which the committee may find helpful to review.

Historically, our health system has been over-reliant on acute services and primary care has been under-funded. The Alliance believes that the health system must be reconfigured so that people can access care in the most appropriate setting and at the lowest level of complexity.

Despite a significant increase in investment in primary care, problems exist with the development and staffing of primary care teams (PCTs). It was envisaged that 530 PCTs supported by 134 Health and Social Networks would cover the country by 2011. At the end of 2014, there were 85 Primary

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<sup>299</sup> Donnelly, S., O'Brien, M., Begley, E. and Brennan, J. (2016). *“I’d prefer to stay at home but I don’t have a choice” Meeting Older People’s Preference for Care: Policy, but what about practice?* Dublin: University College Dublin.

Care Centres in operation with a further 37 locations planned to be delivered during 2014 to 2016/7<sup>xv</sup>.

The HSE Service Plan for 2015 outlined plans to develop 90 Primary Care Networks with each of the new Community Healthcare Organisations having an average of 10 networks which would support PCTs. The Alliance believes that it essential that these primary care networks and PCTs are adequately resourced with the proper compliment of health and social care professionals on each PCT. Greater clarity about eligibility for primary care services is also needed.

What are the key barriers to achieving this, and how might they be addressed?

Achieving integration of care is complex and there are many barriers to overcome. In Ireland, our health and social care systems are entirely separate with different budgetary and decision-making processes. Access to social care systems is mixed with some services being free, some being charged for and some being means-tested. This is a complicated system for service users to navigate.

We lack the information and communication systems to facilitate adequate information sharing and monitoring of care. Poor use of financial incentives has made the clinical coordination of care difficult<sup>xvi</sup>.

Differences in working practices and employment arrangements exist between health and social care staff and can act as barrier to integrated services.

National policy must support the aim of integration of health and social care. Plans for UHI did not include social care in the basket of services. It is difficult to see how integration can be achieved by continuing the separation of health and social care services in this way. The Alliance believes that it is important that the committee designs a vision for a health and social care system.

The experiences of the people we represent indicate the deep disconnect between health and social care. Need for medical care or personal and long-term care cannot be clearly divided in the lived experience of being unwell, yet policy up to now has dealt with health and social care needs differently. While health need is to some extent met in the public system, social care is primarily viewed as an individual responsibility which is allocated on a discretionary basis, subject to local resources and eligibility criteria. This reflects a Poor Law view of social care as 'charity' for the destitute.

The lack of designated funding for social care forces many families to place a loved one in residential care prematurely, when home help, day-care or respite could have kept them at home.

Consequently, vital social care services are increasingly available only to those with the highest needs and lowest incomes, rather than as a universal service supporting the whole population.

Successful integration requires strong system leadership, professional commitment, excellent management, and consistent clear communication, full and accurate information about a patient's needs and care, and a commitment to multi-disciplinary working<sup>xvii</sup>.

The Adelaide Health Foundation's analysis<sup>xviii</sup> on Integrated Healthcare in Ireland makes a number of recommendations about how better integration may be achieved including:

- Start improving the integration of care by strengthening and investing in primary care
- Promote parity between physical and mental health
- Shift historic behavioural and cultural attitudes in health and allied services
- Budget pooling or special ring fenced funding for integrated services
- Incentives for providing comprehensive, coordinated and continuous care for prevention and management of chronic diseases
- Put in place a well-resourced integrated Information and Communication Technology system

Are there any examples of best practice that the committee should consider? Please refer to any evidence you have to support this.

There are a number of international examples at approaches to integrating care which the committee may find useful to study including the UK, US, Germany and Denmark.

The Scottish Government has introduced legislation to integrate health and social care. The Public Bodies (Joint Working) (Scotland) Act 2014 sets out a framework for integrating adult health and social care services. Under the legislation, providers must work together to agree national outcomes which apply across health and social care and introduce integrated budgets which apply across health and social care systems<sup>xix</sup>. The legislation only came into effect in April 2016 but it would be helpful for the committee to look at the Scottish experience to date.

## Funding Model

Do you have any views on which health service funding model would be best suited to Ireland?

The HRA believes that a universal and publicly funded health system is the most effective and financially sustainable way to provide universal access to health and social care based on need and not on ability to pay.

Universal health care describes the depth and breadth of coverage of health and social care services, ranging from health promotion, prevention, primary care, secondary care to palliative care services.

Plans to introduce Universal Health Insurance have been abandoned due to unacceptable estimated costs.

A system where payment is to be according to ability would be better delivered through progressive taxation or through pay-related social insurance<sup>xx</sup>.

Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating

In a tax funded system (for example UK, Denmark, Norway, Sweden) everyone who pays taxes contributes to financing healthcare. General revenues are generally the most equitable way to pay for care, depending on the progressivity of the taxation system. Advantages of taxation funded systems are that they have a large scope for raising resources and the potential for administrative efficiency and cost control. However, the level of funding may be subject to annual budget negotiations<sup>xxi</sup>.

In a social health insurance (SHI) system (for example France, Belgium, Germany, Austria) insured people pay a regular, usually wage-based contribution and independent quasi-public bodies act as the payers for healthcare. Advantages of SHI systems are that they deliver an earmarked fund for healthcare, with transparency between contributions and expenditure<sup>xxii</sup>.

The HRA believes that it may be pragmatic to deal with the system as it currently exists and that the 10-year plan for the future of the health service should focus on our primarily tax-funded system.

It is worth exploring the merits of using our current tax-based system to provide universal access. A significant amount of the Irish population currently receives free access to primary care under the medical card and GP visit cards systems. This access could be extended to cover the rest of the population. Theoretically, universal access to hospital care exists but access to private health insurance results in some groups being able to access initial specialist appointments of treatment

ahead of others. The introduction of a single waiting list for elective treatments for public and private patients in public hospitals could address this.<sup>xxiii</sup>

What are the main entitlements that patients will be provided under your funding model?

No two countries health and social systems are the same and the extent of universality provided varies. The Alliance believes that curative, rehabilitative, long-term nursing, ancillary and prevention services as well as medical goods should be free at point of access. Services should include:

- Primary care - access to all allied health team members, i.e. not limited to GP access
- Acute care, including diagnostics
- Multi-disciplinary team rehabilitation and re-ablement in acute, step-down and community settings
- Chronic disease management (including medications)
- Step-down care and community services (home care)
- Preventative care, e.g. diet, smoking, blood pressure, cholesterol, etc
- No charges at the point of access (such as 'nominal' fees for GP services) should be introduced
- Mental health services including social inclusion supports
- Long-term care

Of particular importance is the inclusion of both primary and secondary care services. For example, the roll out of free GP care to all citizens and removal of the €750 charge for inpatient stays in public hospitals will be important milestones on the road to a single tier health and social care system. It is estimated that removing this charge would cost €17.7 million<sup>xxiv</sup>.

Please provide examples of best practice, or estimated costs of such models if available.

Estimating the costs of different models is a complex process and depends on many variables such as the what health and social care services are to be covered, the out of pocket expenses citizens are expected to pay, the level of additional tax revenue available.

The ESRI is currently researching the costs of reforming the health system based on different models. The Trinity College Pathways project is also modelling what universal healthcare would mean in Ireland and will indicate what parts of the system need further development. The Alliance recommends that the committee's decisions in relation to the proposed funding model be informed by this research.

For further information, please contact: Rachel Wright, Health Reform Alliance  
[info@healthreformalliance.ie](mailto:info@healthreformalliance.ie)

<http://healthreformalliance.ie/wordpress/>

World Health Organisation - universal coverage - three dimensions.

[http://www.who.int/health\\_financing/strategy/dimensions/en/](http://www.who.int/health_financing/strategy/dimensions/en/)

<sup>ii</sup> Wren, M.A., Connolly, S. and Cunningham, N. (2015) *An Examination of the Potential Costs of Universal Health Insurance in Ireland*. Dublin: ESRI. <http://www.esri.ie/pubs/RS45.pdf>

<sup>iii</sup> Ibid

<sup>iv</sup> Ibid

<sup>v</sup> Colombo, F. and Tapay, N. (2004), *Private Health Insurance in Ireland: a Case Study*, Paper No. 10, OECD Health Working Papers, Paris: OECD. Available at  
<https://www.oecd.org/ireland/29157620.pdf>

<sup>vi</sup> Thomas, S., Burke, S. and Barry, S. (2014) 'The Irish health-care system and austerity: sharing the pain'. *The Lancet*, 383 (3), 1545-6.

<sup>vii</sup> Ibid

<sup>viii</sup> Ibid

<sup>ix</sup> Health Services Executive, [National Services Plan 2013](#), p.12

<sup>x</sup> Thomas, S., *et al.* (2014) 'The Irish health-care system and austerity: sharing the pain'. *The Lancet*, 383 (3), 1545-6.

<sup>xi</sup> Central Statistics Office. Census 2011 Profile 2 - Older and Younger [Internet]. Dublin; 2011. Available from: <http://www.cso.ie/en/census/census2011reports/census2011profile2-olderandyounger/>

<sup>xii</sup> National Cancer Registry Ireland (2013), 'Cancer projections for Ireland 2015 – 2040'.  
<http://www.ncri.ie/sites/ncri/files/pubs/Cancer%20projections%20for%20Ireland%202015%20-%202040.pdf>

<sup>xiii</sup> Balanda, K.P., *et al.*, (2010), 'Making Chronic Conditions Count: A systematic approach to estimating and forecasting population prevalence on the island of Ireland'  
[http://www.publichealth.ie/files/chronic\\_main.pdf](http://www.publichealth.ie/files/chronic_main.pdf)

<sup>xiv</sup> Pike, B., & Mongan, D. (2014). The integration of health and social care services. Health Research Board, Dublin.

<sup>xv</sup> Department of Health, 2014 cited in Social Justice Ireland. (2016) Socio Economic Review 2016. Available at <https://www.socialjustice.ie/content/publications/type/socioeconomic-review>

<sup>xvi</sup> Darker, C. (2014) 'Integrated healthcare in Ireland – a critical analysis and a way forward'. Dublin: Adelaide Health Foundation.  
<http://www.adelaide.ie/files/Integrated%20Healthcare%20in%20Ireland.pdf>

<sup>xvii</sup> Pike, B., & Mongan, D. (2014). The integration of health and social care services. Health Research Board, Dublin.

<sup>xviii</sup> Darker, C. (2014) 'Integrated healthcare in Ireland – a critical analysis and a way forward'. Dublin: Adelaide Health Foundation.  
<http://www.adelaide.ie/files/Integrated%20Healthcare%20in%20Ireland.pdf>

<sup>xix</sup> Audit Scotland. (2015) 'Health and Social Care' [http://www.audit-scotland.gov.uk/uploads/docs/report/2015/nr\\_151203\\_health\\_socialcare.pdf](http://www.audit-scotland.gov.uk/uploads/docs/report/2015/nr_151203_health_socialcare.pdf)

<sup>xx</sup> - Wren, M.A. and Connolly, S. (2016) *Challenges in Achieving Universal Healthcare in Ireland*  
<https://www.esri.ie/pubs/BP201701.pdf>

<sup>xxi</sup> Ibid

<sup>xxii</sup> Ibid

<sup>xxiii</sup> Wren, M.A., Connolly, S. and Cunningham, N. (2015) *An Examination of the Potential Costs of Universal Health Insurance in Ireland*. Dublin: Economic and Social Research Institute,  
<https://www.esri.ie/pubs/RS45.pdf>.

<sup>xxivxxiv</sup> Health Service Executive (2016), Response to Parliamentary Question [PQ 10286/16].

## Health Research Board

Health research saves lives. International evidence shows that research-active healthcare systems have significantly better outcomes for patients. For this reason, advanced healthcare systems around the world invest significantly in R&D.

As the lead agency in Ireland with responsibility for supporting health research, the HRB has worked to embed research at the heart of the Irish health system, develop a strong evidence base for health policy, and translate research and evidence into better outcomes for people's health, patient care and health service delivery.

Despite recent economic difficulties, great progress has been made towards achieving these goals. In our submission, we set out a number of examples of HRB supported work that demonstrate the value of research and evidence to our health system. The challenge for the years ahead is to continue and, if possible, increase our investment in research, bringing it to the same level as that found in other developed countries. But equally important is a commitment to the development of a strong research culture in our health service. In working to achieve a consensus on a ten year vision, we strongly recommend that research be explicitly recognised as a core activity in the Irish health system - one that is fundamental to high quality patient care - and that appropriate supports are put in place to ensure that people in Ireland enjoy the benefits of a research active health service.

### INTRODUCTION

The Health Research Board (HRB) is an agency of the Department of Health with an annual budget of €40.6 million. Our vision is *healthy people through excellent research and applied knowledge*. We welcome this opportunity to make a submission to the Oireachtas Committee on the Future of Healthcare and in particular, to outline to the Committee the important contribution that research can make to the health of the population and the future of our healthcare system.

Health research saves lives. International evidence shows that research-active healthcare systems have significantly better outcomes for patients. For this reason, advanced healthcare systems around the world invest significantly in R&D to ensure they have a 'self-learning' capacity, one that benefits the patients and populations they serve. As well as having a positive impact on health, research plays an important role in economic development by supporting new products, processes and technologies, and ultimately, high value jobs. This is a cornerstone of Innovation 2020, the Government's strategy for R&D, and science and technology.

The HRB has taken a deliberate approach in recent years to embed research at the heart of the Irish health system, develop a strong evidence base for health policy, and translate research and evidence into better outcomes for people's health, patient care and health service delivery. Despite recent economic challenges, great progress has been made towards achieving these goals. By investing carefully, we now have a well-developed clinical research infrastructure with dedicated research facilities in all our hospital groups, a mechanism in place to co-ordinate clinical research at national level, and increased research training opportunities for healthcare staff. We are supporting healthcare policy and practice by investing in research that makes a real contribution to the

needs of the healthcare system and to patient safety. We fund training in health services research, health economics and population science to ensure that the country has the expertise it needs to make informed decisions about our health system. We provide a dedicated evidence review service to the Department of Health to assist in the formulation of policy, and the five national information systems that we manage in the areas of disability, drug use and mental health help to inform service planning in the HSE.

Over the years ahead, continued investment in health research will enable the health service in Ireland to derive greater value from its expenditure and deliver even better outcomes for patients. The next section describes the main areas of focus for the HRB and gives examples of how research can have a positive impact on patient care and the health of the population, as well as helping policy makers and managers to make the best decisions.

## THE WORK OF THE HEALTH RESEARCH BOARD

The mission of the HRB is *to improve people's health and to enhance healthcare delivery*. It does this by:

- supporting health research in higher education institutions & healthcare settings via competitive grants;
- collecting data that supports health service planning in selected areas e.g. disability, drugs & mental health;
- synthesizing evidence from the international literature to support policy making in the DoH.

*Research Evidence Action*, HRB's strategic plan for the 2016-2020, focuses on three key areas and a number of enabling themes. These are illustrated in the figure below and briefly summarised by way of simple examples.



### Focus 1. Address Major Health Challenges

By definition this type of research support by the HRB is designed to encourage new thinking, methodologies & technologies in healthcare. With HRB support, many of our

leading researchers have established excellent international links, enabling them to both contribute to the latest scientific developments in healthcare and to bring the benefits of those developments to the health system in Ireland. Projects funded in this focus area span health services research, patient oriented research and population sciences.

For example, 'Mapping the Pathways to Universal Health Care' is a three year collaborative research programme between the Centre for Health Policy and Management TCD, and staff from the Health Systems Strengthening Office of WHO Europe and the European Observatory on Health Systems and Policies. The project has three components:

- i. Assessing the gap between current Irish health system performance and universal health care, using and adapting World Health Organisation (WHO) concepts;
- ii. Evaluating the strengths and weaknesses of different models of universal health care and assessing their feasibility within the current context according to key criteria such as affordability, human resources and complexity of design.
- iii. Assessing the organisational challenges of moving to universal health care by reviewing the experience of other countries and exploring the current capacity and constraints facing decision makers throughout the system.

We expect the results of this project will help to provide an excellent evidence base that will inform the strategic direction and implementation of universal health care in Ireland.

Other examples of major health challenges include hospital acquired infections and antibiotic resistance. Hospital acquired infections are a major cost and burden for the health service. A discovery by researchers in NUI Galway and published in [\*The Journal of Infectious Diseases\*](#), of how bacteria cling to the surfaces of medical devices, has the potential to significantly reduce infections from devices like catheters and other lines inserted into the body. Tuberculosis (TB) kills more than one million people each year. Antibiotics have been the mainstay of TB treatment for many years but emerging antimicrobial resistance now poses a major threat and TB is on the rise again globally. Through HRB grant funding, researchers in St James's Hospital recently identified an entirely new pathway in our immune systems by which TB develops. This finding is a true world first, as evidenced by its publication in the prestigious journal *Immunity*; more importantly, it opens up a new front on which we can potentially treat this disease with existing immune system drugs rather than increasingly ineffective antibiotics.

## **Focus 2. Support Healthcare Interventions**

HRB's support in this area is very much about the testing & validation of potential new healthcare treatments/interventions. Access to high quality intervention studies and clinical trials is an important determinant of quality outcomes in any health system. For this reason, the HRB is committed to increasing the number of interventions and trials in Ireland and helping more people

to benefit. With the help of HRB investment, 2,329 cancer patients have been recruited onto clinical trials through Cancer Trials Ireland (formerly ICORG). In addition, there are now 135 clinical trials underway at HRB funded Clinical Research Facilities, with over 1800 patients participating.

For example, HRB-supported clinical trials have tested and proven a new technique, called thrombectomy, for treating certain types of severe stroke, thereby preventing lifelong disability and, in some cases, death in stroke patients. This approach to stroke is now offered in all stroke units in Ireland. It not only benefits patients directly but it avoids enormous financial burdens on the State in terms of disability supports and nursing home costs.

The SCOPE project (Screening for Pregnancy Endpoints), is an international study, that aims to develop screening tests to predict and prevent the major complications of late pregnancy, such as pre-eclampsia. More than 1,500 Irish mothers and babies participated in this international research project which was based in Cork University hospital and included 5,700 first-time pregnant women in four countries.

In breast cancer, following surgery some women have a low likelihood of tumour recurrence whereas others have a high risk. Only those with higher risk require follow-on radiation and chemotherapy. Until recently there was no way of identifying those at higher risk from those at lower risk and hence all women underwent radiation and chemotherapy. Thanks to HRB-supported clinical trials a new genetic test has recently been approved in Ireland which can differentiate the risk of cancer recurrence and thereby allow a woman make an informed choice with her oncologist regarding post-surgery radiation and chemotherapy. In effect this test has reduced ineffective radiation and chemotherapy in up to half these cancer patients, saving them an unpleasant and arduous experience and avoiding wasteful use of resources in the Irish healthcare system.

### **Focus 3. Address the Research Needs of the Irish Health & Social Care System**

The driver for the research, data and evidence supported by the HRB in this area is the needs of the Irish health system today rather than the generation of new knowledge for tomorrow (as in Focus 1).

Poorly defined/implemented clinical guidelines and variations in clinical practice can lead to compromises in patient safety, as demonstrated in a number of recent high profile obstetric cases. The National Clinical Effectiveness Committee (NCEC) has been established to oversee the development and implementation of clinical guidelines prioritised by the Minister for Health. The HRB is rolling out a service that will provide systematic reviews & economic budgetary impact analyses to the NCEC in pursuit of its agenda to increase patient safety and clinical effectiveness.

Patient safety is a key concern for our health services. New research funded by the HRB shows that one in eight patients admitted to hospital during 2009 experienced adverse events. This is the first time such research has been carried out in Ireland and the figures are broadly consistent with baseline studies conducted in other countries. The establishment of a baseline offers an opportunity to build on the success of the Clinical Care Programmes, improve and monitor patient care and enhance the way services are delivered.

An example of research with an impact on health practice is the STOPP/START project. STOPP/START was devised and validated in University College Cork (UCC) to detect instances of inappropriate prescribing in older people. This HRB-funded study has shown how a simple

intervention can substantially reduce adverse drug reactions, improve patient outcomes and make significant savings to patient and exchequer medication costs.

The HRB's Evidence Unit provides an important service to the Department of Health by synthesising evidence that can inform policy. As an example, HRB data collection and research has built much of the evidence base underpinning the Public Health (Alcohol) Bill which aims to reduce the burden of harm caused by alcohol in Ireland, estimated to cost in excess of €1.5 billion per annum. Similarly, the key data regarding treatment of and deaths due to the main drugs of abuse in Ireland is collected and published by the HRB; this type of evidence has led to the emerging policy on supervised injection centres.

Policy makers in the DoH are also supported by the HRB in terms of assessing & brokering the international evidence in particular areas e.g. updating the food pyramid or fluoridating the community water supply. An evidence review conducted recently for the Department of Health entitled "*Health workforce planning models, tools and processes in five countries*" describes the health workforce planning models, tools, and processes used in a range of comparator countries to learn from their experiences, and to understand which tools and processes are best suited to the Irish context. Also on the theme of new approaches to the delivery of health services, the HRB conducted a review of minor ailments schemes in other countries, including an assessment of how such schemes are structured, regulated and resourced.

Finally, the HRB recently completed a review of the different approaches taken to individualised budgeting for social care services for people with a disability, and the related outcomes and experiences. The review also examined the financial sustainability of alternative approaches. This research will help to inform the work of the Task Force on Personalised Budgets, a key element in the Programme for Government's commitment to give people with disabilities more control in accessing services, together with greater independence and choice.

## **Enabling Themes**

### **These three Focus Areas are enabled by:**

- A. providing career support to exceptional researchers and leaders e.g. PhD studentships, post-doctoral fellowships, clinician scientist & health research leader award programmes. An example of this is the SPHeRE Programme in health services research and population health sciences. As well as training PhD students in these areas, the SPHeRE Programme is creating a network of highly trained researchers who can competently research the current Irish health system, making recommendations and informing policy and implementation initiatives.
- B. building a strong enabling environment; for example, the HRB has established three Clinical Research Facilities (CRFs) on the sites of teaching hospitals along with a new initiative called Clinical Research Coordination Ireland (CRCI) which will support multicentre clinical trials. Note that both of these enablers are influential in retaining outstanding clinicians trained in this country and in attracting the best healthcare staff from abroad.

- C. achieving and sustaining outstanding levels of organisational performance on the part of the HRB itself.

### **AN OPPORTUNITY TO BUILD A WORLD CLASS HEALTH SYSTEM**

By continuing to invest in health research, we can ensure that our health service is informed by the most up to date evidence and research. Ireland is fortunate in having some of the most highly skilled health professionals in the world, many of whom trained in research active health systems overseas. In addition, the HRB's investment in health services research and population health research has resulted in a significant increase in capacity in these areas. This is crucial if we are to develop a properly integrated health system with an emphasis on primary and community care.

Investment in research and development is essential in any modern healthcare system. The challenge for the years ahead is to continue and, if possible, increase our investment, bringing it to the same level as that found in other developed countries. Related to this, the HRB welcomes the commitment in the Programme for Government to increase support for the HRB. But equally important is a commitment to the development of a strong research culture. In working to achieve a consensus on a ten year vision for the health service, we strongly recommend that research be explicitly recognised as a core activity in the Irish health system - one that is fundamental to high quality patient care - and that appropriate supports be put in place to ensure that people in Ireland enjoy the benefits of a research active health service.

At a time of significant health system reform (for example the establishment of hospital groups, community healthcare organisations and the new children's hospital, and the move towards primary and community care), the opportunity to integrate health research into our healthcare system at a meaningful scale affords us the prospect of significantly increasing the effectiveness of our healthcare spend and effectively addressing the issues, current and future, facing our healthcare system. The HRB looks forward to continuing to work with the Department of Health, the HSE, and the health research community towards achieving these goals.

<http://www.hrb.ie/home/>

## Healthcare Enterprise Alliance

Healthcare Enterprise Alliance (HEA) are a grouping of industry leaders active in the healthcare and pharmaceutical market in Ireland, who have come together to promote reform within Irish healthcare. Our objective is to drive reforms in Irish healthcare, particularly in the provision of and access to the widest range of medicines.

HEA members work in partnership each day with numerous stakeholders across our health service. We see first-hand the positive work being undertaken to improve the health of patients. We also see where challenges exist within the health service and where pressures are emerging with the potential to impact on quality of care, such as the burden of chronic illnesses. It places our health services under huge strain and looks set to increase in the decades ahead.

### Role of medicines

The availability of appropriate medicines to effectively treat patients is key to keeping Irish people healthy, keeping patients out of hospital and ensuring they can be treated in their communities, at the lowest and most cost-effective level.

The provision of medicines is a critical part of our national health spend. Currently almost 15% of our annual healthcare bill (€2 billion out of €13.6 billion) is spent on medicines for Irish patients.

Even if the medicine budget remains unchanged over the next ten years, it will mean that the State will spend over **€20 billion on medicines** over the period.

In recent years, meaningful reforms have taken place through the introduction of generic substitution and reference pricing. Both have positively impacted on the cost of medicines, competition in the market and access to new medicines.

Yet there is still a need for further reforms, particularly in areas of the medicine market which are *still* not open to competition. For example, biologics, and their equivalent medicines, biosimilars. This lack of competition coupled with inadequate medicine pricing agreements which have been negotiated over the years, most recently in July this year, are costing the State and our health services tens of millions of euro. A better approach to both could fund vital services in other areas of our health service.

The HEA has comprehensive proposals, which if implemented in full, have the potential to provide the HSE with significant savings. These are detailed in full herein.

### **Who are the Healthcare Enterprise Alliance?**

Launched in September 2015, the Healthcare Enterprise Alliance is a coalition of Irish healthcare industry leaders which includes KRKA Pharmaceuticals Ireland, Mylan and Teva Pharmaceutical Ireland.

Our objective is to affect positive change in the delivery of healthcare and medicines to Irish patients and to play our part in advancing meaningful reforms across the healthcare system. Our member companies include some of the largest suppliers of prescription medicines in Ireland and are active in over 150 countries worldwide. We produce biosimilar, biopharmaceutical, medical devices, and over-the-counter (OTC) medicines, both branded and generics medicines, including injectables, transdermal patches and vaccines. We supply pharmacies, public and private hospitals, primary care centres and nursing homes.

## FACTS ABOUT THE HEALTHCARE ENTERPRISE ALLIANCE

**Members have a combined 15% share of the Irish medicines market in volume terms and account for exports worth over €1.3 billion (2014)**

**Key treatment areas include cancer medication, pain management and medication for respiratory conditions cardiovascular disease, central nervous system disorders and women's health**

**Members employ 2,000 people in Ireland directly and many thousands more indirectly through the support of local enterprises**

### **The Irish Healthcare system: challenges ahead**

The Irish healthcare system is the second largest budget expenditure item at €13.5 billion for 2015, after social protection at €19 billion.

In 2013, the year for which the most recent figures are available, 72.8 million medicine items were dispensed under the HSE's three community medicine schemes – General Medicine Scheme, Drugs Payment Scheme, and Long Term Illness Scheme. This figure equates to a 50% increase in the number of items dispensed over 2005.

Over the coming years, Ireland's healthcare budget and treatment needs will increase. The burden of illness facing our population and pressure on our existing services will grow as our population ages and the incidence of chronic diseases such as cardiovascular disease, diabetes and cancer increases. According to the 2013 HSE policy document 'Healthy Ireland', chronic disease incidence will increase by a further 40% by 2020 and 30,000 new cancer patients will be diagnosed each year between now and 2020.

The Irish Longitudinal Study on Ageing (TILDA) states that the "*combination of population growth and ageing will increase demands for treatments by between a quarter and a third by 2026 if current approaches to treatment continue.*" According to 2011 Census figures, the number of people over 65, will grow from 532,000 in 2011 to 860, 700 in 2026 or at a rate of 20,000 per annum.

All factors above point to a number of key considerations:

- While people are living longer and this is positive, they will have increased healthcare needs;
- Coupled with greater longevity, the incidence of chronic disease amongst Irish people will place a considerable strain on existing services and significant demands on healthcare budgets;
- The annual healthcare budget will inevitably have to increase;
- In addition to initiatives which promote healthier lifestyles such as the Department of Health's own, Healthy Ireland, we have to start planning now to meet these challenges in the most effective and cost-efficient way, without compromising patient welfare.

### **Medicines in Ireland: Current and Future trends**

- In 2015, Ireland spent €2 billion on its medicines budget, equating to 15% of the total healthcare budget.
- However, in the years ahead, this figure is expected to rise further because of the pressure which our healthcare service will face. In February 2015, the European Commission recommended that the Irish Government introduce initiatives to further reduce our medicines budget.
- Planning our medicines spend over the next 5, 10 and 20 years is the most effective way to ensure that patient access to medicines is maintained and patients are assured of best health outcomes. This must be a priority for this Committee.

### **2006-2016 Medicines Reform**

- Savings in Ireland's medicines budget have been delivered in two ways over the period:
  - **A. Medicine pricing agreements** agreed between the Department of Health and the pharmaceutical industry – both branded and generic representative organisations – have delivered almost €800 million over the period 2006 to 2014. The presence of generic alternatives and effective competition within the Irish medicines market in recent years have been persuasive in positively impacting upon the extent of savings negotiated and realised under these agreements. A new agreement was reached in July, 2016. See further on same below.
  - **B. Generic substitution and reference** pricing through the 2013 Act have delivered savings, to date, in excess of €210 million.
- Combined, these equated to over €1 billion in savings in medicine prices over a 10-year period.

### **Medicines Pricing in Ireland:**

Medicine usage and the pricing of medicines has changed dramatically in Ireland in recent years. The introduction of the Health (Pricing and Supply of Medical Goods) Act 2013 (the '2013 Act') revolutionised the way Ireland prescribes, dispenses and prices medicines. This legislation allows for compulsory generic substitution and reference pricing.

The 2013 Act ensures a more cost-effective approach to medicine dispensing: pharmacists must now automatically substitute generic medicines, over more costly branded equivalents. The legislation paves the way for the achieving of savings – in the hundreds of millions – by the Irish healthcare system through the increased usage of 'generic' drugs, chemically identical drugs in terms of quality, characteristic, and intended use, to their more expensive branded equivalent.

The legislation also benchmarks Irish prices against the wider European market in the form of 'reference pricing'. Irish generic medicine prices are now equivalent to, or below in some cases, the European average price of medicines.

Prior to these changes, around 10% by volume medicines used in Ireland were generic medicines, which compared very unfavourably with the UK where the equivalent figure was 80%. Generic medicines now account for around 50% of the total pharmaceutical market by volume in Ireland, with certain therapeutic classes reaching as high as 92% (anti-cholesterol) and 88% (anti-ulcer) and total market share continuing to grow.

The membership of HEA were to the fore in delivering the changes outlined above. We now strongly support a second wave of reforms within our healthcare system to enhance our existing services and to ensure medicines are supplied to patients in a more cost-effective and efficient manner.

Further reforms to Ireland’s medicines policy will also reap significant additional savings and enhance patient access to medicines. We believe that the pace of reform and overall approach to medicine spending must change. The introduction of generic substitution has been an important milestone; Ireland now needs to push on with its reform agenda.

**Medicine Pricing Agreement – July 2016 to July 2019**

**Outdated nature of the pricing negotiations**

The basis on which the negotiations between the Department of Health and pharmaceutical industry representatives currently take place are outdated and not conducive to achieving the best value for the State. This is because despite significant and growing cross-over between traditional branded and generic pharma companies, with most now having a blend of both types of medicines in their portfolios, the Department of Health continues to conduct negotiations with each sector separately. This means that the process is neither inclusive nor transparent. The result is also a one-sided agreement which does not encourage meaningful negotiations and impedes the State’s ability to get the best possible deal.

**The current pricing agreement**

In July 2016 the Department of Health announced a new drugs pricing agreement, with the pharmaceutical industry. This new pricing agreement, will run for four years commencing 1<sup>st</sup> August 2016 with estimated savings of €600 million. The deal is a ‘missed opportunity’ as the agreement blocks competition and prevents new, better value drugs, which are up to 30% cheaper, becoming available to Irish patients. This is due to the inclusion of an artificial pricing clause which protects more expensive medicines and block drugs known as ‘biosimilars’ – which are up to 30% cheaper – from entering the market.

A recent report on biosimilars found that between now and 2020 European and U.S. states will save €110 billion from the launch of new biosimilars, which will become available as patents expire. Ireland must also seek to benefit from these savings. Currently, it will not.

**CURRENT COST OF BIOLOGIC MEDICINES TO THE STATE**

<b>TOTAL ANNUALISED COST TO STATE OF BIOLOGIC MEDICINES FOR WHICH PATENTS HAVE EXPIRED OVER THE LIFETIME OF CURRENT MEDICINES AGREEMENT (UP TO END 2019)</b>	<b>€298m</b>
<b>CUMULATIVE COST TO STATE FOR THIS GROUP OF BIOLOGIC MEDICINES OVER THE NEXT FIVE YEARS</b>	<b>€1.29bn</b>

**HEA proposals**

As a progressive and proactive group, the HEA support change which benefits our healthcare system and our patients. With the right kind of reform, we can lower medicine costs and deliver better, outcomes for patients.

**Our proposals include:**

- Switching prescribing from biologics to equivalent biosimilar medicines (saving of €40 million);
- Opening up the €200 million, low-value medicines market to increased competition (saving of €60 million);
- Treating all new patients with a generic medicine from the outset (saving of €11 million);
- Incentivising GPs to prescribe more cost-effective medicines (saving of €18 million).

Our proposals can be introduced in a short time frame, with minimal effort. Most are already the norm across the EU.

### 2016-2026: HEA Proposals for further medicine reforms

HEA members were to the fore in delivering medicines savings in Ireland over the last 10 years. We have identified the potential for further significant savings over the next ten years. These can be achieved if policymakers and industry work together to implement a number of key reforms in the period ahead.

- Our medicine policy proposals are outlined below. These proposals have the capacity to deliver savings of €129 million per annum.
- These savings provide the opportunity for the HSE to invest in other priority areas of the health services. For example, €100 million in savings would pay for 3,000 additional nurses or 2,000 nursing home places in our health service.
- HEA members are committed to working with all relevant stakeholders to affect positive change and have these proposals implemented in full. We urge this Committee to incorporate our proposals into your final Health Strategy. Equally we are committed to working with the Department of Health, HSE and wider Government and health decision-makers to prioritise their full implementation.

### HEA Proposals

The HEA estimates that some **€129 million in additional annualised savings** can be achieved if reforms are introduced across four specific areas:

	CURRENT ANNUALISED SPEND	POTENTIAL ANNUALISED SAVINGS 2016
<b>A. Switching from biologics to biosimilars</b>	€160m	€40m
€40 million can be saved by mandating our prescribers to switch from expensive biologic medicines to the more affordable, but equally effective, biosimilar medicines when available and appropriate.		
<b>B. Facilitating generic competition in the low-value medicine segment</b>	€200m	€60m
€60 million can be saved by opening up competition in the low value medicines market, which currently cost taxpayers €200 million each year.		
<b>C. Substitution for patients prescribed non-interchangeable medicines for the first time</b>	€92m	€11m
€11 million can be saved by allowing pharmacists to dispense more affordable generic medicines to those patients who are prescribed for the first time otherwise non-interchangeable medications, ensuring that Irish patients who start out on a therapy for the first time do so on an affordable generics.		

<b>D. Cost-effective prescribing of respiratory medicines (e.g., inhaler devices)</b>	€70m	€18m
€18 million can be saved by incentivising cost-effective prescribing for ‘non-interchangeable’ respiratory devices which currently have an annual cost of €70 million.		
<b>TOTAL</b>	<b>€501m</b>	<b>€129m</b>

## **Conclusion**

Just as our healthcare services have been severely impacted during the past ten years as a result of Ireland’s economic crash, the next ten years will be equally as challenging. Demand on services will continue to grow, particularly as science continues to push the boundaries of medical and treatment innovations, with health budgets remaining stretched to meet this increasing demand.

We have to start planning now to meet these demands and maintain, at a minimum, existing levels of service provision. Prudent medicine management and careful budgeting is a reality which policymakers’ or wider stakeholders cannot shy away from.

As recent controversies around the high cost of medicines have shown, the State’s capacity to pay is not limitless yet the need to fund such next generation medicines places a moral and social obligation on all governments.

Enacting meaningful medicine reforms is one measure which can drive change in how we prescribe and dispense medicines, thus assisting with cost containment and also creating financial ‘headroom’ for Governments to fund higher cost, more individualised medicines.

The HEA’s proposals herein offer immediate savings which over the next ten years can deliver significant savings and contribute to the wider goal of ensuring affordability and accessibility of medicines.

We urge this Committee to carefully examine our proposals and include them in your final Strategy.

## **APPENDIX**

### **What are biosimilars?**

Biosimilars are ‘biological’ products that have been proven to be as safe and effective as an original ‘biological’ drug, but cost less. Biologics treat patients with conditions such as cancer, chronic kidney disease and autoimmune diseases like rheumatoid arthritis and inflammatory bowel disease. These drugs offer new and effective treatment for patients and real hope for many unmet needs, particularly for patients with complex diseases.

The use of biosimilar medicines is commonplace across Europe with increasing numbers of member states recommending/legislating for active switching from biologics to biosimilars.

### **Currently no interchangeability between biologics and biosimilars**

In Ireland, unlike other EU states, there is neither incentive nor disincentive for physicians to prescribe alternatives to the high-cost originator biologic, and current legislation blocks pharmacists from initiating substitution or offering a biosimilar for new patients.

The result is the lack of a structured pathway for the increased usage of biosimilars within our healthcare service. The absence of a mechanism to facilitate this process, contrasts with the approach taken by the State's own medicine regulatory body, the Health Products Regulatory Authority (formerly Irish Medicines Board).

In April, 2015 the HPRA launched a public consultation on the Guide to Biosimilars for Healthcare Professionals and Patients. This consultation has now been completed and is expected to be published shortly.

In Ireland, there are currently six biosimilars marketed. However, over the next five years a significant number of biologics will come off patent. This will open the way for healthcare professionals to endorse biosimilars for new patients.

Interchangeability between biologics and biosimilars, particularly for new patients entering treatment for the first time, has been endorsed by a number of other EU health authorities including Finland's FIMEA, MED in the Netherlands and Germany's PEI. Outside of the EU,

Australia allows for interchangeability between biologics and biosimilars.

Yet, notwithstanding the fact that interchangeability is common across the EU and in spite of the significant potential for cost savings, some of the country's largest hospitals continue to ignore biosimilars when undertaking their medicine procurement processes.

## **HEA MEMBERSHIP**

### **KRKA Pharmaceuticals Ireland**

KRKA Pharmaceuticals is an exclusively Europe-based producer of high quality generic prescription and OTC medicines. The company is ranked within the top 5 generic producers in Europe. KRKA has demonstrated the efficacy, quality, and safety of its medicines in clinical studies with over 270,000 patients in 27 countries. It has had a commercial operation in Dublin since 2011. During this relatively short time, it has launched 42 separate molecules and in the past 12 months alone has supplied over 1.1 million packs of prescription medicines.

### **Mylan**

Mylan is one of the world's leading global pharmaceutical companies and employs approximately 1,500 people in Ireland. With its manufacturing facilities in Galway and Dublin exporting globally, its Global Respiratory R&D Centre and European Business Centre of Excellence is in Dublin, Mylan has deep roots in Ireland and is a proven top employer. Its medicines include vaccines, medical devices, generics, biosimilars, over-the-counter, and brand-name products. It provides multiple dosage forms, such as difficult-to-manufacture injectables, transdermal patches and HIV/AIDS therapies. It has innovative research and development capabilities, a robust pipeline, and are one of the world's largest active pharmaceutical ingredient manufacturers.

### **Teva Pharmaceuticals Ireland**

Teva Pharmaceuticals Ireland employs over 500 people in two sites in Ireland, a R&D and manufacturing facility in Waterford and a commercial office in Dundalk. In 2013, Teva became Ireland's largest generics company (volume and value) and is also the largest supplier of prescription medicines to Irish patients, placing over 9 million packs of medicine on the market each year. Teva's portfolio encompasses a large and growing range of generic medicines together with branded specialty medicines for the treatment of diseases in the areas of CNS, cancer, respiratory conditions and pain management. Teva also has the growing range of biosimilar medicines.

## Heart Children Ireland

Heart Children Ireland (HCI) is a non-government funded, registered charity founded in 1990 for parents and families of children born with Congenital Heart Disease (CHD). We also support parents and families of children with acquired heart disease. Increasingly, we are also supporting those who survive into adulthood. We provide practical, financial, social and psychological support to HCI members. We have also funded staff and equipment in the Health Service, in both the paediatric and adult congenital cardiac services. This submission is made by Heart Children Ireland on behalf of its members.

Congenital heart disease is the most common of all congenital conditions, affecting approximately one in every hundred children born.

*Up to 4 decades ago, most of those born with CHD died in early childhood. However, due to medical and surgical progress, the numbers of those surviving in childhood and into adulthood is increasing rapidly.*

*In recent years, new research has been emerging about the complexity of the medical, surgical, practical, financial, psychological, social, educational and occupational needs of these individuals and their families.*

In addition to the medical/surgical stresses and uncertain future associated with CHD, families regularly highlight the frustrations they encounter when they meet a lack of awareness or up-to-date knowledge about the nature and impact of CHD throughout the health service, at every level.

Furthermore, the dearth of many support services as well as the lack of timely service responsiveness and flexibility add considerably to negative impact of CHD on the lives of those with CHD.

The health service plan needs to account for the varied, complicated and changing needs of the growing, diverse population of children and adults with CHD. The planning should be considered in terms of:

- 1) The services needed (given the increasing population, the increasing complexity of need and the changing profile in terms of age)
- 2) How the services are delivered (given individuals' varying requirements over time in relation to the type and amount of service and support needed in the hospital and/or community).

Congenital Heart Disease (CHD) is the most common form of major birth defects, affecting around 1% of newborns. Those with CHD differ from those with other types of acquired heart disease. Those with CHD themselves form a group that differ from each other in many ways (e.g. initial diagnosis, intervention history, disease complexity as well as cardiac and non-cardiac comorbidities).

## **FUTURE DEMOGRAPHIC PRESSURES:**

### **THE RAPIDLY CHANGING POPULATION OF THOSE WITH CONGENITAL HEART DISEASE**

Up to 4 decades ago, most of those born with CHD died in early childhood. However, due to medical and surgical progress, the numbers of those surviving to adulthood is increasing rapidly. In recent years, new research has been emerging about the complexity of the medical, surgical, practical, financial, psychological, social, educational and occupational needs of these individuals and their families.

### **EXAMPLE OF ONE SPECIFIC AREA WHERE SERVICES FOR THOSE WITH CHD ARE NEEDED URGENTLY: NEURODEVELOPMENTAL SUPPORT**

The growth in the surviving CHD population has not been matched by an appropriate increase in the support for the interacting physical and psychosocial challenges that may arise for those with CHD, in either the health or education services. A brief review of the emerging congenital cardiac-related neurodevelopmental research provides an example of one area (of many) in which there is a stark need to develop supports rapidly for those with CHD.

The research highlights that:

- Different neurodevelopmental issues may arise for those with CHD at different stages of the lifespan, thus requiring ongoing assessment and flexible intervention, particularly during infancy and childhood.
- For those with complex CHD, distinct and significant patterns of vulnerability are being identified within areas such as communication, language, attention, organisation skills, motor skills and mood.
- For those with complex CHD, many will require input from a wide range of support services in health and education (e.g. speech and language therapy, physiotherapy, occupational therapy, psychology).
- In the absence of appropriate supports, the potential long-term personal costs to individuals with CHD and their families across a wide range of domains are numerous. The potential practical and financial cost to the health service are also potentially significant (e.g. children presenting later with more established neurodevelopmental difficulties that require more multidisciplinary support over longer periods).

See “Congenital Heart Disease and Neurodevelopment : Understanding and Improving Outcomes” (2016) Edited by Christopher McCusker and Frank Casey, which provides a thorough overview of the emerging research in this area.

### **FACTORS FOR CONSIDERATION WHEN DEVELOPING A HEALTH SERVICE PLAN TO ACCOUNT FOR THE NEEDS OF THOSE WITH CHD**

- There are more children surviving with CHD now, than at any other time.
- The numbers of children living with complex CHD are increasing.

- The numbers of individuals with complex CHD surviving into adulthood are increasing.
- Due to the nature of congenital heart disease, particularly in relation to complex conditions, individuals' medical, surgical, psychosocial and other support interventions may need to change at short notice/from review to review, depending on their cardiac wellbeing (e.g. need for surgery, type of surgery, timing of surgery, type of home care required, type of follow-up supports required).
- There is a growing body of research which highlights the impact of CHD on individuals' energy/tiredness, neurodevelopment, learning profiles, co-ordination and emotional wellbeing.
- Some individuals with cardiac issues also have additional health concerns (e.g. as part of a syndrome) for which they need support.
- In addition to the medical/surgical stresses and uncertain future associated with CHD, families regularly highlight the frustrations they encounter when they meet a lack of awareness or up-to-date knowledge about the nature and impact of CHD throughout the health service, at every level.
- Furthermore, the dearth of many support services as well as the lack of timely service responsiveness and flexibility add considerably to negative impact of CHD on the lives of those with CHD.
- The health service plan needs to account for the varied, complicated and changing needs of the growing, diverse population of children and adults with CHD.
- In this context, planning should be considered in terms of :
  - 1) The services needed (given the increasing population, the increasing complexity of need and the changing profile in terms of age)
  - 2) How the services are delivered (given individuals' varying requirements over time in relation to the type and amount of service and support needed in the hospital and/or community).

## **10 YEAR HEALTH SERVICE PLAN: REQUIREMENTS**

***Please note that there is currently major work underway between the paediatric cardiology services in Northern Ireland and the Republic of Ireland, in order to develop an All-Island Paediatric Cardiology Service. As part of this, all paediatric cardiac surgery conducted on the island of Ireland currently takes place at Our Lady's Children's Hospital, Crumlin and will continue to do so. The points raised in this submission should be considered in conjunction with the All-Island Network Board plan but not overshadowed by it.***

- Additional staff in the adult and paediatric cardiac centres, across all the relevant disciplines, to support the increasing population and reduce waiting lists (e.g. paediatric and adult CHD cardiologists, speech and language therapists for cardiac-related feeding issues among infants) (Current specialised staffing levels do not meet international recommendations.)
- Additional training for community staff (e.g. public health nurses, GPs, paediatricians in non-acute hospital services) and allied health care professionals around CHD to build awareness of CHD related issues, update relevant skills and encourage timely referrals to relevant services.
- Additional community staff to support those surviving now with complex needs (e.g. occupational therapists to address cardiac-related dyslexia, dyspraxia and attention issues, psychologists to provide psychosocial support for the families). (Even families who have the means to access such services privately experience difficulty locating healthcare professionals with specialised CHD knowledge.)
- Funding for new technologies/ interventions/ approaches which are leading to changes in the recommended best practice procedures and service delivery methods in the field of CHD (e.g. less invasive treatment equipment, warfarin clinics, transition clinics).
- Pathways to financial supports that are more flexible and responsive to those with CHD. (Families regularly report significant stresses in accessing financial support to which they are entitled, due to assessors' poor/inaccurate understanding of the different congenital, cardiac conditions, the structure of CHD services and why families' support needs may vary over time).

Margaret Rogers  
CEO Heart Children Ireland

<http://www.heartchildren.ie/>

## Heartbeat Trust

It is clear to all of us involved in health care delivery in Ireland that we have substantive and serious challenges, which require novel solutions. Most of these challenges arise due to the epidemic of chronic diseases which is causing huge concern internationally about the sustainability of health systems.

The Heartbeat Trust through its international leadership in heart failure care is developing a number of innovative strategies in the prevention and management of heart failure that can have significant impacts on the management of chronic diseases in the healthcare system. In particular

1. The development of personalised prevention strategies for those with established cardiovascular risk factors which focuses care on those with the highest risk of disease with community based diagnostics and collaborative primary-secondary care. This model has been shown to be cost effective and is now part of international guidelines (the STOP HF model)
2. The development of structured care programmes for the management of heart failure
3. The development of a “virtual consultation” service to enable specialists and GPs to discuss cases and reduce the need for outpatient department referral by 80%

We need to apply across the system proven, integrated interdisciplinary evidence based protocol driven cost-effective care and treatment regimes which support patients and their carers in a personalised manner. The work of the Heartbeat Trust can provide a template for chronic disease management that is applicable to a wide range of chronic diseases.

Secondary prevention supported by a strongly focused long-term government commitment to Healthy Ireland is also essential.

Effective heart failure management regimes offer a proven methodology and model to assist our resource challenged service to stabilise and address effectively the health needs of our citizens. In particular heart failure affects an older population with multiple morbidities requiring complex comprehensive care providing an ideal bedrock on which to test and build a health system structure for the future.

### **MAIN BODY OF SUBMISSION**

The major manifestations of the challenges of chronic diseases are the ongoing congestion in the Emergency Departments (ED), continuing high levels of delayed discharges, continuing difficulties experienced by GPs in sourcing timely diagnostics and specialist advice, and in long delays in gaining access to the traditional outpatient services. The downstream consequences of these problems are well described, and include heightened risk of death, prolonged in-patient stays, and unnecessary morbidity developing in the community due to the inability of GPs and Primary Care Teams to deliver safe, cost-effective patient centred team and collaborative care with timely specialist input when required.

Solutions put in place to date to address the above have included the provision of additional acute beds, facilitated discharge to the traditional community based settings and use of the National Treatment Purchase programme to buy in outpatient appointments and traditional

nursing home beds. It is clear that these strategies will not have a significant medium or long-term positive impact. The ED challenge will remain. In addition, while outpatient waiting times may be reduced in the short term through buying in private specialist services a failure to address the need for collaborative interdisciplinary integrated care, for an aging population presenting in the main with multiple chronic disease will lead to increased referral to specialist services due to lack of resources in the community. Approximately 50% of those over 65 have a chronic disease, with very high proportions of those presenting with two or more chronic diseases leading to the need to develop personalised care strategies rather than disease based care strategies. It is estimated 75% of attendances at EDs present with challenges associated with chronic disease management. Cost-effective, evidence-based chronic disease management is essential if we are to meet the normative health needs of our citizens in an equitable and affordable manner.

Heart failure is where the heart does not work as efficiently as it should. Heart failure is a very common condition and there are about 90,000 people living with heart failure in Ireland today. Up to one in five people is expected to develop heart failure at some point in their life, and the burden of heart failure on individuals, their families and the health service is increasing due to our ageing population, better survival after heart attacks, and poorly controlled risk factors such as high blood pressure, high cholesterol, obesity and smoking. Across the globe, 17–45% of patients admitted to hospital with heart failure die within 1 year of admission and the majority die within 5 years of admission. Heart Failure is one of the most common causes of hospitalisation in patients over 65 years of age

The team at the Heartbeat Trust have developed solutions to the many challenges facing our health service, by methods which focus on keeping patients well in the community. A major focus of these new strategies has been the development of a patient centred team and collaborative care model, involving the patient and their carers, novel eHealth interactions between primary and secondary care health professionals, and revolutionising the way ambulatory and outpatient services can be delivered. Our approach offers patients treatments for which there is credible research evidence to support their efficacy in treating heart failure and other comorbidities.

### **Prevention Strategies – Predicting, Preventing and Protecting**

The Heartbeat Trust's landmark STOP-HF (Screening TO Prevent Heart Failure) study showed that in individuals over 40 years of age who have one or more cardiovascular risk factors, such as high blood pressure or diabetes, an inexpensive blood test collaborative care between primary and secondary care can predict and, through targeted interventions, prevent not just heart failure but other cardiovascular diseases and allows focused to be directed to these at risk individuals in a most effective manner.

The Heartbeat Trust's prevention initiative is based on using community-based diagnostics to broaden the amount of people who can benefit from our STOP-HF programme. It is also based on bringing the next generation of newer, more specific treatments to the at risk population, as well as delivering care in the community using eHealth initiatives such Virtual Consultations between hospital and community care physicians.

- HBT has proven a first-of-type approach to the prevention of Heart Failure and other Cardiovascular diseases

- Shown by the National Centre for Pharmacoeconomics to be cost-effective
- Internationally accepted and already has influenced international guidelines on cardiovascular health care delivery
- Is now established in Ireland East and Midlands on a pilot basis

### **Structured care programmes for the management of heart failure**

The integrated disease management programme for severe heart failure has been established for more than 15 years in St Vincents and St Michaels hospital with the support of the Heartbeat Trust. It has integrated its multidisciplinary services into primary care, providing a rapid diagnostic service where early medical treatment can provide a remarkably positive clinical outcome for patients. The programme aims to support general practitioners and provide rapid access to specialist opinion for complicated or deteriorating patients, avoiding the Emergency Room.

### **Virtual Consultation Service**

Virtual consultation is the use of webconferencing between multiple GPs and specialist simultaneously to discuss and develop treatment plans for patients with complex heart failure needs. Through the use of Virtual Consultation we have demonstrated;

- A reduction of 80% referral to routine outpatient services
- Speedier provision of specialist opinion
- Separately, we have shown that 3 out of 4 acute emergencies for HF can be managed in a community setting with proactive care involving telehealth, reducing the ED burden.
- These Virtual Clinics are more time efficient, as they can handle 6 -7 new patients per hour. In addition, as the Clinic structure allows for up to 25 practices to be involved in any clinic, this strategy also provides education benefit to GPs, as all present hear typical cases presented and thereby learn critical management strategies reducing down the line referral. Similarly it allows hospital and community teams to discuss difficulties in management strategies and the impact of co-morbidities on heart failure to ensure shared learning between the teams. We are encouraging health providers to collaborate effectively using shared care plans created by senior clinical decision makers in the community and hospital setting.
- Effective collaboration means tracking and reaching out to patients in a responsive way. It's important to remember co-location does not mean collaboration. We have perfected a Population Based Care approach and a Management –Based Personalised Treatment approach which keeps people well in the community and provide responsive rather than reactive care.

### **A list of recommendations you, or your group, would like to be considered by the Committee.**

1. Implement across the country an Action Plan for Chronic Disease Management with full accountability of clinical and general management across the system.

2. eHealth is the key to smart ageing, smart caring and smart living. The Heartbeat Trust is currently engaged with the major eHealth players, pharmaceutical industry and the medtech and medical devices industries to perfect and design solutions for application in enhancing the management of chronic disease.

The initial and robust early experience of the work of the Heartbeat Trust clearly demonstrates how we could radically alter the care and treatment system to deliver responsive ambulatory and outpatient services involving patients and their carers, reducing waiting times and provide speedier effective specialist advice and inputs. Furthermore, what has been shown with Heart Failure management is clearly applicable to other chronic illnesses.

The HBT are currently engaged in formal dialogue with the relevant major industries to maximise the economic potential for Ireland and we have developed partnerships with key stakeholders and health systems in the EU, US and Canada to facilitate the implementation of effective collaborative ambulatory care and treatment in their health care systems.

These well documented important advances and the further development of these approaches can be rolled out and applied nationally, if the Government is willing to promote and support the implementation of this evidence based collaborative ambulatory care and treatment model. In excess of € 50million was spent on buying in private specialist opinion last year, we can demonstrate that a fraction of that amount would be a critical investment in the development of modern day health care delivery which will form the foundation of the permanent solution to the challenges outlined above. We note that HSE Service Plan for 2016 encourages innovation and the roll out of cost-effective solutions. We are firmly convinced we have a credible implementable solution. We are very pleased to endorse and support the “Demonstrator Research Project in Community Heart Failure management in partnership with Ireland East Hospital Group, St Vincents Hospital Group, St Lukes Hospital, HSE-CHO5 and UCD. We are confident this excellent project will be successful and will demonstrate the benefits of integrated care patients with reductions in referrals for in-patient and outpatient services. This builds on the success of initiatives in the Midlands and Wicklow/North Wexford area in providing community based diagnostics and novel prevention and diagnostic strategies for general practice.

**Recommendations for action by Government or other actors which should consider be considered in preparing the report.**

- The HSE, Health Insurers and Life Insurers have a vital role in ensuring citizens avoid unnecessary levels of mortality and avoidable expensive chronic disease. Early interventions will mitigate the risks to patients and minimise the costs. More cost effective care and treatment and prevention regimes add real value and reduce costs. This requires the immediate prioritisation of the primary prevention of Chronic Disease by systematically dealing with the challenges associated with obesity, the systemic lack of community based physical exercise programmes and nutrition programmes across society. Alcohol abuse and tobacco consumption continue to cause significant mortality and morbidity in our society. 40% of the total expenditures on our health care system are directly related to alcohol abuse,

tobacco and obesity. We strongly support the Healthy Ireland and its direction of travel. Governments need to invest in it and regularly monitor the Health Status of our Population.

- We believe that the Chronic Disease tsunami will greatly challenge and possibly overrun the public and private health system unless we reengineer Chronic Disease Management and fund an integrated interdisciplinary evidence based approach to its management. This requires an Executive Clinical Directorate for Chronic Disease Management in every Hospital Group, Community and Primary Care Organisation leading and implementing a Population Based Care approach and a Management – Based Personalised Treatment approach. New contracts for all Health professionals with new models of funding based on money following the patient, supported by an objective funding and pricing model, will be essential to reward excellence and encourage innovation and maintain continuity of care in the community.. Current contracts can stifle innovation and mitigate against structured proactive interdisciplinary care. There is also a need for clinicians contracts to recognise the time required for population based care as well as individual based care.
- The reconfiguration and reorientation services within the Hospital Groups and Primary Care is essential. Prioritising the development of new Ambulatory Care environments with Rapid Turnaround Diagnostics and Virtual consultation facilities will enhance our capability to respond. These environments will require the active direct participation and leadership of specialist Consultants, General Practitioners, pharmacists and nurses and in particular those with a special interest in these areas.
- The HSE, Health Insurers and Life Insurers can now collaborate in changing the model of Chronic Disease Management and Prevention which will deliver improved health outcomes and real value for the economy.
- The HBT model if applied to the Clinical Management of Chronic Disease will radically alter the perception of the health system.

We look forward to exploring how best to find solutions together in the interests of patients. The private sector and the Health Insurance sector have a very important role in driving change, leading implementation and adding real value for their members and society generally. The experience of the Heartbeat Trust can help in the implementation of these strategies and helping to understand their cost-effectiveness.

## **Strategy**

What are the key priorities for inclusion in a ten year plan for the health service?

1. A continuing determined focus on Health and Wellbeing which is driven by all in the Oireachtas and all who are paid out of the public purse. The HBT commends Healthy Ireland to the Oireachtas.

2. A sharper structured systematic support and the full roll out of proven best evidence based care, treatment and preventive protocols. Best outcomes for patients should be prioritised.
3. Progress the Hospital Groups and reconfigure their services into Scheduled and Un Scheduled Care and Treatment services supported by new Ambulatory Care environments with active direct leadership and participation of specialist Consultants, GPs and specialist nurses and pharmacists.
4. Co-locating GPs is not effective unless a new Ambulatory Care integrated interdisciplinary model of care supported by rapid turnaround diagnostics and Virtual Consultation technologies is put in place in every hospital group, community and primary care organisation with appropriate resources.
5. Enhancing and empowering citizens to prevent, predict and protect themselves and their families from Chronic Disease.
6. Shifting the continuous focus on changing structures to evidence best practice care and treatment approaches and regimes will stabilise the system.

**What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?**

The major challenge for Ireland is to find new ways to manage the continuing problems of variation in the quality of healthcare and dissatisfaction among patients, the public, health professionals, policy makers and politicians.

Around the world there is an increased focus on identifying and reducing variation in the provision, uptake, outcomes and costs of healthcare. We can learn from the UK, Australia, Canada, Spain and Germany who are tackling similar problems with varying degrees of success.

The very first and vital step is the systematic and routine collation and publication of accurate relevant and meaningful data on the variations of provision, uptake, outcomes and cost of healthcare in the public and private sector.

- Policy analysts and key decision makers need timely relevant data to take evidence based decisions for which they will be held to account.
- Traditional care and treatment models are producing unacceptable, unexplained and unjustified variations in provision, uptake, and outcomes of Chronic Disease management.
- Where is the waste in the current use of resources? What forms of new care- new designs, can lower cost and deliver better outcomes while taking pressure of the system

We suggest that:

- Systematic evidence based approaches and new better models of care and treatment management and provision are needed.
- Give people the space and time to innovate and reduce the overuse of ineffective interventions particularly in the area of Chronic Disease management with reduction in fragmentation of care and incentivising continuity of care.
- Identify and implement new more cost-effective ways of securing best outcomes.

**What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?**

A shared approach across Government is essential in enhancing the capability of the whole of Government to implement change

Without quality relevant meaningful data on Health System performance and continuing increased investment in longitudinal studies such as TILDA and STOP HF it will not be possible to secure a whole of Government approach.

Health Expenditures and Service Provision in the Public and Private Sector should be the subject of regular inspection and scrutiny by HIQA and reported directly to the Health Committee of the Oireachtas.

**Integrated Primary and Community Care**

**What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?**

1. The development of Ambulatory Care and rapid turnaround community Diagnostic Units with Virtual Consultation technologies to manage the Chronic Disease challenge. The HBT model and approach will be helpful. Demonstrator projects need to be properly funded and independently evaluated.
2. eHealth Care that supports prevention, care and treatment. Again the HBT model and approach will be helpful.
3. A National Executive Clinical Directorate for Chronic Disease management is essential to manage chronic disease cost-effectively. This Clinical Directorate should be resourced to support continuing research and people development programmes across a wide variety of disciplines.
4. Chronic Disease Management Units led by Executive Clinical Directors in each Hospital Group and Executive Clinical Directors in Primary and Community Organisations, and the Health Insurance sector, supported and resourced, to deliver evaluated systematic structured care and treatment systems are essential to deliver on a national strategy to tackle the tsunami of Chronic Disease. The HBT approach with its Executive Directors and interdisciplinary team is delivering in its catchment area.

**What are the key barriers to achieving this, and how might they be addressed?**

- The lack of the appropriate quantum of Governance and Clinical Management competencies that focus on the challenge posed by chronic disease in an ageing population.

The Hospital Groups working with the University Health Science Faculties are capable of developing the appropriate clinical management competencies and skill mix, if targeted resources are made available. In addition the Hospital Groups have developed relationships with Centres of Excellence abroad to support such training and professional development. The HBT is very well positioned to advise and assist.

- The lack of serious investment in eHealth and IT infrastructure across the Health System.

An incremental investment plan targeting Chronic Disease, collaborating with the eHealth R and D industrial community, will also deliver jobs and benefits to the economy. The HBT in the area of Heart Failure is well positioned to assist.

- The scope of practice for GPs, Nurses and Pharmacists need to be expanded to allow them come into line with best evidence based practice particularly in respect of Chronic Disease management with modernised contracts to enable them to provide appropriate care for people with chronic diseases in a personalised manner while maintaining continuity of care.
- Further investment is required into high impact areas of Chronic Disease Management such as Cardiac, Endocrine and Respiratory Disease.

**In your experience, what are the key roadblocks you encounter in your particular area of the health service?**

**How would you ensure buy-in from health care professionals to progress towards an integrated health care model?**

- HIQA needs to be given statutory “Clinical Standard Setting and Evaluation” functions as well as “Clinical Inspectorial” functions for all service funders, providers and settings including the private sector.
- The lack of a Transformation/Modernisation such as the Qualtrum agency in Jonkoping, Sweden which enables and supports focused learning, improvement and collaboration.
- The key roadblock is the lack of accountable effective Executive Clinical Directorate Structures, at National, Hospital Group and Community and Primary Care Level, and within the Health Insurance sector.
- The contractual arrangements and resource allocation models for all professionals and units need to incentivise best evidence based integrated interdisciplinary practice with an emphasis on best outcomes and continuity of care for patients.
- Money following the patient and an objective evidence based funding and pricing model will assist in securing buy in from health care professionals.
- Reconfiguring services with the Hospital groups into Scheduled and Unscheduled care, providing rapid turnaround diagnostics and resourced Ambulatory Care will help. Dedicated community based diagnostic facilities are also required.

**Are there any examples of best practice that the Committee should consider? Please refer to any evidence you have to support this.**

The German model, the Spanish Model and the Scottish NHS model are worthy of consideration.

The Committee would be well advised to visit and be briefed on HBT activities and research. An onsite visit to the HBT service in Dun Laoghaire is advised so the committee can see at first hand the significant progress being made.

## **Funding Model**

### **Do you have any views on which health service funding model would be best suited to Ireland?**

Until we redesign the Clinical Health Care Delivery System and implement best evidence based clinical practice in key areas such as Chronic Disease it will be hugely difficult to be specific about effective funding models with any credibility and acceptability to Governments and senior policy makers.

The electorate may very well have to be provided with a range of funding options in the future.

We must first set out the specifics of we are proposing to meet the normative need of the population and the normative clinical needs of patients who will present with increasing complexity.

### **Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating**

The reality is that we have an existing strong private sector component to our existing health service system and it will be a major stakeholder in integrated interdisciplinary care and treatment in any future system. It is difficult to develop funding models until the structure of care to be delivered is elucidated.

### **What are the main entitlements that patients will be provided under your funding model?**

The important entitlement of a patient, be they a public or private patient, under what we propose is that will be provided with best most cost-effective evidence based care and treatment for Chronic Disease that delivers best outcomes for all in the most appropriate place for that care.

### **Please provide examples of best practice, or estimated costs of such models if available.**

In 2005, Heartbeat Trust established the landmark St Vincent's Screening TO Prevent Heart Failure (STOP-HF) project based in the south east of Ireland. The STOP-HF programme showed that identification of high-risk people in primary care using community diagnostics followed by collaborative-care between the GP and Specialist team could prevent heart failure. Not only does the STOP-HF study show a significant 40% reduction in heart failure over the 4 year period, but also a 40% reduction in other major cardiovascular events.

The STOP-HF programme has been widely acknowledged internationally since it was first published in 2013 in the Journal of the American Medical Association.<sup>300</sup> In 2014 the Royal College of General Practitioners in the UK awarded the STOP-HF study the Cardiovascular and Overall Research of the Year. The work has also been incorporated into the most recent Canadian Guidelines on Heart Failure.

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<sup>300</sup> Ledwidge M, Gallagher J, Conlon C, Tallon E, O'Connell E, Dawkins I, Watson C, O'Hanlon R, Bermingham M, Patle A, Badabhagn MR, Murtagh G, Voon V, Tilson L, Barry M, McDonald L, Maurer B, McDonald K. Natriuretic peptide-based screening and collaborative care for heart failure: the STOP-HF randomized trial. JAMA. 2013 Jul 3;310(1):66-74. doi: 10.1001/jama.2013.7588.PMID: 23821090

New research shows that as well as providing dramatic healthcare benefits to the participants, the programme is cost-effective.<sup>301</sup> The STOP-HF cost-effectiveness study shows that investing in a primary care with a multidimensional, screening and collaborative care programme reduces heart failure as well as the combined rates of death and other major adverse cardiovascular events. This offsets the investment in outpatient and primary care costs. By investing in healthcare in the community, the need for hospital care is significantly reduced. This provides a model of care that can improve cardiovascular disease. It is also a template that can be applied to other chronic illness.

**Prof Ken McDonald**  
**Medical Director**

<http://heartbeat-trust.ie/>

**Heartbeat Trust Limited:** Registered in Ireland. No. 375112. Charity No: CHY 15938. CRA # 20056216

3 Crofton Terrace Dun Laoghaire, Co. Dublin, Ireland. Tel: +353 1 284 5735; Fax: +353 1 230 4639; [www.heartbeat-trust.ie](http://www.heartbeat-trust.ie)

**Chairman of the Board:** Dr. Ambrose McLoughlin

**Directors:** R. Tubridy, F. Lynch, E. Ryan, R. Corbet, T. Ward, A. Dolphin, R. Ryan.

**Medical Director:** Prof. Ken McDonald. **Research/Development Director:** Dr Mark Ledwidge.

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<sup>301</sup> Ledwidge M, O'Connell E, Gallagher J, Tilson L, Voon V, Bermingham M, Tallon E, Watson C, O'Hanlon R, Barry M, McDonald K. Cost-effectiveness of natriuretic peptide based screening and collaborative care: a report from the STOP-HF (St Vincent's Screening TO Prevent Heart Failure) study. Eur J Heart Fail. 2015 Jul;17(7):672-9.

## Helium Arts

### **The value of integrating the arts in future healthcare in Ireland for children and young people**

The Charter on the Rights of Children in Healthcare in Ireland states that it is a child's right to '*participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability*'. This charter is based on international research focusing on the question of how children's rights can not only be promoted and protected, but enforced in healthcare settings used by children. Engagement with the arts is not only a valuable resource in supporting the well-being of children living with chronic and life-limiting illnesses; it is the right of children to be able to access the arts in healthcare.

**An integrated health system is a health system that has established relationships across sectors, and this includes the Arts.** An integrated health system is one that not only prioritises integration within the health service but adopts a cross-sectoral approach, including relationship building with the Education, Leisure and Culture sectors. Caroline Peppard, HSE Senior Health Promotion Officer, contends: '*Healthy Ireland recognises that health is socially produced and that all sectors of society have a role to play in promoting health and wellbeing. Working together in partnership is the most effective way to harness resources and support for work in the area of arts and health.*'<sup>1</sup>

### **Social Prescribing: One model of how to integrate the arts in healthcare**

Integrating the arts within healthcare can be structured within the 'Social Prescribing' model. Social Prescribing is a recent concept in primary care which describes the use of non-medical interventions to support people affected by depression or anxiety. It is one way in which to provide psycho/social support to people who have mental health issues with a variety of proven outcomes on social, emotional, and cognitive levels. A number of studies have suggested that creative activity has positive effects on mental health such as the development of self-expression and self-esteem, opportunities for social contact and participation (Huxley 1997), and/or providing a sense of purpose and meaning and improved quality of life (Callard and Friedli, 2005; Oliver et al., 1996; Tyldesley and Rigby, 2003).

This submission provides an example of an arts project in Ireland which is currently **supporting the Self-Management of Children Living with Chronic/Serious/Lifelong illness during the transition process to adult care**. Helium Arts Fireflies project aims to support **the National Model of Care for Paediatric Healthcare in Ireland** (December 2015) and specifically the section on structured transition, by investigating how the arts can support transition to adult care by promoting independence, decision making skills, communication skills and improved self esteem. The submission finishes with some key recommendations.

<sup>1</sup> Peppard (2014) 'Grey Matters: The role of the Arts and Health in the delivery of "Healthy Ireland"', artsandhealth.ie  
<http://www.artsandhealth.ie/perspectives/grey-matters-the-role-of-the-arts-and-health-in-the-delivery-of-healthyireland/>

## **A sick child's right to well-being: The value of integrating the arts in future healthcare in Ireland for children and young people**

### **I) Child friendly healthcare includes a child's right to access the arts**

The Charter on the Rights of Children in Healthcare in Ireland states that it is a child's right to '*participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability*'. This charter is based on international research focusing on the question of how children's rights can not only be promoted and protected, but enforced in healthcare settings used by children.<sup>2</sup> An holistic approach to children's rights requires a healthcare system that connects health rights to the child's other rights. Article 31 of the UN Convention on the Rights of the Child states:

1. Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity. Engagement with the arts is not only a valuable resource in supporting the well-being of children living with chronic and life-limiting illnesses; it is the right of children to be able to access the arts in healthcare.

### **II.) An integrated health system is a health system that has established relationships across sectors, and this includes the Arts**

As the challenges to creating a truly healthy population are many and complex, relationships must be built between sectors and their roles acknowledged in addressing the determinants of health and wellbeing. Partnerships – between Government Departments, across sectors or within the community – are essential to the full implementation of the

Framework. – 'Healthy Ireland'<sup>3</sup>

An integrated health system is one that not only prioritises integration within the health service but adopts a cross-sectoral approach, including relationship building with the Education, Leisure and Culture sectors. Caroline Peppard, HSE Senior Health Promotion Officer, contends: '*Healthy Ireland recognises that health is socially produced and that all sectors of society have a role to play in promoting health and wellbeing. Working together in partnership is the most effective way to harness resources and support for work in the area of arts and health.*'<sup>4</sup> In Australia, a Taskforce was initiated by the New South Wales Ministry of Health in 2015 to guide the integration of the arts into NSW's healthcare system. The 2016 framework document draws on the growing evidence base of the benefits of integration of the arts within healthcare, including its use in health promotion and health literacy.

<sup>2</sup> Kilkelly and Savage (2013) 'Child-Friendly Healthcare: A Report Commissioned by the Ombudsman for Children'.

<sup>3</sup> Department of Health (2013) 'Healthy Ireland: A Framework for Improved Health and Wellbeing 2013-2025'.

<sup>4</sup> Peppard (2014) 'Grey Matters: The role of the Arts and Health in the delivery of "Healthy Ireland"', artsandhealth.ie  
<http://www.artsandhealth.ie/perspectives/grey-matters-the-role-of-the-arts-and-health-in-the-delivery-of-healthyireland/>

<sup>5</sup> Peppard argues for the role of the arts in health promotion within the context of the 'Healthy Ireland' framework: 'Reducing health inequalities is a fundamental goal of public health.'

*In order to achieve this, it is essential that people and communities are empowered and supported to take responsibility for their own health and wellbeing [...] Engaging in arts experiences is a good forum for exploring health-related ideas in accessible, safe and non-prescriptive ways. Social engagement is in itself an important health predictor – socially engaged individuals are better disposed to understanding and taking on board health information.'*

### **Social Prescribing: One model of how to integrate the arts in healthcare**

Integrating the arts within healthcare can be structured within the 'Social Prescribing' model: Social prescribing covers a whole raft of possible non-medical interventions aimed at supporting people with mental health needs. That covers all of us, because it includes a major emphasis on health promoting activities, as well as those proven to help people struggling with common mental health illnesses, such as anxiety and depression. - ICGP President Professor Bill Shannon Social Prescribing is a recent concept in primary care which describes the use of non-medical interventions to support people affected by depression or anxiety. It is one way in which to provide psycho/social support to people who have mental health issues with a variety of proven outcomes on social, emotional, and cognitive levels. Among reports reviewed by Celia Kennaghan et al 6,

Social Prescribing includes the following activities: self-help, exercise, green activity, community involvement, and arts and creativity.

### **Evidence for Effectiveness of Social Prescribing Art Interventions**

A number of studies have suggested that creative activity has positive effects on mental health such as the development of self-expression and self-esteem, opportunities for social contact and participation (Huxley 1997), and/or providing a sense of purpose and meaning and improved quality of life (Callard and Friedli, 2005; Oliver et al., 1996; Tyldesley and Rigby, 2003). Creative activity was included in a Social Prescribing Project undertaken by the HSE in Donegal in 2013. The evaluated outcomes of the project were: *"an increase in wellbeing levels, a decrease in anxiety and depression levels, reduced GP visits, a significant increase in levels of community involvement and an overall general satisfaction for the participants, stakeholders and health professionals involved."*7

The evaluation of the Donegal Social Prescribing Project depicts a useful model which could be replicated including:

The role of the Social Prescribing Coordinators

The process of the service and the value to the programme stakeholders.

- An assessment of the model adopted in Donegal, with interested and diverse stakeholders driving its development, its desirability and its acceptability, and its effectiveness in meeting the needs of participants
- Its ability to create a bridge between primary care and mental health clinicians, and between community and voluntary sector organisations to engage in promoting health and wellbeing together.

5 NSW Ministry of Health (2016), 'NSW Health and the Arts Framework: Improving the health of the community through integrating The Arts into the design and delivery of health services and public health messaging'.

6 Keenaghan et al (2012), 'Care Options for Primary Care: The development of best practice information and guidance

on Social Prescribing for Primary Care Teams'. Presented to: Care Options for Primary Care Steering Group, HSE West.

7 HSE (2015), 'Donegal Social Prescribing for Health & Wellbeing' Evaluation Report.

## **Comprehensive Recommendations**

An Appendix re: Cost effectiveness and economic impact of Social Prescribing

The 'Social Prescribing' model outlines a key way in which the arts can be integrated within the health system. Indeed, the Donegal Evaluation Report found that '*Social Prescribing as a model is a structured way of supporting partnership working between clinicians and the community and has the potential to harness and nurture the good will that already exists between these partners.*'

## **Teens Transitioning to Adult Care - The Arts supporting the Self-Management of Children Living with Chronic/Serious/Life-Limiting Illness**

Transition is the process of preparing young people living with chronic illnesses for transfer from child to adult healthcare services. It is recommended that this occur as early as possible.

Failure to transfer to adult services successfully can result in poor adherence to medication, poor attendance at follow up clinics and potentially adverse health outcomes. According to Christian et al (1999), intervention strategies should be developed which "*incorporate adolescent developmental needs, determine readiness and motivation to learn, and provide opportunities to practice independence in self-management*". For teenagers who spend long periods of time in hospital, the children's setting is "like going from home to home", "like a family". The move to adult regional services is a major upheaval in their lives, leaving behind life-long friends and people who have cared so well for them. Teenagers have described leaving the children's health service as "frightening" and have relayed feeling "nervous" not knowing what to expect.<sup>8</sup>

In a Systematic Review of the Literature<sup>9</sup> on the use of the arts to support transition for teenagers, two studies (Fleitas 1998, Fumarola 2013) described arts-based interventions for children with chronic illness. The objectives of these interventions were to promote similar outcomes such as selfmanagement, self-care, adherence to medical treatments, autonomy and coping skills. Cespedes-Knadle (2011) describes the development of a group intervention which included arts activities to improve psychosocial functioning and medical adherence in teen participants and to reduce diabetes-specific stress in caregivers. This literature review was funded by Helium Arts and is currently awaiting publication.

## **Case Study: An Arts Project Supporting Teenagers in Transition (to be evaluated in 2018)**

Helium Arts' Fireflies Project aims to support the 'National Model of Care for Paediatric Healthcare in Ireland' (December 2015) and specifically the section on structured transition, by investigating how the arts can support transition to adult care by promoting independence, decision making skills, communication skills and improved self-esteem. The project is taking place in Dublin hospitals over three years (2015-2018) and will be evaluated in 2018. Below are some observations on how support for transition via the arts was addressed in Phase 1, the research and development phase of the project, which took place from February to June 2016 in Temple Street Children's University Hospital.

<sup>8</sup> These experiences of transition have been relayed by teenagers on <http://steppingup.ie/>, a website dedicated to providing information for young people living with long-term illnesses moving to adult health care services.

<sup>9</sup> Callinan and Coyne, "Systematic review of art-based interventions to promote transition of young people with chronic diseases from child to adult services". Commissioned by Helium Arts and currently awaiting publication.

### **Giving young people a voice and space to explore their identity**

The project opened up a conversation with young people about the changes that are happening to them in an informal way, providing an opportunity for young people to take the lead and to discuss the positives and negatives of their situation with an external listener (the artist).

### **Promoting autonomy/independence and decision making skills**

The open-ended methods used on this project promote the teenagers' autonomy and decision making skills. Once the artist has given them some initial prompts, they are free to decide where they take their project, offering them a situation of which they can take control (in contrast to the medical aspects of their treatment).

### **Communication skills**

Phase 1 has shown some evidence of complementing the teenagers' communication skills. Working on a collaborative project gives them something to talk to their caregivers about apart from their illness and treatment. The artist reported that one teenager invited the nurses and other parents on the ward to see her work.

As a healthcare professional when your role is often to establish a relationship with very unwell teenagers and older children, often they do put up barriers to you because you go in as someone who is trying to take care of them and help them and yet you're doing things they don't like; putting in lines, taking bloods off them, doing procedures and examining them, even the process of examining a child/teenager can be very uncomfortable and distressing for them whereas for us, we see it as almost routine.

Something which really opened my eyes during the Helium project was the sense of identity that it gave as well as control and the ability to explore themselves in what is a very unnatural and surreal scenario that no one expects to find themselves in. A hidden aspect of this project when you know these teenagers for such a long time, to actually see their work gives you a real insight into people who may not show that side of themselves to you to maintain the control that they have, but that they'll show it to people like Rachel [the artist]. It's really touching and a really important part of the overall care in hospital. It's something I'd love to see continued. I'm really interested in transition and giving teenagers an opportunity to express themselves during such a difficult phase is fantastic. - Aoibhinn Walsh, Paediatric SpR

### **Building Self Esteem**

Phase 1 demonstrates potential for the project to improve self-esteem: Parents have commented on how positive their children appear when engaging in the project. One commented, *'we've been coming here for years and I've never seen something make her so happy'. 'While we were working she chatted about how much she has lost while she has been in hospital but also the things she has gained. She is looking forward to getting out, having freedom, wearing make up and being "more me". I believe this idea of loss of self during a hospital stay is exactly why we do these projects...these simple words "more me" really sum that up.'* - Observations from artist's journal

### **Recommendations**

Approximately 10% of children (100,000 children) in Ireland are living with a chronic illness. It has been proven that children and teenagers living with chronic/serious/life-limiting illnesses can suffer from anxiety and depression and need psychosocial support in addition to medical and clinical treatment. A major survey of 10-17 year olds in the Republic of Ireland has found evidence of lower levels of happiness and life satisfaction among students with a disability or chronic illness.

10 Molcho et al (2008), 'Inequalities in Health among School-aged Children in Ireland', HBSC Ireland, Health Promotion Research Centre, NUIG.

The Growing Up in Ireland Report, “Impact of Childhood Chronic Illness and Emotional and Behavioural Problems on Educational Outcomes at Nine Years”, found similar outcomes for children within the 9-year age group.

In the context of chronic illness, it has been shown that engagement with creative artistic expression (e.g. visual arts, expressive writing) has significant positive effects on health (Stucky & Nobel, 2010). Arts interventions can support people suffering from anxiety and depression and other mental health issues. Therefore, our recommendation is that the arts are integrated within the psychosocial care of children living with chronic/serious/life-limiting illness:

- 1.) Innovate a model of integrated arts practice which supports the psychosocial needs of children living with chronic/serious/life limited illness
- 2.) Consider the Submission from the Arts and Health HSE and Arts Council Working Group to the Oireachtas Committee
- 3.) Examine further models of arts interventions that support the psychosocial needs of children with chronic/serious/lifelimiting illness
- 4.) Provide professional development for Paediatric clinicians in the area of arts and health for children/teenagers
- 5.) Encourage third level medical courses to include modules/lectures in the area of arts and health and children/teenagers
- 5.) Create a referral system for paediatric clinicians/GPs to refer patients to relevant art and cultural services

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Note:

Although not addressed in this submission, there is evidence also of how the arts can support health promotion, early intervention, and prevention for children, particularly very young children and their parents. Helium Arts is currently finalising a literature review ‘Uncovering the Effects of the Performing Arts on (the nature and quality) of Parent Infant (interpersonal) Relationships’ with partners in the School of Psychology, NUIG.

We also have growing evidence regarding the use of the arts to promote wellbeing for parents and families with toddlers/very young children with illness causing complex disabilities. Please do not hesitate to contact us if you would like further information on any of the above.

<http://www.helium.ie/>

## HIQA

The primary aim of the Health Information and Quality Authority (HIQA) is to advance high-quality and safe care for people accessing health and social care services in Ireland. Putting the needs and the voices of the people who use these services to the fore is the essence of everything we do, and indeed must be at the heart of any future model of health and social care in Ireland.

In HIQA we believe that a ten-year plan for health policy in Ireland creates an opportunity to include a vision not only for the health service, but for an integrated health and social care system. In this submission, we outline what we believe to be the main priorities for inclusion in the strategy. These are grouped into three **categories in reflection of HIQA's key strategic aims**, namely: better decisions, safer services, better care.

### **1. Better decisions**

Many of the major problems currently evident in our health and social care system, for example the ineffective use of public funds, service inefficiencies, inadequate planning and poor oversight of service performance, could be addressed through the introduction of a strong commissioning model. Good commissioning puts people using services first and, at a local level, involves them, their families and carers in the decisions that affect them. It empowers people to have choice and control over their care and treatment as a means to secure improved care and better outcomes. Effective commissioning arrangements at both local and national levels not only ensure that services are designed and delivered to meet the needs of individuals and communities, but also instil a culture of accountability in the health and social care system.

HIQA supports the goal of introducing universal healthcare to Ireland, whereby care is delivered in an equitable manner without discrimination. Decisions on a future health and social care model must be underpinned by a robust information base. Health Technology Assessment (HTA) is a type of evidence-based research that ensures that resources are used to achieve the best possible outcomes for patients. Universal healthcare involves standardising access to care for all citizens and HTA is the ideal tool to define what treatments and interventions should be made available to all citizens.

Effective decisions require accurate, up-to-date information. Access to timely and integrated information is pivotal to achieving reform of our health and social care services. The ten-year strategy should include a commitment to furthering and **adequately resourcing Ireland's eHealth Strategy if we are to be serious about** achieving a modern, efficient and high-quality health system.

### **2. Safer services**

**HIQA's primary aim as a regulator is to protect the most vulnerable in our society.** We believe that now is the time to introduce safeguarding legislation to protect at-

risk adults from abuse and neglect. While national safeguarding protocols are in place following recent high-profile revelations of abuse, these do not go far enough to ensure the safety and rights of vulnerable people. Similarly, measures also need to be taken to ensure that people being cared for in their own homes are receiving safe and high-quality care. Extending statutory regulation to cover all domiciliary care services would provide assurance that vulnerable people are receiving the best possible support at all times.

### **3. Better care**

The introduction of integrated health and social care services support pathways across primary, community and secondary healthcare structures has the potential to vastly improve the quality of care delivered to patients. Integrated care takes a **holistic approach to a person's health and delivers care in a coordinated, person-centred fashion** as close to their home as possible. Similar models across the world have led to improved efficiencies, better health outcomes and lower costs.

In recognition of our aging population, the rapid increase in chronic conditions and the healthcare costs associated with these developments, society needs to explore alternative models for the delivery of social care services. The process of **de-congregation of Ireland's residential centres** continues across the country; nevertheless, consideration must also be given to ways to support older people and people with disabilities to remain in, or as close as possible to, their own homes.

#### **Main body of submission**

The Health Information and **Quality Authority, HIQA, has been Ireland's health and social care regulator since 2007.** During that time we have been responsible for the development and monitoring of standards in health and social care services, the registration and inspection of designated services and the conduct of a wide range of health technology assessments (HTA). We have also played a major role in **facilitating and advising on Ireland's eHealth infrastructure.**

In preparing this submission, we have considered our experience of the regulation of health and social care services and our involvement in a range of quality- and service-improvement initiatives over the past nine years, placing significant emphasis on the quality and safety of services and the experience of those using them. HIQA advocates a policy of universal access to health and social care on the basis of equity and welcomes the political commitment to build a fair, cost-effective and efficient health and social care system that places the individual accessing the service at its heart.

In the conduct of our work, we witness at first hand the significant pressures and challenges facing the Irish health and social care system. These range from familiar demographic and fiscal stresses, to workforce and infrastructural issues. From **HIQA's point of view, the disjointed and reactionary approach to health service reform is leading to increasing instability in the system.**

There is a failure to assess current requirements and plan for the future health and social care needs of the population. There is also a reticence to recalibrate the current focus on acute hospital services to an integrated health and social care model. In our daily work we witness good quality care services; however, risk is evident in areas where there is inadequate planning and poor performance management of services - whether directly provided or procured by the State. These unsatisfactory services repeatedly point to weak governance and accountability arrangements.

As a country we have repeatedly failed to ensure that person-centred care is integrated across primary, community and acute care services. The fragmented approach to the funding of health and social services, the duplication of services and the lack of population-based planning are further areas that need to be addressed.

Furthermore, institutionalised care services continue to be provided in Ireland. HIQA has repeatedly pointed to the inherent failure to address and safeguard the fundamental rights of the most vulnerable citizens in our society.

Based on our wide regulatory remit and experience across health and social care services, health technology assessment, health information and standards development, we will propose workable, effective solutions to the challenges highlighted above. **In doing so, we group our main proposals under three of HIQA's key 2016-2018 strategic priorities:**

1. Better decisions
2. Safer services
3. Better care.

**1. Better decisions:** We provide information and advice to inform decisions about services

#### Commissioning

HIQA believes that the quality and safety of our health and social care services will be greatly improved by the introduction of a strong commissioning model. Commissioning is only at a developmental stage in Ireland, but is already well established in other jurisdictions, e.g. in Northern Ireland and England. Here it has proven successful in the context of effective service provision, governance, financial efficiency and in improving the quality and safety of services.

Commissioning arrangements explicitly define and separate the roles of purchaser and provider of services; currently both of these functions are usually performed by the Health Service Executive (HSE). An effective commissioning body is responsible for purchasing health and social care services from providers. Procurement is always based on an agreed strategy, assessed need, best available evidence of service efficacy, value for money, and the capacity and capability to deliver a safe and effective service. While cost is, of course, important, quality and the delivery of safe services should be the primary goals.

Implementing a national commissioning approach would involve a radical review of the current health and social care service funding model and allow for the discontinuation of the ineffective practice of legacy block funding. Importantly, a successful commissioning model also allows for the decommissioning of certain services where there is evidence that they are no longer required.

Commissioning frameworks can provide for national, regional and local procurement arrangements that are person-centred and address local needs. This facilitates a focus on the health and wellbeing of local people and on achieving the best possible outcomes within available resources. While procurement decisions are made locally, the service itself is delivered in the most effective, efficient manner, whether in the community or at a national level.

Local commissioning involves community and primary care professionals and, most importantly, people who use services. This empowers them to become a partner in their care and exercise choice and control over their lives.

Local commissioning in turn informs national commissioning arrangements. A strong, national commissioning model would contribute to effective medium- to long-term planning by gathering evidence of current and future service needs. It would also optimise service configuration based on sound strategic planning. The introduction of a standardised framework to commission services would help, by way of example, with the implementation of national clinical care programmes and strategies such as the National Maternity Strategy.

Most importantly, such a framework would allow for effective oversight of service provision and hold providers accountable for the delivery of safe, quality services with the transparent, effective use of public resources. Strong, clearly-defined performance management structures and clear accountability arrangements are an essential component of good commissioning models.

The introduction of commissioning to Ireland creates an opportunity to develop legislation providing for structural change to the health and social care systems, enshrining in law the critical concepts of accountability and responsibility. This **legislation would explicitly set out “a statutory duty of care” for “accountable officers”, and make not only the providers of services, but also those procuring them, accountable for their decisions.**

#### Evidence-based decision-making

Fair, equitable and timely access to high-quality care is a central goal of our healthcare system. The efficient delivery of healthcare programmes minimises the wastage of resources, making funding available for new and innovative technologies that deliver better outcomes for patients, albeit at a higher cost.

The rationing of care is an inevitable consequence of a fixed healthcare budget. Currently, we have a system characterised by rationing by delay, crudely manifested in the form of waiting lists. Health technology assessment (HTA) is evidence-based research widely used internationally to assess the costs and benefits of healthcare treatments. The aim of HTA is to guarantee the best use is made of resources

through rationing by design. This ensures that the right healthcare is targeted to the right patient at the right time in the right place, delivering the best outcomes for the individual and the most efficient use of the healthcare budget. Since 2009, HIQA has been engaged in the delivery of HTAs at a national level to inform major health-policy and health-service decisions.

Using independent evidence to inform decision-making must be a fundamental principle of the ten-year strategy for Irish healthcare. Upon the introduction of universal healthcare, agreement must be reached on what treatments and technologies should be included in the standardised basket of care to be provided to all patients, regardless of income. Expanding the use of HTA in the Irish healthcare system would ensure that this decision-making process is independent, rigorous, transparent and based on high-quality information. It must stand up to public scrutiny. The basket of interventions would require regular review and updating with regard to the clinical and cost-effectiveness of both new and established health technologies and treatments.

Successful implementation of a ten-year vision for health and social care and the introduction of a universal, single-tier health service will be driven by long-term planning informed by the best available data and evidence, not on crisis management. The effective use of HTA will deliver this objective.

### eHealth

eHealth is another process which supports better decision-making. The development of a long-term strategy presents us with the opportunity to future proof our health and social care systems in order to effectively and safely handle the demographic and technological changes ahead.

Ireland is one of the last developed countries to harness the technology currently available to advance our health and social care service. Most countries are investing heavily in eHealth because they realise that it can significantly reduce clinical errors, improve patient safety, create efficiencies, and, if properly installed and supported, reap economic benefits.

**Ireland's eHealth Strategy was launched in December 2013. The establishment of eHealth Ireland and the appointment of a Chief Information Officer is a positive development, and national initiatives such as the rollout of eReferrals to all public hospitals earlier this year are welcomed.**

The 2014 Health Identifiers Act provides for the establishment of national registers for Individual Health Identifiers (IHIs) and the associate Health Service Provider Identifiers. The restructuring of our health service towards a model based on integrated primary, secondary and community healthcare can only succeed if IHIs are introduced to the system along with the necessary supporting information and communications technology (ICT). This needs to be expedited. The Health Information and Patient Safety Bill, which sets the legislative remit for numerous health information initiatives, awaits enactment.

eHealth has the potential to transform current practice and to put the needs of the person using the service, rather than those of the service provider, at the heart of system. This will lead to a shift in focus from individual illnesses and conditions towards a more holistic, integrated approach to pathways of care.

A strategy on the future of health and social care in Ireland must include a commitment to modernise our healthcare infrastructure by developing and sufficiently resourcing eHealth and ICT strategies. Further progress with regard to eHealth requires not only significant capital investment, but also the buy-in and commitment of frontline staff and senior healthcare management.

Both evidence-based decision-making and eHealth are essential components of effective commissioning.

**2. Safer services:** We help to protect and safeguard people who use our services

#### Safeguarding legislation

**HIQA's mission is to drive high**-quality and safe care for people using our health and social care services. In developing a ten-year strategic plan we believe there is an opportunity which should not be missed in introducing statutory measures to protect the health, human rights and wellbeing of individuals who are potentially, or actually, at risk of abuse, neglect or harm.

There is a national imperative to enshrine in law the safeguarding of vulnerable **adults which acknowledges the State's responsibility to protect and safeguard** vulnerable citizens who may be at risk of abuse or exploitation.

While HIQA currently has statutory powers of enforcement and prosecution; other health authorities do not hold the same explicit powers. The introduction of safeguarding legislation will provide for explicit powers of investigation and prosecution, define the roles for statutory agencies and give clear definitions of offences in respect of the abuse of vulnerable adults.

In response to the circumstances exposed in Áras Attracta, the National Inter-Sectoral Safeguarding Committee was established. One critical objective of this Committee is to influence the development of safeguarding legislation and the progression of a more effective range of national policies and procedures. HIQA supports, and will contribute to, the work of this Committee and is committed to working with the Department of Health and the Oireachtas to drive forward safeguarding legislation.

#### Homecare regulation

The Programme for a Partnership Government outlines the desire to introduce a uniform service to standardise the quality of homecare provision. While HIQA **advocates the extension of homecare packages, we, as the State's health and social** care regulator, are aware of the specific vulnerabilities of people in receipt of personal care and support services within their own homes. Hence there is an imperative to ensure statutory regulation of the domiciliary care sector.

The Health Research Board has been asked to identify and describe approaches to this issue in other relevant jurisdictions, and we would like to see this work progressed, and prioritised, as soon as possible.

Currently, a large proportion of national funding for the disability and older person's sectors is allocated to day-care and residential services. We propose an exploration of new approaches to service delivery and funding, while at the same time empowering individuals to make decisions on the type of care best suited to their needs and circumstances. The traditional model of funding is outdated and a move towards individualised or personalised budgets would provide flexibility and enable people to make independent decisions about their lives.

### **3. Better care:** We work to improve health and social care services

#### Integrated care

There is a consensus that Ireland needs to move away from the current hospital-centric model of care and to introduce integrated care pathways across primary, community and secondary health and social care structures. HIQA believes this should be expedited.

Such a model would promote seamlessness in the transition of people across services, providing multi-disciplinary care at the lowest level of complexity closer to where people live. The focus should be on improving access to, and the responsiveness of, primary and community care services, and make more specialised services available at the local level, including the provision of enhanced diagnostic and treatment capability. Examples of best practice include the integrated early intervention teams, age-related care units, stroke care clinical pathways, the new National Maternity Strategy, and numerous examples from other jurisdictions, including the dementia care model in Scotland. The experience from other countries has shown that integrated care is more efficient, reduces costs, enhances the quality of care and improves the overall health and wellbeing of the community.

#### Alternative social care models

In accordance with the principle of providing person-centred care, and in recognition of the demographic pressures facing Ireland, more consideration needs to be given to developing alternative models for the delivery of services for older people and people with disabilities. Such models would potentially provide incremental pathways of support and care aligned with the changing needs of the person, thereby allowing them to be supported to stay longer living in their own homes, nearer their families and friends. This process should be supported by local commissioning arrangements.

HIQA is committed to improving health and social care services and supporting people to meaningfully direct their own care. In the context of the development of a ten-year strategy, it is opportune to explore new arrangements that allow people with chronic conditions, older people and people with disabilities, where possible, to be cared for safely in their homes and not in a hospital or residential setting.

One such arrangement is that of rehabilitation, whereby support services are provided to older people or people with disabilities in their own homes following a hospital stay, accident or illness. This service allows people to regain confidence and relearn skills in familiar settings and reduces unnecessary hospital admissions. This **concept is known as 'reablement' in Northern Ireland and has shown to be an effective way to keep people independent for longer.**

### **List of Recommendations**

- Introduce an effective commissioning model at local and national levels that promotes and addresses the needs of people using services as well as effective service configuration. This would drive quality and performance improvement, be based on high-quality information, and ensure accountability and value for money.
- Should universal healthcare be introduced, ensure that any decisions on the basket of interventions to be made available to all citizens are based on the best available data and evidence. Health Technology Assessment would be the ideal tool to define what treatments and interventions should be included in the health basket.
- Modernise our healthcare infrastructure by developing and sufficiently resourcing eHealth and ICT strategies.
- Introduce national safeguarding legislation that **acknowledges the State's** responsibility to protect the most vulnerable in society, and provides all health authorities with explicit powers of investigation and prosecution.
- Introduce statutory regulation of the homecare sector.
- Expedite the introduction of integrated health and social care services support pathways across primary, community and secondary healthcare structures.
- Develop alternative models for the delivery of services for older people and people with disabilities, which would provide them with the necessary support to remain at home for as long as possible.
- Examine new approaches to traditional models of funding for the disability **and older person's sectors, e.g. individualised or personalised budgets.**

<https://www.hiqa.ie/>

## **Irish Association for Infant Mental Health**

This submission has been prepared by the Irish Association for Infant Mental Health (I-AIMH). The submission highlights the need for infants and toddlers to be named as a distinct group within the vision for healthcare developed by the all-party committee on the Future of Healthcare in Ireland and for the government to provide a dedicated funding commitment for the 0-3 years period.

Beyond its effect on individuals, poor health early in life also imposes significant societal costs. Thus, a focus on health promotion in the period of 0 to 3 years—where an extensive body of evidence supports the promise of effective prevention programmes **that can change the trajectory of children’s lives**—can help reduce the social and economic burdens of illness, not only in childhood but also throughout the adult years. This connection between early life experiences and the health of a nation underscores the importance of strategic investments in the care and protection of pregnant women, infants, and young children, and it suggests that most current attempts to prevent adult disease and create a healthier workforce may be starting too late.

To give children the best start in life it is important to promote emotionally healthy environments and prevent emotional harm by reducing as many of the factors that can lead to mental ill-health and, for those children who need it, ensure there are services and systems that can provide best psychological care and intervention, in the right place, at the right time. Mental health and psychological wellbeing must be promoted and delivered in whole community systems that integrate health, social care, education and the voluntary sectors. It is our view that the Department of Health can take a lead on this.

Furthermore, a rich and growing body of epidemiological evidence and research indicates that reducing the number and severity of early stressful and traumatic experiences, such as child maltreatment, family violence, parental mental illness and substance abuse, and the adversity associated with significant economic hardship, will decrease the prevalence of a wide range of stress-related physical and mental health problems.

### **Introduction**

The Dept. of Health has previously acknowledged the importance of the first years of life in the document, Healthy Ireland 2013-2025, which states that child health, wellbeing, learning and development are inextricably linked, and the most effective time to intervene in terms of reducing inequalities and improving health and wellbeing outcomes is before birth and in early childhood.

In this submission I-AIMH advocates for the need to now ensure that infants and toddlers are named as a distinct group within the vision for healthcare developed

by the all-party committee on the Future of Healthcare in Ireland. It is our strongly held view, based on scientific evidence, that being identified as a distinct group is essential in order to guarantee that the mental (social and emotional) health needs of infants and toddlers are identified and therefore more likely to be addressed. Our submission also advocates for the principles of prevention and early intervention with this group. It is written from an Infant Mental Health perspective (IMH) and knowledge base.

## **Overview**

Infant mental health is defined as the developing capacity of the infant (from birth to 3 years of age) to experience, express, and regulate emotions; form close and secure relationships; and explore the environment and learn—all in the context of cultural expectations.<sup>1</sup> The field of infant mental health is multidisciplinary and requires expertise and conceptualization from a variety of perspectives, including clinical practice, research, and public policy. Strategies to improve IMH fall along a promotion, prevention and treatment continuum.

Typically, infancy refers to the period from birth to three years but because of the considerable evidence regarding prenatal influences on many clinical problems in early childhood, prenatal experience is often included in a definition of infant mental health.

Social and emotional wellbeing provides the building blocks for healthy behaviours and educational attainment. It also helps prevent behavioural problems and mental illness. Emotional and psychological wellbeing includes being happy and confident and the ability to be autonomous, manage emotions, experience empathy, and be resilient and attentive. Social wellbeing refers to our ability to have positive relationships with others.

A complex range of factors have an impact on social and emotional development. The infant's relationship with their mother (or main carer) is one of the main factors. In turn, the mother's ability to provide a nurturing relationship is dependent on her own emotional and social wellbeing and on her living circumstances. The latter includes family environment, social networks and employment status.<sup>2</sup>

We know that the challenges that families with infants face are relational, between parents and babies, between the parents themselves, or between a parent and their memories of caregivers. These challenges also raise issues in **the family's relationships with professionals and the services around them.**

Services that focus on Infant Mental Health and emotional wellbeing reflect the value placed on early emotional experience by our society, and in years to come our society **will reflect the quality of experiences that exist for today's babies and**

infants. The problem for our babies and preschool children is that it is possible for us as a society to ignore them as for the most part their emotional difficulties **don't come to the attention of our health or welfare systems. Thus, historically** services to under threes and their families have been poorly resourced. I-AIMH believes that there needs to be protected resources within the health services for the under 3s and their families. It is our view that it makes sound economic sense to invest in early intervention services but more importantly we also argue that tackling distress and promoting positive emotional wellbeing in babyhood is as relevant and valuable as at other ages.

### **Why We Should be Concerned**

Figures suggest that the number of children and young people in Ireland who are presenting with mental health difficulties is increasing. This increase can reasonably be expected to continue as evidenced by the findings from the first report of the Psychiatric Epidemiology Research across the Lifespan (PERL) Group Dublin at the Royal College of Surgeons in Ireland <sup>3</sup>:

- By the age of 13 years, 1 in 3 young people in Ireland is likely to have experienced some type of mental disorder. By the age of 24 years, that rate will have increased to over 1 in 2.
- The experience of mental ill health during adolescence is a risk factor for future mental ill health and substance misuse in young adulthood, and is associated with an increased risk of unemployment during early adult years.
- High numbers of young Irish adults aged 19-24 years are engaged in the misuse of alcohol and other substances, with over 1 in 5 meeting criteria for a diagnosable substance use disorder over the course of their lives.
- Significant numbers of young people are deliberately harming themselves and by the age of 24 years, up to 1 in 5 young people will have experienced suicidal ideation.

A large prevalence study in 2006 of 3,374 children screened in Co. Tipperary, estimated that nearly 15% of under 5 year olds, 18.5% of 6-11 year olds and 21% of 12-18 year olds met the criteria for at least one psychological disorder.<sup>4</sup> It is critical to note that most of those identified as either being at risk of or meeting the criteria for a psychiatric disorder were receiving no professional help.

At a time of global economic austerity with the numbers of families living in poverty increasing<sup>5</sup>, a continued rise in mental health problems in children and young people is likely.

## **What Science tells us about Emotional Wellbeing**

The development of new scientific techniques in recent years has resulted in research which points to the significant impact of the early caregiving **environment (i.e., the baby's relationship with key people in their environment)** on the developing **brain, a child's development and psychological outcomes**. Science tells us that meeting the developmental needs of infants is about building a strong foundation for lifelong physical and mental health.

Studies consistently suggest that children raised in warm and nurturing homes are more likely to feel better about themselves as people, do well in school and make thoughtful choices about their relationships and careers in early adulthood.<sup>6</sup>

Early childhood is a time of rapid development in the brain and in many of the **body's biological systems that are critical to sound health**. **When these systems are being constructed early in life, an infant's relationships, experiences and environments** have powerful influences on both their immediate development and subsequent functioning. These effects may appear early and be magnified **later as children grow into adolescence and adulthood**. Thus, **"getting things right" and establishing strong biological systems in infancy can help to avoid costly and less effective attempts to "fix" problems as they emerge later in life**.

Infants and young children can and do experience serious mental health problems that are comparable in severity to what we observe in older children and adults, and we know that these mental health problems can have lasting effects. And, contrary to traditional views, highly negative emotional experiences **in infancy are not "forgotten"; they are built into the architecture of the developing brain** and can have a sustained impact that extends well into the adult years, especially when they are severe, persistent, and uncontrollable.<sup>7</sup>

**It is not just the 'size' of the experience that matters, but also the number of negative experiences** that an infant or young child faces that impacts on their psychological wellbeing. Many children growing up in adverse social circumstances including poverty, domestic violence, or parental substance misuse, will endure a number of the factors which are known to be harmful to good psychological development, more likely resulting in complex patterns of difficulties.

## **What Works to Promote Positive Emotional Wellbeing**

When infants and toddlers are provided with predictable, consistent care-giving environments where they are supported and nurtured, they are afforded the best possible opportunity to develop positive health and wellbeing. This enables their capacity to make healthy transitions into education and their capacity to sustain this health and wellbeing across later developmental stages in childhood,

adolescence and throughout adult life. The care that infants receive, whether from parents, extended family members, neighbours, or child care professionals, lays the groundwork for the development of a wide range of basic biological processes that support emotion regulation, attention, and ultimately all psycho-social nurturing.

Positive caregiving early in life is also associated with better physical and mental health, fewer behavior problems, higher educational achievement, more productive employment, and less involvement with social services and the criminal justice system in adulthood. **In biological terms, an infant's environment of relationships can affect lifelong outcomes in emotional health, regulation of stress response systems, immune system competence, and the early establishment of health-related behaviors.**

We also know that the quality of the family environment is predicted by risk and **protective factors present within the family's community and wider social networks.** Studies consistently and overwhelmingly suggest that **social disadvantage makes it difficult for parents to effectively meet their children's needs and thus wide and persistent gaps in children's wellbeing and development may emerge very early in life.** For example, Belsky and Fearon **observed that sensitive parenting was significantly associated with the family's overall level of deprivation, the parents' mental and physical health, the quality of their support networks and the quality of their couple relationship.**<sup>8</sup>

These factors have important consequences for future and intergenerational outcomes. Instead of thinking about how to help when problems arise, I-AIMH advocates that the health service in Ireland should think about what it can do to promote the positive development, psychological wellbeing and resilience of all our children and young people. Primary prevention and early intervention should become a core activity of our health services in the future.

## **The Economic Argument**

Our knowledge to date of the impact of poor early health points to two clear conclusions. First, health promotion and disease prevention policies focused on adults would be more effective if evidence-based investments are also made to strengthen the foundations of health in the prenatal and early childhood periods. Second, the increasing prevalence of chronic disease across the life course could be lowered by reducing the number and severity of adverse experiences threatening the wellbeing of young children and by strengthening the protective relationships that help mitigate the harmful effects of toxic stress.

In 2013 a cross-party coalition in the U.K. produced a manifesto entitled, **The 1001 Critical Days: The Importance of the Conception to Age 2 Period.**<sup>9</sup> This document highlights the importance of intervening early in order to enhance outcomes for children. As part of the work a review was undertaken of both U.K.

and international studies which looked at the question of the advisability of agencies with responsibility for child health and welfare to spend proportionally more on the early years. They looked at the research from a number of different but complementary perspectives and found that:

- there was general expert consensus that it is somewhere between ***economically worthwhile*** and ***imperative*** to invest more heavily, as a proportion of both local and national spend, in the very earliest months and years of life
- every approach – even the most cautious and circumspect in its recommendations – found that returns on investment on well-designed **early years’ interventions significantly exceed their costs. The benefits** ranged from 75% to over 1,000% higher than costs, with rates of return on investment significantly and repeatedly shown to be higher than those obtained from most public and private investments.
- **where a whole country has adopted a policy of investment in early years’** prevention, returns are not merely financial but also in strikingly better health for the whole population. The benefits span lower infant mortality at birth through to reduced heart, liver and lung disease in middle-age.
- the logical links between the investments and the health benefits are **described in the ‘Adverse Childhood Experiences’ (ACE) studies which** reveal that for every 100 cases of child abuse society can expect to pay in middle or old age for (amongst a wide range of physical and mental health consequences):
  - one additional case of liver disease
  - two additional cases of lung disease
  - six additional cases of serious heart disease, and
  - 16% higher rate of anti-depressant prescriptions (Felitti and Anda, 2009)<sup>10</sup>
- none of the estimates took account of the economic value of the knock-on effect that child abuse averted in one generation will itself result in a cumulative reduction in this dysfunction during future generations.

The link between poor health (in the broadest meaning of the word) and inequality is also highlighted in the **Fair Society Healthy Lives**<sup>11</sup> review which was commissioned by the U.K. government to propose the most effective evidence-based strategies for reducing health inequalities in England.

In the report it is argued that the link between social conditions and health should be the main focus of all health strategy. The authors identify six policy objectives aimed at reducing health inequalities. The first of these are: Give every child the best start in life and enable all children young people and

adults to maximise their capabilities and have control over their lives . They make recommendations on how to achieve this in order to see improved wellbeing and better mental health.

In Northern Ireland the recent document, ***Making Life Better: a Whole System Strategic Framework for Public Health (DHSSPS, June 2014)***<sup>12</sup> takes a life course approach to health and wellbeing and one of its key themes is 'Giving every child the best start'.

All of these reports highlight the importance of early intervention and support for the pre-natal to three years of age and how such investment sets the context for promoting positive infant mental health. We know also from the work done in this area that there are fewer opportunities after the preschool period to close the gap in behavioural, social and educational outcomes (Allen 2011; Field 2010).<sup>13,14</sup>

Although much important research still remains to be done, sufficient knowledge to address these challenges more effectively is already available.

## **Conclusions**

Converging evidence from a number of scientific domains has led to the following three conclusions in relation to the importance of the early years:

- Experiences are built into our bodies (for better or for worse) and significant adversity early in life can produce physiological disruptions or **embedded biological "memories" that persist far into adulthood and lead to lifelong impairments in both physical and mental health**
- **Genes and experiences interact to determine an individual's** vulnerability to early adversity and, for infants who experience severe adversity, environmental influences appear to be at least as powerful, if not more powerful, than genetic predispositions in their impact on the odds of having chronic health problems later in life
- Health promotion and disease prevention policies focused on adults would be more effective if evidence-based investments were also made to strengthen the foundations of health and mitigate the adverse impacts of toxic stress in the prenatal and infancy periods.

## **Recommendations**

Guided by this scientific knowledge, the Irish Association for Infant Mental Health advocates for early childhood strategies that promote secure attachment relationships as the first building blocks for healthy social and emotional development. These strategies include:

- Expanding the competencies of non-familial caregivers, health professionals and allied social and health care service providers and others to promote the emotional wellbeing of infants and families;
- Putting a structure in place that will ensure frontline staff have the necessary knowledge and skills to assess risks to the mental health of infants by early identification of factors associated with parent-infant interaction and to meet the mental health needs of all children and parents;
- Helping families of infants and toddlers to overcome whatever barriers **they face to ensure that their children's emotional development is not compromised**;
- Greater recognition of the mental health needs of parents ante- and post-natally. Given the potentially serious impact of maternal psychopathology on both foetal and infant health, obtaining appropriate treatment is of critical importance. There is a clear consensus that the focus of support that is provided to both mothers and fathers during the perinatal period should be the parent-infant relationship;
- Given that infant mental health is fundamentally connected to the physical and mental health and wellbeing of the primary caregiver, as well as their ability to parent, service development is as relevant for those providing **adult services as it is for children's services. Ideally there should be an increase in interventions that focus on supporting the parent –infant relationship where the parent faces challenges to their own emotional wellbeing**;
- Developing a stepped care model including early intervention, preventative and therapeutic interventions in order to improve child social, emotional and physical health in Ireland. The value of early intervention to improve infant mental health is that it can both prevent infant problems and treat existing parental problems. Interventions targeting parents and pre-school children show a high level of effectiveness. Attention should be drawn to the important role of the parent/caregiver relationship in supporting and promoting the mental health of the young child;
- **Infant mental Health is everyone's business. A key step in change in our health service delivery is awareness raising at a societal level about the importance of IMH. This should include policy makers and health practitioners.**

**These recommendations are in keeping with the government's commitment to children as laid out in the Better Outcomes Brighter Futures Document.**

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## Irish Cancer Society

Established in 1963, the Irish Cancer Society is the national cancer charity. Our vision is that every person in Ireland will have access to the best possible cancer services; will have the lowest risk of getting cancer, the highest survival rates and the best support and information available when affected by cancer. Our goals are cancer prevention, early detection and fighting cancer with three programme areas to achieve them: advocacy, cancer services and research.

The Irish Cancer Society is a founding member of the Health Reform Alliance. Alliance members share a common belief that reform is needed to create a more equitable system. We have developed a consensus on five principles to underpin reform. The Irish Cancer Society supports the submission made by the Alliance to this consultation as well.

### *Executive Summary*

The Irish Cancer Society welcomes the opportunity to respond to the Committee on the Future of Healthcare's request for submissions.

In the last 15 years there have been successive health policy documents outlining the various building blocks towards a reformed healthcare system, including *Primary Care Strategy* (2001), *Tackling Chronic Disease* (2008), *White Paper on UHI* (2014), *Future Health* (2012), and *A Vision for Change* (2006). However, these policy documents have been developed in isolation without an overarching, coherent and integrated plan for Ireland's health service.

Additionally, while these policy documents undoubtedly had merit, like many policy documents, they remained as such and without an implementation and action plan, little has changed.

The Society welcomes the establishment of the Committee, and its work to develop a ten year strategy for the health service in a planned, collaborative and cohesive fashion.

The problems in Ireland's health service will not be tackled in one Government term, so it is necessary to have a long term vision supported across the political spectrum.

Ireland is facing a health crisis in the coming decades. By 2036 there will be 1.1 million people over 65 in Ireland, bringing with it significant challenges for the health system.

Cancer incidence is due to double by 2040 to 56,000<sup>302</sup> cases a year and the number of adults with chronic disease will reach 40% by 2020<sup>303</sup>. These are stark figures.

In order for the health service to cater for this increased demand it needs to become more efficient, better funded, more closely integrated and care needs to be reoriented from the acute hospital setting to primary and community care.

Ireland has a two tier unequal health system where those who can pay have better access to healthcare.

The Society welcomes the Committee's recognition of the need to establish a universal single tier service, and is hopeful that its work will provide a basis to progress towards a publically funded health system based on progressive taxation or social insurance that is financially sustainable and provides universal access to the health and social care system to every citizen.

In relation to cancer care, this is an opportune time to discuss reforming the health services to better meet the needs of this patient cohort.

40% of cancer is preventable<sup>304</sup> and enabling GPs to play a greater role in prevention is key to tackling the increase in cancer incidence. There are more cancer survivors than ever now and a more integrated, patient-centred healthcare system would benefit this group. While we have made significant strides in treating cancer, the poorest in Ireland are twice as likely to die of cancer<sup>305</sup>. Additionally, it is expected that the Minister for Health will publish a new draft ten year cancer strategy before the end of the year, which the Irish Cancer Society hopes will inform the Committee's work on cancer services and care, and may also provide a basis for a model of care for other chronic diseases.

### *Demographics*

Ireland is facing a cancer crisis. In our lifetime one in three people will get cancer. This year 40,000 people will be diagnosed with cancer, 10,000 of these will be non-melanoma skin cancer. By 2040 this is due to double<sup>306</sup>.

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<sup>302</sup> 'Cancer projections for Ireland 2015 – 2040' NCRI

<sup>303</sup> KP Balanda 'Making Chronic Conditions Count' Institute of Public Health (2010).

<sup>304</sup> Parkin, M, et al. (2011), 'The Fraction of Cancer Attributable to Lifestyle and Environmental Factors in the UK in 2010', *British Journal of Cancer*, 105(2): 1-81

<sup>305</sup> Dr. Jan Rigby, Centre for Health Geoinformatics at NUI Maynooth

<sup>306</sup> <sup>306</sup> 'Cancer projections for Ireland 2015 – 2040' NCRI

Cancer is the second leading cause of death in Ireland after diseases of the circulatory system<sup>307</sup> - in the under-65s cancer accounts for 50% of all deaths in women and 1/3 of deaths in men. 62,000 years of life were lost to cancer in 2010, more than to any other cause.<sup>308</sup>

There are two main reasons for the increase in cancer incidence. 40% of cancers are preventable and lifestyle factors such as smoking, alcohol consumption, sun exposure, physical exercise and diet play a role, but predominantly it is because cancer is a disease that affects older people. 63% of cancers occur in men over 65 and 57% in women over 65<sup>309</sup>.

As Ireland's population ages - by 2036 the population over 65 will reach 1.1 million, doubling in 25 years - the number of cancer cases will rise in tandem.

In addition to an increase in the number of cancer cases, more people than ever are now surviving cancer. A total of 123,342 patients diagnosed with cancer between 1994 and 2013 were alive at the end of 2013<sup>310</sup>. Survivorship brings with it new challenges for the health system.

As well as facing a cancer epidemic, Ireland is facing a chronic disease crisis. By 2020, the number of adults with chronic diseases will increase to around 40%. The majority of these cases will impact the poorest in Irish society.

80% of GP consultations and 60% of hospital day beds are related to chronic disease. 86% of deaths and 77% of the disease burden are caused by chronic disease.<sup>311</sup> Cardiovascular disease and cancer are key diseases contributing to the chronic disease burden accounting for two thirds of all deaths.

The projections of Ireland's cancer and chronic disease epidemic, alongside the ageing health population are stark. They have major implications for the provision, configuration and resourcing of the health service in the coming decade. Currently, Ireland's 'healthcare' is concentrated in the acute hospital setting and does not have the infrastructure, workforce or budget to cope with these demands.

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<sup>307</sup> 'Cancer in Ireland 1994-2012' NCRI 2013 – in 2011-2012 8,827 people died from cancer.

<sup>308</sup> IBID

<sup>309</sup> IBID

<sup>310</sup> IBID

<sup>311</sup> 'Tackling Chronic Disease: A Policy Framework for the Management of Chronic Disease' DOH (2014)

In order to deal with these demographic challenges, Ireland's health service needs to reconfigure care away from the acute hospital into primary, community and social care settings.

### *Health Inequalities*

Overall, the health of the population is improving but this is not the case in certain parts of the population, where ill-health is increasing.

Thanks to advances in cancer treatment over the last few decades more people than ever are surviving cancer, but some sections of society are being left behind.

You are more likely to get stomach, lung and cervix cancer if you come from a disadvantaged area<sup>312</sup>, and you are twice as likely to die from cancer.<sup>313</sup>

A map of cancer death rates published by NUI Maynooth (2014)<sup>314</sup> shows there are shocking health gaps even within small areas of Dublin.

Cancer death rates in Dublin during 2009 - 2011 (combined) varied from:

- 381 per 100,000 in Blakestown North-West
- 310 per 100,000 in Blanchardstown North
- 265 per 100,000 in Ballymum East
- 141 per 100,000 in Foxrock/Cabinteely SW
- 138 per 100,000 in Malahide East
- 128 per 100,000 in Castleknock South-East

Tobacco is the biggest contributor to health inequalities in Ireland and accounts for up to half the difference in life expectancy between the richest and the poorest groups.<sup>315</sup>

If we do not begin to tackle the cancer gap between the most affluent and the most disadvantaged it will grow even bigger as the rising cancer cases and chronic disease burden will be borne by the poorest.

The Irish Cancer Society has made health inequalities in cancer a primary focus of its work. In the Society's 5 year strategy '*Towards a future without cancer*' 2013-2017, we

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<sup>312</sup> 'Cancer Inequalities in Ireland' NCRI (2016)

<sup>313</sup> IBID - Lung and head and neck cancer incidence is 1.7 times higher among the most deprived group; Cervical cancer incidence is 1.9 times higher among the most deprived.

<sup>314</sup> Dr. Jan Rigby, Centre for Health Geoinformatics at NUI Maynooth

<sup>315</sup> 'Tackling Health Inequalities, An All-Ireland Approach to Social Determinants.' Combat Poverty (2008)

highlighted the cancer gap and have been working to raise awareness of the issue, and provide solutions.

The Society welcomes the Government's population health and wellbeing cross-departmental strategy *Healthy Ireland* (2013), which has identified reducing health inequalities as one of its four main goals. However, the document is largely aspirational, without specific targets to reduce health inequalities. It concentrates on mitigating lifestyle factors, and while this is part of the solution, a more comprehensive strategic plan to tackle health inequalities needs to be developed in line with this.

Eliminating socio-economic mortality differentials in Ireland would mean over 13.5 million extra years of life for Irish people.<sup>316</sup>

While the Society welcomes the goals of this Committee we note with concern that health inequalities has not been mentioned in the terms of reference, interim report<sup>317</sup> or in the consultation documents. We believe it would be short-sighted to develop a ten year health service reform plan and not take this the opportunity to make reducing health inequalities a primary focus and goal of any future health service reform.

Although Britain has a free health service, since 1948, health inequalities are still rising. The Marmot Review (2010)<sup>318</sup> found people living in the poorest neighbourhoods in England will die seven years earlier than people living in the richest.

It is imperative that any future health care plan is cognisant of the health needs of the populations who need it most, and target services into those areas. Otherwise, we will develop a modern, integrated, universal healthcare system that isn't meeting the health needs of the unhealthiest sections of society.

The Society calls on the committee to ensure that any ten year strategy they develop for the health services:

- Ensures reducing health inequalities is a primary aim of the plan
- Targets health services and resources to the population groups with the largest health needs
- Measure health inequalities over time
- Recommends the establishment of a Cabinet sub-committee on health inequalities

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<sup>316</sup> 'Eliminating Health Inequalities' TASC (2011)

<sup>317</sup> Although health deprivation data is mentioned on page 8 of the Committee's Interim Report

<sup>318</sup> 'Fair Society, Healthy Lives' The Marmot Review (2010)

- Mandates that all health policies should be equality proofed

### *Access to the health system*

The Society welcomes the current Government policy to end the two tier health system and the terms of reference of this Committee to develop a health system based on need and not an ability to pay.

Currently the biggest roadblock in the health service is access to it. In the first instance applying for a medical card is a barrier. If you do not have a medical card you have to pay to attend your GP or ED, another barrier. If you are referred for diagnostic tests, your ability to pay means you can skip the long public waiting lists and enter the private system.

An ICGP survey of GPs commissioned by the Society<sup>319</sup> this year highlighted the public private divide in stark terms. 88.5% of GPs surveyed said a patient's ability to pay affected their ability to access diagnostic tests used to detect cancer.

The report showed:

- Waiting times for MRI brain scans were 20 times higher in the public system than private
- On average, wait times were 70 days longer for abdominal or pelvic ultrasounds in the public system
- Waiting times for a brain CT scan in the public system were 46 days, 49 days for chest CT scan and 55 days for abdomen CT. In comparison you can get a CT scan in 5-6 days in the private system
- For upper GI endoscopy and lower GI endoscopy waiting times were 12 weeks in the public system versus 10 days in the private system.

It is unacceptable that your ability to pay means you could have your cancer diagnosed quicker. A delay in your cancer diagnosis can limit your chances of survival and cost the State more to treat the cancer. A report by Cancer Research UK showed that treatment for stage 3 and 4 cancers costs nearly two and half times the amount spent on stage 1 and 2 cancer services.<sup>320</sup>

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<sup>319</sup> 'Access to Diagnostics Used to Detect Cancer' Irish Cancer Society, ICGP (2016)

<sup>320</sup> 'Saving Lives, Averting costs' CRUK (2014)

In order to tackle increasing cancer incidence we need to ensure as many people as possible are being diagnosed early. This will improve their chances of survival and cost the health service less to treat them.

The Society welcomes a move away from the two tier inequitable health system to a universal healthcare system accessible to all. But in order to do this it is essential to tackle the waiting lists in the public system in the immediacy.

### *The importance of primary care in cancer care*

Primary care is a central tenet of any healthcare system. There is widespread evidence to show that investing in primary care will improve your health system. Lack of an effective primary care system is associated with spiralling healthcare costs and decreasing value for money from public expenditure on healthcare.<sup>321</sup>

Ireland has lagged behind other developed countries in its development of our primary care system. We are the only EU country without universal free primary care and primary care is poorly funded and under-resourced. (The Government spends just 2% of total expenditure public and private on General Practice compared to 9% in the UK.<sup>322</sup>)

A report on integrated healthcare stated: *“Health systems built on the principles of primary care achieve better health and greater equity in health than systems with a speciality care orientation”*.<sup>323</sup>

There is also evidence to show that reorientation to primary care lowers total healthcare costs,<sup>324</sup> while evidence from three large systematic reviews shows that primary care helps prevent illness and death and is associated with a more equitable distribution of health in populations. This finding is supported in both cross-national and within-national studies<sup>325</sup>.

GPs are the first port of call for most people entering or engaging with the health system. For cancer they can play a central role across the cancer journey - through preventing cancer by mitigating harmful lifestyle factors, educating patients on the signs of

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<sup>321</sup> Darker C., ‘Integrated Healthcare in Ireland – a Critical Analysis and a Way Forward’ – The Adelaide Health Foundation (2014)

<sup>322</sup> ‘Budget Submission 2015’ Irish Medical Organisation (2014)

<sup>323</sup> Darker C., ‘Integrated Healthcare in Ireland’ The Adelaide Health Foundation (2014)

<sup>324</sup> Starfield B, Shi L., ‘Policy relevant detriments of health’ *Health Policy* 2002 67(7).

<sup>325</sup> Starfield B., et al. (2005) ‘Contribution of Primary Care to Health Systems and Health’ *The Milbank Quarterly*, 83 (3): 457 - 502

symptoms, being the first port of call for a patient with a suspected cancer symptom, guiding a cancer patient through palliative care, prescribing for treatment side-effects and supporting cancer survivors post-treatment.

Developing free primary care for all and placing a greater importance on primary and community care is key to tackling Ireland's cancer and chronic disease crisis - and is likely to be a key element of the national cancer strategy for the next ten years. Ireland's acute hospital setting cannot cope with the demands from demographic changes in the next few decades, and GPs can play a greater role in chronic disease prevention and management.

The Government has recognised the importance of primary care in managing chronic disease in its chronic disease policy and the Government Health Strategy 2011-2014. The Society also welcomes the current Government's commitment to universal free primary care, however we are concerned about its delay. The first stepping stone to achieving a health system based on need rather than ability to pay is universal free primary care so this needs to be implemented as quickly as possible.

While the Society welcomes the distinct policy shift from acute to primary and community care, we are concerned that these policies are not achievable or realistic without a significant increase in primary care expenditure and the education and recruitment of more GPs.

The Society asks the Committee to consider the following recommendations in relation to the ten year strategy:

- Universal free access to primary, community and social care is a cornerstone of the ten year strategy and the Government needs to increase the funding of primary care and bring in universal primary care as a matter of urgency
- GPs need to be educated and incentivised to provide chronic disease prevention and management strategies
- Implement the *Primary Care Strategy* (2001)
- Primary care practices in disadvantaged areas need additional resources to allow them to deal with a population with greater health needs

#### *Integrated care model*

Along with developing primary and community care as a fundamental pillar of the health system, it is essential that any future healthcare model contains a fully integrated healthcare system.

In 2015 the Adelaide Health Foundation published *Integrated Healthcare in Ireland - a critical analysis and a way forward* which said: “integrated health systems are widely considered to provide superior performance in terms of quality and safety as a result of effective communication and standardised protocol”.

The Irish Cancer Society supports the ethos embodied in the Adelaide Health Foundation’s document, and would ask the Committee to have regard to this document in its considerations.

In relation to cancer care, better integration between primary, secondary, community and acute care would hugely enhance the cancer patient’s experience. It would ensure continuity of care and be more cost-effective.

The development and reorganisation of Ireland’s cancer care in the last 20 years has been one of the success stories in Ireland’s health system. Since the establishment of the NCCP in 2007 and the first cancer strategy in 1996<sup>326</sup> the diagnosis, screening and treatment of cancer has made significant strides. This is reflected in our increased survival rates - 40% colorectal cancer patients, 67% of breast and 63% of prostate cancer patients diagnosed since 1994 were still alive at the end of 2013.<sup>327</sup>

However, cancer ‘care’ has primarily been about the treatment of cancer. With more people surviving cancer integration between services is more relevant than ever. The Society would welcome a move towards an integrated healthcare model providing appropriate care to the patient in an appropriate setting.

We would recommend that the Committee examine the approaches to integrated care systems in the UK, USA, Germany and Denmark.

### Challenges

In the first instance, the underfunding of our health system over the last few years is a challenge. During the recession the health budget was slashed by a quarter between 2009 and 2013<sup>328</sup>

In 2012 Ireland’s health expenditure was 8.1% GDP which is below the average of 8.9% for OECD countries.<sup>329</sup>

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<sup>326</sup> Cancer Services in Ireland: A National Strategy’ DOH (1996)

<sup>327</sup> NCRI ‘Cancer in Ireland 1994-2013: Annual Report’ NCRI 2015

<sup>328</sup> Thomas, S., Burke S. and Barry S. ‘The Irish health-care system and austerity’ *The Lancet* (2014)

The health budget needs to increase and be less susceptible to change in economic variances. A recent study has found that increases in public health-care expenditure as a percentage of gross domestic product were significantly associated with cancer mortality reductions.<sup>330</sup>

The Irish population's reliance on private health insurance is also a challenge - at present 46% of the population have private health insurance.<sup>331</sup> This reliance has created the unequal two tier system by enabling patients to effectively skip the queue into the private system. One of the main reasons people purchase private health insurance is because access to the public health system is difficult. If measures were introduced to rectify the waiting times in the public system and there was universal free access to all, this would diminish the need for private health insurance.

Ironically, from the perspective of funding, private health insurance constitutes a very small contribution to overall health expenditure at only 10% of health costs.<sup>332</sup>

A current challenge in the health system is workforce - from a shortage of GPs to nurses, and many other areas of expertise as well. For instance in cancer care there is a shortage of urologists, radiologists, advanced nurse practitioners and chemotherapy nurses. Any strategic ten year plan for the health service needs to contain a comprehensive workforce plan that takes account of changes in demographics, as well.

### *Future Model*

The funding model of Ireland's health service is unique - a tax funded public health system, which doesn't provide universal access to all, private health insurance and co-payments.

The Society would like to see a publically funded health system based on progressive taxation or social insurance that is financially sustainable and provides universal access to the health and social care system to every citizen.

However, we would emphasise that the funding mechanism is secondary to the objective of universality.

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<sup>329</sup> OECD Health at a Glance 2015

<sup>330</sup> Mahiben M., Watkins J., et al. 'Economic downturns universal health coverage and cancer mortality in high income and middle income countries 1990-2010' *The Lancet* May 2016

<sup>331</sup> Health Insurance Authority (2016)

<sup>332</sup> See reference 31 and ERSI research papers

As we currently have a tax funded system it would seem the most practical to develop this model. When considering the ‘model’ of healthcare the Society asks the Committee to have regard to the Economic and Social Research Institute’s (ERSI) research papers<sup>333</sup> and the work of the Trinity College Pathways Project.

The Society asks that any future health model limits out of pocket payments (OOPs). During the recession these payments increased and the sickest were paying more. Between 2008 and 2013 every person in Ireland was on average paying €100 in additional costs for accessing care and prescribed drugs. The World Health Organisation have urged countries to reduce out of pocket payments so that *“no one should be denied health services, because they can’t afford to pay them”* (WHO 2015), and our OOPs are relatively high when compared to our European counterparts.<sup>334</sup>

We would also ask the Committee to be realistic about the timeframe to implement any reform. In Iceland a move from social health insurance to tax based financing took place over 17 years and in the Netherlands reform of the health financing system happened after 20 years of discussion, and is still in progress ten years after the legislation.

### Conclusion

In conclusion, the Society is encouraged by cross-party agreement to end the two tier health system, reorient care to the primary care setting, and the recognition of the need for chronic disease prevention strategies and managements plans. The formation and remit of this Committee presents a unique opportunity to develop a strategy for healthcare in Ireland that represents a seismic shift in how healthcare is delivered and funded.

ENDS.

For more information contact:

Emma Browne  
Policy Officer,  
Irish Cancer Society,  
44/46 Northumberland Road,  
Ballsbridge,  
Dublin 4  
Tel: 01-2310 518  
[ebrowne@irishcancer.ie](mailto:ebrowne@irishcancer.ie)  
<https://www.cancer.ie/>

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<sup>333</sup> Wren, M.A. and Connolly, S. ‘Challenges in Achieving Universal Healthcare’ ERSI (2016)  
& ‘The 2011 proposal for UHI in Ireland: potential implications for healthcare expenditure’ *Health Policy* 120 (2016)

## Irish College of General Practitioners (ICGP)

- The Irish College of General Practitioners (ICGP) supports a ten-year plan to develop sustainable, efficient, equitable healthcare services, placing emphasis on community-based, personal care.
- In this submission we have detailed fourteen key recommendations, which are central to the creation of a sustainable healthcare system.
- There is unequivocal evidence that a well-resourced, general practice-led, primary care system is capable of managing patients with multiple chronic illnesses (multimorbidity).
- The typical patient in Irish general practice suffers from many chronic illnesses. We describe the experience of one patient to illustrate why our key recommendations are necessary.
- The attached appendices provide detailed insight for each of our fourteen recommendations. Together with the implementation of a new GP contract as an overarching priority, we offer sustainable cost-effective solutions to rising healthcare demand.
- ICGP looks forward to working with the Committee on the Future of Health Care in the coming months on delivering these reforms.

## Key Recommendations

### 1. **New GP Contract:**

ICGP recommends the introduction of a new contract for general practice as an overarching priority, including provision for its review and development as an **on-going** process, between the Department of Health and GPs. The current capitation-based, GP contract was established in 1989 and does not provide for the care of persons with chronic illnesses.

### 2. **Community-based chronic illnesses management:**

A comprehensive community-based chronic disease management programme, encompassing the management of patients with multimorbidity, will reduce healthcare costs and improve patient outcomes. Crucially it will reduce OPD attendances, reduce Emergency Department visits and increase bed occupancy, enabling hospitals to focus on secondary care and facilitating necessary capacity for the creation of a single-tier universal healthcare system. General Practice should have a central, enhanced role in Integrated Care Programs and Clinical Care Programs.

**3. Funding general practice:**

ICGP recommends resourcing Irish general practice **in line** with OECD countries, given historic underfunding and more recent reductions through FEMPI.

**4. Increasing capacity in general practice and primary care:**

ICGP can work with government to urgently address manpower shortages in general practice and primary care. ICGP can increase GP training capacity from 174 to 274 GPs per year, with adequate resources. However, training GPs, only to see them emigrate to other health systems, is not cost-effective. Recruitment and retention of GPs begins with the provision of an adequately resourced general practice system. Increasing the present number of GPs from 4000 to 5000, will require significant investment in general practice, to retain our younger GPs and recruit GPs who have emigrated abroad. ICGP can also collaborate with nursing training bodies enabling the parallel training of additional Practice Nurses.

**5. ICT capacity and monitoring performance:**

ICGP recommends negotiation with GPs of an anonymised aggregated data extraction system, enabling real time data collection for purposes of service development and safety. We recommend the urgent provision of primary care based integrated national electronic health records, using a unique patient identifier. Failure of secondary care to computerise is an outstanding weakness in the Irish health system.

**6. Expanding built capacity / infrastructure in existing general practices:**

To build general practice capacity, ICGP recommends the negotiation, with GPs, of an agreed mechanism to expand built capacity in existing practices. Development of General Practice and Primary Care Teams (PCTs) must be prioritised. Success can be ensured through; a) Liaison with GP representative bodies - as different solutions will be required in different communities; and b) Pragmatic research on PCTs considered successful by their participants and dissemination of best practice.

**7. Medications management:**

ICGP recommends inclusion of a medications management programme in the GP contract, enabling safer prescribing and cost savings for the State and individual patients. ICGP can put in place the educational element of this, collaborating with RCPI and The National Pharmacoeconomics Centre.

**8. Building access to diagnostic services:**

Patients are unable to access necessary diagnostics. ICGP recommends immediate expansion of radiological, cardiac and endoscopic investigations for all patients. Diagnostic facilities need to be considered separate to hospitals. We recommend a uniform national standard waiting time for key investigations based upon reasonable international standards.

**9. Building access to primary care and mental health services:**

ICGP recommends expansion of allied primary care professionals, including psychologists, community psychiatric nurses, and occupational therapists in primary care, with improved nursing capacity in communities (Nurses / Health Assistants /

Carers). GPs manage the majority of mental health complaints in the Irish State, such as addiction, anxiety and depression. A severe shortage of primary care psychological services in particular is curtailing effective management of these mental health conditions.

**10. Universal primary healthcare:**

ICGP supports increasing access to general practice and primary care, contingent on building capacity in personnel, IT infrastructure and built infrastructure in existing premises. Expanding access through means testing is the fairest mechanism.

**11. Universal secondary healthcare:**

ICGP supports the creation of a single-tier secondary care system, underpinned by principles of solidarity, equity, fairness and efficiency. We recommend an all-party taskforce works with key healthcare stakeholders to consider either a) a tax-funded, publicly delivered single-tier system, or b) a single payer model (with split in payer and provider functions).

**12. Emergency Department overcrowding:**

As part of the overall ED taskforce recommendations, ICGP recommends the urgent negotiation, with the relevant GP bodies, for the establishment of the contractual basis of chronic disease management programmes, including the ability to manage multimorbidity, together with availability of more step down facilities, enhanced social care in the community, enhanced GP Co-Operative role and development of a Primary Palliative Care Package.

**13. Public health and health promotion:**

ICGP recommends a government-wide approach on obesity, sedentary lifestyle, problem alcohol use, stress and tobacco. GPs and general practice teams are well placed to address health promotion with patients, given adequate expansion of capacity. Simple distribution of resources based on populations or geography is flawed, and distribution should reflect the needs of remote and deprived communities.

**14. Reversal of fragmented care:**

ICGP alerts government to the hazards of an increasingly fragmented and commoditised healthcare system. The solution is to insist, build and develop an encompassing vision for all members of society, efficiently delivering necessary services to all, in an equitable affordable manner, based on need, and closest to where individuals live. Government must adequately resource effective public general practice and primary care.

**Context of this submission**

**General practice is the key to sustainable healthcare**

- It is recognised since the Alma Ata declaration, that strengthening primary care provides the greatest benefit for health systems and populations over time <sup>335</sup>.
- Evidence supporting investment in general practice is compelling:
  - Adding one GP per 10,000 population reduces mortality, ED visits, inpatient admissions, outpatient visits, surgical activity and health inequalities <sup>336</sup>.
  - Resourced general practice prevents serious illnesses (cancer and chronic disease) <sup>337</sup>.
  - Resourced general practice enables early diagnosis of conditions, reducing hospitalisations and unscheduled admissions.
  - Over-diagnosis and over-treatment are amongst the largest challenges facing Western healthcare systems, harming patients through excessive testing, unwarranted treatments, & escalating costs <sup>338</sup>. Resourced general practice protects healthcare systems and patients from harms and costs associated with over-medicalisation,<sup>3</sup> particularly those associated with unregulated fee per item specialist care.
  - Effective general practice is socially redistributive, increases access to health services and delivers better outcomes for deprived population groups <sup>3</sup>.

### Why is general practice effective?

- GPs have a complex, continuing, co-ordinating and central role in healthcare systems.
- GPs are **specialists**, following rigorous postgraduate training, examinations and supervision. Irish GPs are sought after globally. ICGP enjoys an excellent international reputation in postgraduate training, and graduates are particularly open to international market forces.
- Core features of general practice:
  - 1. Continuity of care:**
    - Continuity of care means patients attend the same practice and staff over time.
    - GPs know patients and families deeply, understanding medical history and background. GPs are expert at exploring hidden concerns and unmet needs of patients, leading to tailored, effective and patient-centred care.
    - Continuity is associated with patient satisfaction and efficient use of resources <sup>339</sup>

<sup>335</sup> WHO. Declaration of Alma- Ata. 1978.

<sup>336</sup> Starfield B. Primary care: an increasingly important contributor to effectiveness, equity, and efficiency of health services. SESPAS report. 2012.

<sup>337</sup> Starfield B, et al. Contribution of Primary Care to Health Systems and Health, The Millbank Quarterly. 2005.

<sup>338</sup> Moynihan R. Preventing overdiagnosis: how to stop harming the healthy. BMJ. 2012.

<sup>339</sup> RCGP. Promoting continuity of care in general practice. 2011.

## 2. Coordination of care:

- Excessive outpatient (OPD) appointments in the healthcare system cause confusion, poor concordance with treatments, duplication of testing, and care which is essentially ungovernable and stressful for patients.
- GPs coordinate complex care needs of patients, helping patients navigate a system, which often feels difficult and fragmented.
- Coordination of care across providers and settings is felt to be essential to chronic disease management in particular<sup>340</sup>. The GP performs a *generalist* role, unique among doctors, combining diagnostic and management skills which ignore the boundaries of specialty practice<sup>341</sup>. This allows the GP to integrate the broad scope of general practice with the individual circumstances of the patient (and their family) and guide the patient through the often fragmented world of healthcare<sup>342</sup>.

## 3. First contact for patients in the healthcare system:

- GPs are gatekeepers, controlling entry to the secondary system (except in emergency situations)<sup>343</sup>.
- Costs escalate if GPs are not enabled to gatekeep appropriately.

## 4. Comprehensive care

- GPs manage every health problem a patient may bring.
- GPs can manage the majority of mental health problems in the State; they can treat all chronic illnesses (if resourced), musculoskeletal conditions, paediatric complaints, women's health, minor surgery etc.
- Over 90% of presentations to GPs do not require referral to secondary care<sup>344</sup>.

## Chronic illnesses and multimorbidity

- The Irish population is aging and living longer.
  - Currently ~10% of the Irish population is over 65, increasing to ~25% by 2040<sup>345</sup>.

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<sup>340</sup> Rothman AA et al. Chronic illness management: What is the role of primary care. *Ann Int Med*. 2003

<sup>341</sup> McKee et al. Responding to the challenge of chronic disease: ideas from Europe. *Clinical Medicine*. 2004

<sup>342</sup> Philips W et al. The Domain of Family Practice: Scope, Role and Function. *Family Medicine*. 2001.

<sup>343</sup> Forrest C. Primary care gatekeeping and referrals: effective filter or failed experiment? *BMJ*. 2003.

<sup>344</sup> Gouda P et al. Treat or refer: Factors effecting GP decisions. *Forum*. 2013.

<sup>345</sup> IMO. Solving the Chronic Disease Problem through General Practice. 2016.

- This means sustained increases in the prevalence of chronic illnesses, which the health system will need to a) prevent and b) manage optimally.
- Chronic illnesses include coronary heart disease, chronic obstructive pulmonary disease, arthritis, mental health conditions, the dementias, and major cancers.
  - Chronic illnesses should be managed with community services, led by GPs; this is a key but yet unrealised policy objective of successive governments <sup>346</sup>.
  - The GP contract precludes GPs managing chronic illnesses (diabetes excepted).
  - Chronic illnesses are now managed inadequately in outpatient hospital settings, despite overwhelming evidence this is sub-optimal and that GPs and practice nurses are willing to take this work on <sup>347</sup>.
  - The present system is ruinously expensive. Each individual outpatient visit in an Irish public hospital costs ~ €167 per annum. The cost for a GMS patient in general practice for one whole year is €116 <sup>348</sup>. This out-dated model overwhelms public outpatient waiting lists and exacerbates ED visitation rates.
- 'Multimorbidity' is a medical term defined as an individual having two or more chronic illnesses.
  - 65% of those aged more than 65 years and almost 82% of those aged 85 years or more have two or more chronic conditions.
  - Patients with multimorbidity include one third of consultations in general practice <sup>349</sup>.
  - International consensus in high performing economies / health systems is that outpatient-hospital management of multimorbidity is prohibitively expensive, unsafe and ineffective.

## **The view from general practice**

### **A typical day in general practice:**

- GPs consult with over thirty-five patients per day.
- GPs would also attend house calls and nursing home visits.

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<sup>346</sup> Department of Health. Tackling Chronic Disease. A Policy Framework for the Management of Chronic Diseases. 2008.

<sup>347</sup> Darker C et al. Chronic Disease Management in Ireland. Perspectives from Patients and Clinical Stakeholders- implications and recommendations for the Irish healthcare system. 2015.

<sup>348</sup> PCRS. Statistical analysis of claims and payments 2014.

<sup>349</sup> Barnett K et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet. 2012.

- Each consultation generates three problems, two brought by the patient and one identified by the GP <sup>350</sup>. Patients are effectively managed in general practice with onward referral in less than 1:10 cases <sup>351</sup>.
- GPs manage growing volumes of administration from a range of agencies.
- GPs review and sign 15-30 repeat prescriptions, most with multiple items.
- Practice Nurses see similar numbers of patients, performing phlebotomy (taking blood), cervical smears, dressings, triaging urgent cases and immunising children, all working under GP supervision.
- GP and Practice Nurses contact many patients daily (or families, nursing homes or hospitals) to give results or answer queries (by text/ phone/ email).

### A typical patient in general practice:

- The following de-identified real case study is a typical patient cared for in general practice:

#### Case study:

- Mary Smyth is 67 years old and has a medical card.
- Living alone in a deprived inner-city community, her husband died of lung cancer (2015).
- Her GP emigrated to the UK two years ago. Nobody has applied for this list since, and she now receives care from locum GPs.

#### Mary suffers from eight chronic illnesses ('multimorbidity').

- a) She has several **cardio-metabolic conditions**:

Mary has high blood pressure (2001) and type 2 diabetes mellitus (2006). She does not attend hospital for appointments, leaving her diabetes poorly controlled. She had a heart attack (2011), with two stents inserted into her coronary arteries. She was diagnosed with an irregular heart rate (atrial fibrillation) (2013), and now takes a blood thinner (warfarin). She has an underactive thyroid (2006).

- b) She has a **chronic respiratory disease**:

Mary smoked for thirty years, and has a respiratory condition called **chronic obstructive pulmonary disease (2005)**. Her GP encouraged her to quit smoking at the time of the heart attack.

<sup>350</sup> Salisbury C et al. The content of general practice consultations: cross-sectional study based on video recordings. BJGP. 2013.

<sup>351</sup> Gouda P et al. Treat or refer: Factors effecting GP decisions. Forum. 2013.

c) She is in **constant pain**:

She has osteoarthritis of her hands, knees, hips and lumbar spine. She was referred one year ago for an orthopaedic appointment for hip replacement, but is still on the waiting list for the initial appointment.

d) Mary suffers from significant **mental health difficulties**:

Mental health difficulties include anxiety and depression, relating to difficult psychosocial circumstances (one son in jail, two other children addicted to heroin).

**Medications:**

- Mary takes thirteen regular long-term medications, requiring regular monitoring and review by her GP.
  - Aspirin (for heart disease)
  - Atorvastatin (for heart disease)
  - Ramipril (for high blood pressure, diabetes and heart disease)
  - Bendroflumethiazide (for high blood pressure)
  - Bisoprolol (for high blood pressure and heart disease)
  - Warfarin (for atrial fibrillation)
  - Metformin (for diabetes)
  - Gliclazide (for diabetes)
  - Buprenorphine patch (an opiate patch medication, for pain)
  - Paracetamol (for pain)
  - Topical anti-inflammatory (for pain)
  - Thyroid hormone (for underactive thyroid)
  - Inhalers X 2 (for chronic obstructive pulmonary disease)

**Healthcare utilisation:**

a. General practice:

- She attends her GP approximately **ten times per year**, usually for infective exacerbations of her bronchitis, for pain, and mental health difficulties.
- With her GP emigrating recently and rising waiting lists, it now takes over one week to make an appointment to see a GP.

b. Hospitals:

- Outpatients:
  - She had 21 appointments at two local hospitals in 2015 – she frequently misses appointments.
  - She attends nine outpatient services (between two different hospitals), including cardiology, diabetes, orthopaedic, and

respiratory OPDs.

- She required twelve blood tests each year for warfarin alone.
  - Public OPD clinics (often run by Junior Hospital Doctors) order X-rays and bloods, frequently duplicating tests, which is very frustrating for Mary.
  - She often misses hospital clinics, citing the cost of a taxi and seeing “a different doctor every time”. She has missed her diabetes and respiratory appointments the last two years.
- Emergency Department:
    - She attended the local Emergency Department twice this year with infective exacerbations of her chronic obstructive pulmonary disease, being unable to obtain timely appointments with her GP (estimated cost of unscheduled ED admissions is estimated at £3,200 per admission in the NHS).

## Appendix 1: Challenges for a sustainable healthcare service

**There are several challenges, from a general practice perspective, in delivering a sustainable healthcare service. ICGP has outlined cost-effective solutions for each challenge below.**

### New GP Contract

- The current capitation-based, GP contract was established in 1989 and does not provide for the care of persons with chronic illnesses.
- ICGP recommends the introduction of a new contract for general practice as an overarching priority, including provision for its review and development as an **on-going** process, between the Department of Health and GPs.

### Chronic illness management

- Chronic illnesses are poorly managed in Ireland, with excessive costs from hospital outpatient visits, increases in waiting lists, rising ED visits (from uncontrolled chronic illnesses), worse outcomes for patients and poor medication management<sup>352</sup>.
- In the case study above:
  - Mrs Smyth is unable to have her chronic illnesses managed by her GP, as there is no provision in the GP contract, excepting Diabetes.

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<sup>352</sup> Starfield B. Primary care: an increasingly important contributor to effectiveness, equity, and efficiency of health services. SESPAS report. 2012.

- Mary attends two different hospitals for her outpatient appointments, and also attends the hospital on twelve occasions for blood tests. **All of these visits could take place in general practice.**
- Mary misses hospital-based appointments. She cannot afford a taxi, is chronically unwell and depressed.
- Mary's chronic illnesses are not well controlled (such as her chronic obstructive pulmonary disease), and as a result she gets exacerbations of her illness, and attends the Emergency Department.
- It is internationally recommended that chronic illnesses should be managed in general practice through structured chronic disease management programmes <sup>353</sup>.
- Recent evidence states that patients with multiple chronic illnesses receive conflicting advice, duplicated investigations and unnecessary medications when single disease guidelines are applied to their care. There should be a focus on the management of multimorbidity, rather than single disease protocols, as part of chronic disease management.
- Mary's nine hospital outpatient visits and multiple phlebotomy appointments could be incorporated into a GP led chronic disease management programme. Visits could be **consolidated and reduced in a generalist service**, allowing Mrs Smyth to be treated closer to home, in a patient-centred manner. Managing patients with multiple chronic conditions (multimorbidity) in a person-centred manner can be facilitated in general practice, in accordance with best evidence <sup>354</sup>.
- ICGP has repeatedly demonstrated GP-delivered peer-reviewed clinical evidence to support the requirement for the Government, DoH and HSE, to properly focus on the prioritisation of primary care and General Practice as the solution to Ireland's problems in dealing with Chronic Disease Management (e.g. Heartwatch<sup>355</sup>). Up to 2014, ICGP was engaged with the HSE Clinical Care Programmes, and developed models of care and guidelines to support Ireland's main chronic diseases (Diabetes, Heart Failure/ CAD, COPD, Asthma and Mental Health).
- In particular, **most mental health conditions are treated within the general practice** setting. Addiction, anxiety, depression and stress can all be effectively managed, with supports from primary care colleagues, and occasionally our colleagues in secondary care.
- ICGP welcomes the introduction of a Diabetes Cycle of Care in October 2015, as a first step towards moving chronic disease management to the community.
- The stumbling block for roll out of these clinical models is the underfunding of primary care infrastructure. ICGP supports developing integrated care programs, particularly with the appointment of a GP as National Primary Care Lead. To ensure the success of general practice-based chronic disease management programs, GPs will need to have an enhanced, central role in future Clinical Care Programmes.

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<sup>353</sup> RCGP. Health Select Committee Inquiry on Management of Long-Term Conditions. Available from [http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/\\_/media/Files/Policy/A-Z-policy/RCGP-Written-Evidence-Long-Term-Conditions.ashx](http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/_/media/Files/Policy/A-Z-policy/RCGP-Written-Evidence-Long-Term-Conditions.ashx)

<sup>354</sup> Wallace E et al. Managing patients with multimorbidity in primary care. BMJ. 2015.

<sup>355</sup> O'Riordan M. Chronic disease care- redressing the balance. Forum. March, 2015.

- High quality training, research and continuous medical education (CME) enable continuous quality improvement in the health sector.
  - CME for GPs and Practice Nurses needs to be enhanced to meet future healthcare and regulatory requirements. This is best achieved by a collaborative approach between ICGP and Government.
  - Research is essential for health system development, enabling analysis of workforce planning, enhancing quality and safety, researching prescribing and patient outcomes. Enhanced government funding of primary care research, with structured career pathways for GPs, Nurses and other primary care professionals wishing to pursue academic interests, would deliver value for the investment.
- ICGP supports advancement of the role of GPs with special interests, aligning themselves to agreed areas of priority (e.g. clinical programmes, minor surgery and minor injury programmes).

**Solution(s):**

- ICGP recommends the urgent negotiation, with the relevant GP bodies, to establish the contractual basis of chronic disease management programmes, which will recognise the comprehensive management of multimorbidity and mental health conditions.
- General Practice should have a central, enhanced role in Integrated Care Programmes and Clinical Care Programmes.

## **Funding deficits in Irish general practice**

- **Irish general practice is under-funded** compared with OECD nations.
- **Government spends just over 2% of the health budget in general practice, compared to 11% in the UK** <sup>356</sup>.
- The 'business model' of modern Irish general practice is becoming increasingly dysfunctional.
- FEMPI legislation has removed over 30% of government income for GMS services, which is crippling general practice, limiting the care patients receive and adding to difficulties in retaining GPs.
- A sustainable healthcare service needs to invest in general practice.

<sup>356</sup> ICGP. Pre-Budget submission 2015. Available from <http://www.icgp.ie/go/library/catalogue/item?spId=5F92634A-B5A0-F573-848D76D9F4D72662>

**Solution(s):**

- ICGP recommends resourcing Irish general practice **in line** with OECD States.
- ICGP requires that the impact of FEMPI cuts in general practice is practically recognised and addressed.

**Personnel capacity: GP and Practice Nurse capacity in Irish general practice**

- Ireland has low numbers of GPs per head of population in the OECD <sup>357</sup>. The aging GP workforce, low numbers of postgraduate training places for GPs, and failure of retention of young GPs all contribute. Failure of retention is driven by aggressive recruitment of Irish GPs internationally, an out-dated and inflexible GP contract, and the realisation that inequity and inefficiency in the present Irish health system are incompatible with the practice of good medicine. Further, established GPs are now beginning to leave mid career <sup>358</sup>.
- **GP training:**
  - ICGP embraces the transfer of GP training to the ICGP (HSE SLA with ICGP).
  - ICGP recommends increasing capacity of the National GP Training Programme
  - ICGP recommends development of multidisciplinary postgraduate training of specialist GP Trainees, Nursing graduates and Practice Administrators.
- **Recruitment and retention:**
  - Training GPs, only to see them emigrate to other health systems, is not cost effective. Failing to retain our GPs will erode and prevent the creation of a sustainable primary care-based healthcare system in the future. Recruitment and retention of GPs begins with the provision of an adequately resourced general practice system. Many younger GPs emigrate to work in healthcare systems where there are comprehensive chronic disease management programs and there are no delays accessing diagnostics. Engaging with emigrated and emigrating GPs and evaluating their reasons to stay/ return must be a priority of government.
  - ICGP published a report in 2015 highlighting that only one third of current GP trainees are confident enough in their futures in the Irish health system to consider planning on staying in Ireland <sup>359</sup>. Viability of general practice in Ireland (20%) and financial prospects (36%) are main reasons cited for leaving.
- **Areas of deprivation:**
  - The case of Mrs Smyth highlights what is happening in areas of deprivation. It is a direct example of Julian Tudor Hart's Inverse Care Law. "*The availability of good medical care tends to vary inversely with the need for it in the population served. This ... operates more completely where medical care is most exposed to market forces.*" <sup>360</sup>. Evidence highlights the association between socio-economic deprivation and poor health. One in four practices in Ireland are in deprived

<sup>357</sup> Oireachtas Library and Research Service. GPs and the Irish primary care system: towards Universal Primary Care? No. 1. 2014.

<sup>358</sup> O'Kelly M et al. ICGP. Structure of General Practice 1982 – 2015. 2016.

<sup>359</sup> ICGP. Bridging the Gap- How do GP Trainees and Recent Graduates identify themselves as the future of Irish GP Workforce. 2015

<sup>360</sup> Tudor Hart J. The Inverse Care Law. Lancet. 1

communities.

- Practices in deprived communities have differing financial, personal, professional and educational needs. A fundamental solution to present health inequalities, glaringly evident in deprived communities, is strong, well-resourced general practice / primary care.
- It is difficult to recruit new GPs to work in areas of deprivation. At present, it remains financially penalising and professionally challenging. Deprived areas have fewer GPs making it more difficult for patients to access services. Nationally there is one GP per 1600 of population (less than the OECD norm). In North Dublin there is one GP per 2500 population.
- **Rural general practice:**
  - A second 2015 ICGP Report (“*A vision for the future of Rural General Practice*”) highlighted challenges facing rural general practice. Rural GMS lists remain vacant. Substantial cuts in top line payments (FEMPI) and discontinuation of rural distance codes have rendered rural practice non viable at present.
  - The Rural Practice Allowance (RPA) is an essential support for rural general practice and restoration of this allowance is welcome as a first step.
  - We recommend additional financial, educational and professional supports, highlighted in this ICGP report <sup>361</sup>.
- **Out of hours:**
  - Out of Hours (OOH) services are under pressure to maintain care with rising attendances in recent years, exacerbated by introduction of the Under 6 contract.
  - We recognise the potential of GP Co-operatives and recommend they are supported in expanding roles in minor injuries management, co-ordinating care with CITs, augmenting primary palliative care and supporting day time general practice with overflow clinics, locum placements and complaints management. All of these additional elements are underway in individual co-operatives, and directly assist in addressing pressing issues in both general practice, and the health system. These activities enable more care in the community, at reduced cost, with higher patient acceptability.
- **Practice Nurses:**
  - There are currently approximately 1,700 practice nurses working in general practice, many part-time. To meet demand in chronic disease management, we also recommend additional full time Practice Nurses equivalents. ICGP asks the government to work with the ICGP and relevant nursing training bodies to address this issue.

**Solution(s):**

- ICGP recommends government to address the recruitment and retention of newly trained GPs as a matter of urgency.
- ICGP requests government to work with ICGP and relevant nursing training bodies to qualify more GPs and practice nurses to meet future workforce planning requirements.

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<sup>361</sup> ICGP. A vision for the future of Rural General Practice. 2015.

## ICT capacity and monitoring of performance

- National GP dataset/ IPCRN/ Monitoring quality:
  - Chronic disease programmes require assessment of efficacy. Given the structure of GP electronic medical records systems, this is set up but not utilised in the Irish system. We recommend the usage of anonymised aggregated datasets (agreed by GP representative bodies). This involves real time capturing, monitoring and feedback to guide performance and development. The Irish Primary Care Research Network ([www.ipcrn.ie](http://www.ipcrn.ie)) has been developed as a real time method of data analysis based on use of agreed coding. IPCRN involves collaboration between ICGP and academic partners (NUIG, AUDGPI, HRB Centre for Primary Care Research (RCSI)). This collaboration can now easily deliver, with the HSE, a high quality evolving real time dataset, based on detailed activities of GPs, Practice Nurses and Practice Administrators.
- Integrated health records:
  - ICGP recommends each individual has a single electronic medical record, accessible to them, held and managed by their nominated GP, shared by their GP with allied agencies, as required.
  - ICGP recommends all health professionals maintain clinical notes on electronic records.
  - The costs of implementing new IT infrastructure, and on-going maintenance, will need to be adequately resourced by government, in agreement with GP representative bodies. ICGP recommends the continued involvement of the GPIT group, with the HSE and DoH, in national IT projects and eHealth Ireland, to ensure integration of health records.

### Solution(s):

- ICGP recommends negotiation, with GPs, of an anonymised aggregated data extraction system, enabling excellence in health services research and monitoring, ensuring quality and safety.
- ICGP requests urgent provision of integrated national electronic health records.

## 6. Built capacity

- There are over 25 million GP consultations per annum in Ireland <sup>362</sup>. This will increase given expansion of GP/ Practice Nurse activities from chronic illness management, and increasing access provided by expanding PCRS eligibility.
- Physical capacity of GP surgeries to address workload requires to be expanded.

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<sup>362</sup> Behan W et al. Are Irish Adult General Practice Consultation Rates as Low as Official Records Suggest? A Cross Sectional Study at Six General Practices. IMJ. 2013

- Government and GP organisations must collaborate to ensure resources and arrangements to enable augmentation of GP capacity grow in line with patient need.
- ICGP supports GP involvement in primary care teams (PCTs) <sup>363</sup>. PCTs do not need to be geographically co-located. Constructing primary care centres without involvement of local GPs does not mean a PCT care team is functional. It is a top-down approach to policy implementation, which at present only appears to work sporadically <sup>364</sup>.

**Solution(s):**

- To enable the expansion of primary care and general practice capacity ICGP recommends development with GPs of a range of agreed mechanisms to expand capacity in all existing practices.
- Primary care teams must be prioritised. The most effective ways to ensure their success is to:
  - a. Liaise with GP representative bodies - as different solutions will be required in different locations - not always requiring the construction of large centres.
  - b. Conduct pragmatic research on PCTs, which are considered by their participants to be successful.

## Medications management

- The cost of the community drugs bill was €1.1 billion, including payments to pharmacists, in 2014. As an example this compares to the overall GMS payment to GPs in 2014 which was €428 million <sup>365</sup> (proportionally five times less than the UK).
- For patients like Mrs Smyth, biannual reviews **by GPs** of medications are recommended <sup>366</sup>. ICGP recommends Government liaise with GP organisations to establish medication review structures as integral to the GP contract.

**Solution(s):**

- ICGP recommends immediate development of a medications management element in the GP contract, enabling safer prescribing and savings, based on an expanded Preferred Medicines Scheme, coordinating with Integrated Care Programmes and the National Pharmacoeconomics Centre

<sup>363</sup> ICGP. Primary Care Teams. A GP perspective. Forum. 2011. Accessed at <http://www.icgp.ie/go/library/catalogue/item?spld=2E2053C3-2415-497E-AA0CF5883AFEC988>

<sup>364</sup> <http://www.irishtimes.com/news/health/delays-to-35-out-of-36-planned-primary-care-centres-1.2741670>

<sup>365</sup> PCRS. Statistical analysis of claims and payments 2014.

<sup>366</sup> Wallace E et al. Managing patients with multimorbidity in primary care. BMJ. 2015

## Building access to diagnostic services

- GPs are unable to access radiological, cardiac and endoscopy investigations for non-private patients.
- For radiological (e.g. CT and MRI) and cardiac (e.g. echocardiography) investigations, GPs do not have effective access for public patients. GPs must therefore refer patients to Outpatient Departments or Emergency Departments. This is wasteful of OPDs, EDs, compounds delays and represents a clear level of medical risk for public patients in delayed diagnoses.
- The 2016 ICGP report '*Access to Diagnostics Used to Detect Cancer*' highlights the lack of access to tests for cancers, which can lead to delays in diagnosis, predominantly for public patients. Delayed diagnoses lead to worse outcomes for public patients, increasing costs, with need for more invasive / expensive treatment, of more advanced disease <sup>367</sup>. A recent UK study demonstrates this regarding comparative costs of treating Stage 1 Vs. Stage 4 colorectal carcinoma.
- A uniform national standard waiting time for key investigations needs to be implemented against which services can be benchmarked, based not on incremental improvement on historic performance, but on neighbouring health systems. For example

▪ Routine endoscopy:	12 weeks
▪ Urgent endoscopy:	3 weeks
▪ Routine ultrasound:	6 weeks
▪ Urgent ultrasound:	2 weeks
▪ Routine OPD appointment:	12 weeks
▪ Urgent OPD appointment:	2 weeks

### Solution(s):

- The gap in access between public and insured patients in accessing diagnostics requires to be closed.
- Independent analysis of public radiological, cardiac and endoscopic investigations against independent / international standards, and system wide adoption of national standard waiting times.
- ICGP recommends development of free standing diagnostic facilities.

## Building access to primary care services

- Primary care staff: GPs experience difficulties for both GMS and private patients, relating to referral to primary care services. For GMS patients, there can be inordinate delays in referrals to certain services (e.g. long waiting lists for physiotherapy), resulting in clinical deterioration, and in requirement to refer to

<sup>367</sup> Incisive Health and Cancer Research UK. Saving lives, averting costs. Analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer. 2014.

OPD. Many non-GMS patients have no access to public primary care services and must pay the full costs of seeking primary healthcare (e.g. attending a private physiotherapist).

- Primary care teams: GPs must be enabled to attend multidisciplinary meetings. Currently, this is largely impossible, and the inability of GPs to engage meaningfully with primary care teams is a major block to efficient and effective care.
- GPs manage the majority of **mental health** complaints in the Irish State (addiction, anxiety, depression). A severe shortage of primary care psychological services in particular is curtailing effective management of mental health conditions.

**Solution(s):**

- ICGP recommends the expansion of allied primary care professionals, including psychologists, community psychiatric nurses, and occupational therapists in primary care, together with effective engagement of GPs in primary care teams.

### **Unfair access to secondary care**

- The discrepancy in access to secondary care, if highlighted as a whole system phenomenon, arguably could precipitate a social / political crisis.
- ICGP has long campaigned for a single-tier access for patients to secondary care services. This requires remodelling of funding of Irish healthcare:

**Solution(s):**

- ICGP requests the creation of a single-tier healthcare system, with principles of solidarity, equity, fairness and efficacy.

### **Universal healthcare and funding models**

- Effective universal healthcare systems are underpinned by strong primary care, centred on effective and resourced general practice. Urgent investment in general practice and primary care is required to enable the introduction of a single-tier system.

**a) Universal secondary healthcare:**

- ICGP supports universal healthcare with single waiting lists for secondary care.
- Three funding options are available to create such a system:
  - a) Tax-funded, publicly delivered single-tier system
  - b) Single payer model/ single-fund insurance (single-tier) system

- c) Universal health insurance (single-tier) system, with competing insurers
- ICGP is well placed to assist in evaluating proposals for system reform.

**b) Universal primary care:**

- ICGP supports primary care and general practice free at point of contact.
- Most OECD countries have removed cost barriers to general practice and primary care services, either through free access (taxation or insurance funded) or subsidised payments <sup>368</sup>. Ireland is an outlier. Whilst ~45% of the population can see their GP for free (with GMS cards, doctor visit cards, under 6 doctor visit cards), the rest of the population pays full costs of attending GPs, allied professionals and pharmacy costs.
- Providing 'free' at point of care access is positive for population outcomes. However free care increases demand, with increases in contacts with the health system. In a fixed supply system this creates frontloading in terms of capacity and initial cost, but in the long term, costs are powerfully contained, and outcomes improved. 'Free' care for U6s has markedly increased utilisation rates, and capacity is now stretched. Improvements in paediatric asthma care, childhood overweight and reduced admissions will take several years to become evident, particularly given poor present use of information technology.

**Insurance:**

- ICGP is critical of the failure of Insurance Companies to recognise/ reflect primary care. Given escalating costs of chronic disease management, ICGP recommends all health insurers be required to reimburse fair primary care costs in all insurance products, as a statutory condition of operating in the Irish economy, and that relevant legislation be enacted as a priority.
- ICGP recognises inconsistent incentives supported by most Insurance Companies in preferentially funding hospital-based services at higher rates than when these same services are provided in primary care. These incentives require to be removed. An example includes the reimbursement for venesection for haemochromatosis (€400 in hospital setting, but €90 in general practice).
- ICGP recognises the inadequate regulation of use of investigative resources and cross referral between specialists of the insured population, placing patients at risk of iatrogenic illness, adding substantially to medical inflation, and wasteful of finite resources in the context of the total health budget.

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<sup>368</sup> European Observatory. Building primary care in a changing Europe. 2015.

**Solution(s):**

- Universal secondary care: create a single-tier access to secondary care services, as part of an all-party taskforce working with key healthcare stakeholders by either:
  - a) a tax-funded, publicly delivered single-tier system, or
  - b) a single payer model (with a split in payer and provider functions).
- Universal primary care: ICGP supports increasing access to general practice and primary care, subject to building capacity in general practice and primary care.

**GP role in Emergency Department over-crowding**

- The ED Overcrowding Taskforce recommends reduction in ED Overcrowding, through increasing bed capacity, improving community supports and improving step down facilities <sup>369</sup>.
- Well-resourced general practice also reduces unscheduled ED visits. A functioning chronic disease management programme will enable general practice reduce ED visitations and healthcare costs, if undertaken with improved step down facilities and community care packages.
- Provision of an effective Primary Palliative Care Package will enable more end of life care to be delivered in communities, avoiding unwelcome over medicalisation of end of life, presently a cause of inappropriate unnecessary acute admissions.

**Solution(s):**

- As part of the overall ED taskforce recommendations, ICGP recommends the urgent negotiation, with the relevant GP bodies, for the establishment of the contractual basis of chronic disease management programmes, including the ability to manage multimorbidity, together with availability of more step down facilities, enhanced social care in the community, enhanced GP Co-Operative role and development of a Primary Palliative Care Package.

**Health promotion and public health**

- ICGP supports Healthy Ireland, the national framework to improve health and wellbeing of the people of Ireland.
- GP Teams are the point of first/ continuing contact in healthcare, and well placed to systematically address unsafe alcohol & tobacco use, stress, obesity and sedentary lifestyles.
- Strong evidence supports consistent brief interventions addressing these risks.

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<sup>369</sup> Department of Health. Emergency Department Task Force Report. 2015.

- Given resource contraction in general practice, prevention potential is only partially exploited at present.
- Addressing resource deficits in primary care together with a multi departmental government approach represents the optimal direction in addressing key public health challenges facing Irish society.

**Solution(s):**

- ICGP recommends government-wide approach to obesity, sedentary lifestyle, problem alcohol use, stress and smoking.
- GP Teams require resources to address health promotion with patients, to build capacity, and deliver on Healthy Ireland framework.

**Fragmentation of care**

- Continuity of care is key to managing complex patients. In our example, Mrs Smyth’s care is fragmented, and her GP service is now compromised.
- GPs and public patients experience at first hand an increasingly complex secondary healthcare environment, with multiple corporate healthcare providers attempting to deliver care and potential deleterious effects for patients and broader society.
- ICGP formally alerts government to costs and dangers of fragmented care and corporate ‘for profit’ environment of modern healthcare.
- ICGP strongly notes the negative effects of corporatization in general practice, which has begun in Ireland. This trend is will affect younger, establishing GPs disproportionately, dissuaded from practicing in Ireland as Principal GPs, with corporate companies filling the gap. Young, establishing GPs need to be supported and incentivised to take up Principle GP positions, not demoralised into taking salaried jobs for profit-making companies.

**Solution(s):**

- Adequately resource effective public general practice and primary care.
- ICGP alerts government to the hazards of an increasingly fragmented and commoditised healthcare system. The solution is to insist, build and develop an encompassing vision for all members of society, efficiently delivering necessary services to all, in an equitable affordable manner, based on need, and closest to where individuals live.

**Appendix 2: Six ‘Quick Wins’ for Irish Society**

1. Payment must cease to be a barrier to essential medical care
2. Universal use of electronic medical records

3. Build capacity in primary care
4. Fully establish chronic disease management in primary care
5. Support end of life care in the community
6. Health Insurers must recognise Primary Care if operating in the Irish economy

<http://www.icgp.ie/>

## Irish College of Ophthalmologists

The Irish College of Ophthalmologists, which is the training and professional body for eye doctors in Ireland, makes the following points for consideration by the Committee;

- The most appropriate health care model for Ireland is one that provides a continuum of quality health services spanning health promotion, prevention, self-management support, primary and specialist, to the whole population.
- There is a clear need to move away from an over-reliance on care delivered in the acute sector. A regionalised community based care model, with clear pathways of referral into acute care services and back to the community where clinically appropriate is suitable.
- Electronic patient records are an essential feature of care provision. Its use will have a very significant role in reducing unnecessary duplicated testing in patients and will be the bridge linking hospital and primary care/community care services. If rolled out in conjunction with an appropriate telemedicine program, it will facilitate access to senior medical opinions thereby cutting out unnecessary travel on the part of many patients.
- The true cost of illness and disease must be understood when making decisions on the investment required to treat and manage those illnesses.
- Education of the public on the role they as individuals can play in proactively looking after their eye health is an essential part of reducing the prevalence of debilitating vision loss and alleviating future dependency on health care services.
- Changing skill-mix will not necessarily result in cost savings. Role substitution without acknowledgement of the differences in the depth and breadth of knowledge will not result in automatic savings.
- Quality needs to be a fundamental priority in the health system and on-going audit of practice is essential.
- Training and research must be embedded and protected in the health service.
- A caring, supportive and encouraging environment must be created for patients but also for staff members. Acknowledging the contribution of staff will enhance buy-in and facilitate progress towards an integrated health care model.

The Irish College of Ophthalmologists (ICO) welcomes this opportunity to make a submission for consideration by the Committee on the future of healthcare in Ireland and commends the Government and legislators on the intention to develop a ten-year plan for health care and health policy in Ireland.

The ICO is of the view that the health care system in this country developed in too highly a fragmented manner with an over focus on episodic care. The most appropriate model for Ireland is one that provides a continuum of quality health services spanning health promotion, prevention, self-management support and primary and specialist care to the whole population.

While this submission will at times focus on eye care, the specialty looks after patients with chronic conditions (e.g. diabetes), emergency conditions (e.g. trauma), conditions associated with visual development in childhood (e.g. squint) and scheduled surgical interventions (e.g. cataract) and so the principals under-pinning what is good for the provision of eye care will equally apply across all areas of health care.

### **Why a Continuum of Care?**

Feeling well is not as a result of any one thing but rather a complex and inter-related web of factors such as our diets, activity level, families, homes, work, friends, communities, in addition to other biological, social, environmental and economic factors. Good health must also be viewed as a broad spectrum of factors including prevention, early detection, specialist care where required and self-care where appropriate.

### **The Challenges**

- Patient Demand

Ireland has experienced and continues to experience, significant population growth. The total population is expected to increase by 22% - 28% between now and 2026. The greatest increases are projected in the over 65-year age group. A significant proportion of the older population in Ireland experience sight loss which is to a large extent preventable.

It is estimated that there are currently 225,000 people living with low vision and sight loss in Ireland. This is projected to increase to 272,000 by 2020. It is also important to consider that with Ireland's expanding and ageing population, the impact of sight loss or vision impairment will become more evident as the incidence of eye disease increases with age.

- Chronic Disease

Many people living in Ireland and their families are affected by chronic diseases and disabilities related to poor diet, smoking, alcohol misuse and physical inactivity. Enjoyment of health is not evenly distributed in society, with prevalence of chronic conditions and accompanying lifestyle behaviours being strongly influenced by socio-economic status, levels of education, employment and housing.<sup>370</sup>

Increasing patient numbers and the growing incidence of chronic diseases are placing an enormous strain on the current model of care.

Many eye conditions such as glaucoma and age related macular degeneration are chronic conditions which require on-going treatment and management

- True Cost of Disease and Illness

The true cost of illness and disease is much greater than just the cost of diagnosis and treatment. Viewing the cost of blindness and vision impairment narrowly in just medical terms leads to a significant underestimation of its true impact. Blindness and vision impairment can significantly

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<sup>370</sup> Healthy Ireland Frame Work, HSE 2013-2025

reduce quality of life by affecting physical, functional, emotional and social wellbeing. All this translates into a significant economic impact on individuals, families, society in general and the state.

Blindness and vision impairment has a major health, social and economic impact and cost the state €205 million in 2010, but a Report on the cost of blindness highlighted that investment in cost-effective interventions could save the state up to €76 million per annum.<sup>371</sup>

The cost to the state increases significantly if a person progresses from being visually impaired (€1.7K per person p.a) to being blind (€21K per person p.a).

Given the ageing population and the growing incidence in key underlying causes of vision loss such as obesity and diabetes, these projections probably represent an underestimation of the likely number of Irish people to have vision loss and blindness by 2021.

The true cost of illness and disease must be understood when making decisions on the investment required to treat and manage those illnesses.

- Capacity

Demand for services currently outstrips supply. This is a significant issue which must be addressed. Hospital centres are overburdened by chronic diseases, most of which could be appropriately diagnosed, treated and managed in the community by eye doctors in a decentralised model.

- Staff Morale

Ten years of reducing budgets, restrictions on headcount and increasing patient numbers have impacted on the people working in the HSE. The sustained negative reporting on the health service has contributed to a strained working environment for the many, many staff members who are dedicated to providing the best care they can for their patients. While the media has a duty to ensure that stories about failures in care are publicised, it has to be acknowledged that constant negative reporting has a detrimental effect on staff morale and this is not conducive to the delivery of consistently high quality care.

## **The Solutions**

- Prevention

The importance of good health and wellbeing and its impact on the prevention of disease cannot be underestimated. Education of the public on the role they as individuals can play in proactively looking after their eye health is an essential part of reducing the prevalence of debilitating vision loss and alleviating future dependency on health care services. Sight loss is not something that is inevitable as we age. We need people to be aware that having regular eye examinations when required and taking positive lifestyle changes can reduce the risk of developing eye sight problems in the future. A change in attitude and instilling an increased sense of confidence in people so they can take better charge of their eye health is needed. Educating the public on understanding the

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<sup>371</sup> . The Economic Cost and Burden of Eye Diseases and Preventable Blindness in Ireland, Deloitte Access Economics, Deloitte Consulting, 2014.

importance of eye health as part of their overall health and wellbeing is essential. Making good eye care a health priority, especially for those in the higher risk categories, will help people proactively protect their vision.

It is also essential that the public understand the significance lifestyle can have on eye health and the importance of reacting to any change noticed to their sight. After ageing, smoking is the biggest risk factor for developing AMD and also increases the risk of developing cataracts and glaucoma.

- Early Intervention

Eye doctors recognise that they are in a position to help allay fears and to guide their patients through their sight threatening conditions and illnesses. In the last number of years there have been exciting new treatments developed in this speciality with the result that some diagnoses which would previously have led to certain vision loss can now be successfully treated.

For example, the introduction of intraocular therapies for people with Age-related Macular Degeneration (AMD), which affects 1 in 10 people in Ireland over 50, has been of enormous benefit and now the diagnosis of a condition that would previously have led to certain sight loss is not so fearful for patients.

- Integration of Primary and Acute Care

There is a clear need to move away from an over-reliance on care delivered in the acute sector. A regionalised community based care model, with clear pathways of referral into acute care services and back to the community where clinically appropriate should be implemented in Ireland. This should be accompanied by increased elective surgical activity in hospitals to address existing waiting lists.

A decentralised model of care requires appropriate workforce planning and management in order to reflect a greater level of care in the community. This transfer of care to the community will enable surgeons to have more time available to carry out procedures. Increased access to theatre is a key enabler for increasing the capacity for surgical procedures.

To ensure the effective functioning of this model of care it is important that a new systematic approach to tracking patients is put in place. Electronic patient records are viewed as an essential feature of care provision. This will enable more effective and efficient treatment of patients in the community.

An integrated model must facilitate rapid access to the acute hospital network for appropriate conditions and to ensure that as many procedures as possible are carried out as day-cases. Protocols and guidelines aimed at reducing the number of inappropriate referrals are required in an integrated model.

- Skill Mix

The human resource, both clinical and non-clinical, is the most important input in the health system. Health systems rely ultimately on the knowledge, skills and motivation of the people responsible for delivering services. The World Health Organisation, 2000 Health Report, noted that determining and

achieving the right mix of health personnel are major challenges for most health care organisations and health systems across the globe.<sup>372</sup>

Healthcare education and practice have developed in such a way that most professions today share some skills or procedures with other professions. The various professions involved in healthcare no longer have a completely unique scope of practice, exclusive of all others. Many health systems have implemented reforms based on changing scopes of practice for a range of health care professionals.

Scope of practice changes must reflect the development of abilities of each healthcare discipline and crucially must be focused on patient safety. Changing the skill mix of the healthcare workforce and role substitution is often suggested as the solution to staffing and resourcing problems.

In 2000, the National Health Service in the UK adopted a ten-year investment plan, which included the Changing Workforce Programme aimed at pioneering new ways of working in the health sector. Bohmer & Imison (2013) analysed the lessons learned from the workforce redesign and concluded that if the sole purpose of a workforce redesign is cost reduction rather than service improvement, then the experience in the UK suggests that policy makers who pursue a similar strategy may be disappointed.<sup>373</sup> The authors' outline how the underlying assumption in workforce re-design is that those in new roles will substitute for those in existing roles. The reality is, however, that the new personnel often become additions to complement rather than substitutes and therefore adding to costs. New roles can also increase demand either as a result of improved access unmasking unmet need or through supply-induced increased demand.

It is often assumed that in changing the skill mix costlier workers will be substituted by less costly workers, an understandably appealing proposition for policy makers. However, if the assumption is based on a description of professional roles purely in terms of technical skill sets without acknowledgement of the differences in the depth and breadth of knowledge, then the assumption may be false. Research has shown that despite the salary differential, early assessment by a senior doctor is more cost effective than one by a junior doctor as senior staff have a higher threshold for risk and are therefore less likely to admit a patient. Bohmer & Imison reveal that the potential savings from role substitution can be offset by the longer times that less expensive staff need for consultations and their higher rates of referrals, repeat patient visits and testing. The authors also highlighted the increased transaction costs implicit in expanding multi-disciplinary teams, as staff spend increasing amounts of time discussing patients with consequently less time available for direct patient care.

Bohmer & Imison propose a number of general principles that would increase the chances of success of a workforce redesign including redesigning the work before the workforce, clarifying and supporting new roles and responsibilities, providing statutory guidance and regulation and focusing on existing roles and staff first.

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<sup>372</sup> World Health Organisation (2000) The world health report 2000 - Health systems: improving performance, WHO, New York.

<sup>373</sup> Bohmer, R. & Imison, C. (2013) 'Lesson's from England's Healthcare Workforce Redesign; No Quick Fixes, Health Affairs, 32, No 11.

Multi-disciplinary team working is an important feature in any modern health service but team delivered care must be under-pinned by a clear understanding of the roles and responsibilities of all team members

- Technology

Eye care is one of the areas of health care in which the rise of new technologies has had a significant impact both in terms of diagnostic capabilities and in increased workload. The development of new imaging techniques that require less specialised clinical skills than traditional instruments like the slit lamp and lenses, means that the use of technicians as assistants to the ophthalmologist is appropriate when undertaking highly automated processes such as hi-tech diagnostic testing. De Mul, De Bont & Berg describe how the expansion in the use of information systems in the delivery of eye care has also necessitated a redistribution of tasks to optimise their potential impact.<sup>374</sup> The use of Electronic Patient Records which support the decision making process require the input of detailed information. Highly trained doctors are not the correct personnel for data entry tasks, nor necessarily are nursing or allied health staff. A technician or clerk, with specific time allotted for the uploading of electronic information may be more efficient and disciplined in data entry than clinical staff and the use of non-clinical staff to support the diagnostic and treatment process would lead to efficiencies.

- Audit, Benchmarking and Quality Assurance

Quality needs to be a fundamental priority in the health system and on-going audit of practice is essential. Quality standards measure outcomes and can facilitate adjustments where necessary. Quality standards also assist in maintaining efficiency and optimisation in the delivery of healthcare.

The important role of evaluation and the need to enhance evaluation capability is referenced in a range of policy documents including the Department of Health's Statement of Strategy 2015-2017, where the measurement of the outcome of each action is an intrinsic part of that action. The HSE 's Quality and Safety Clinical Governance Development Initiative recommends that health service providers, policy makers and commissioners place quality and safety at the top of the agenda (2014). A report published as part of the initiative explains that understanding the quality and safety of the health service requires a comprehensive approach to collecting, analysing and discussing data. Legislative changes aimed at enhancing accountability have furthered endorsed the importance of monitoring and evaluation in health care management.

A key focus of health sector evaluation must be to understand if the interventions and programmes being implemented are having a positive impact on patient outcomes. Healthcare evaluation plays an important role in helping clinicians and managers determine whether they have achieved high standards of efficiency, effectiveness, quality, equity and value for money in the service they provide. Robust evaluation can provide the necessary evidence for effective decision making and facilitates appropriate accountability.

Implementing an appropriate clinical governance framework would support the provision of quality services by ensuring integrated care via clear referral pathways and formalised networks and

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<sup>374</sup> De Mul, M., de Bont, A. & Berg, M. (2007) IT-supported skill-mix change and standardisation in integrated eyecare: lessons from two screening projects in The Netherlands International Journal of Integrated Care

enabling a culture of continuous quality improvement. The governance framework must encompass all five directorates of the HSE.

<http://www.eyedoctors.ie/>

## Irish Congress of Trade Unions

The establishment of the Oireachtas Committee on the Future of Healthcare and the attendant focus on formulating a long term vision for a reformed public health service is a positive development.

The establishment of the Committee presents an opportunity to make a declaration of intent that, over time, we will move to a universal, fully integrated, single tier public health service that guarantees access and quality care, regardless of income.

The public health service should be funded through a progressive taxation system. At a minimum, the service should be allocated dedicated funding of 10% of GDP per annum, with a further recognition that significant additional capital spending will be required in some years. Over time, the state will cease to subsidise all forms of private health care provision.

For the vast majority of citizens the first point of contact with the public health service should be a network of public, locally based community health care centres. These Primary Care Centres will provide an expanded range of clinical and diagnostic services and will lead health promotion campaigns in the communities in which they are based.

The network of public hospitals will continue as a vital cornerstone of the public health service, but the role of the public hospital will be re-focused with some services devolved to the Primary Care Centres. Vital to reform the health service will be a move to a team-based approach to patient care which is consultant delivered and where all hospital staff are respected and enabled to perform tasks appropriate to their qualification levels and competence.

The increase in the number of older people living longer lives is the biggest challenge facing our public health service. This challenge is such that it will require the state to reverse its current policy of privatising elder care and re-engage as the principal provider of health care services for older people.

The incidence of mental health disorders continues to rise and demands a renewed commitment to deliver in full the proposals contained in the Vision for Change strategy published in 2006.

Not for profit organisations currently provide the bulk of health services to people with disabilities. A small number of highly publicised failures have highlighted the need for better oversight and a focus on quality assurance and patient care. A

strategy of providing services in community-based settings must be part of an overall approach to the care of people with disabilities.

The Committee must accept that moving to a universal, fully integrated, single tier public health service presents a number of workforce planning challenges, not the least of which is understaffing. In designing the new system, full regard must be had for appropriate remuneration, reward and recognition systems and other conditions of employment, such that the Irish public health system is ultimately viewed as the employer of choice and is capable of attracting and retaining the most talented staff.

## **Introduction**

- 2.1** An essential function of Government is to create the conditions under which all citizens can access high quality public health services.
- 2.2** The public health service in the Republic of Ireland is staffed by a wide range of highly qualified and dedicated healthcare professionals who strive to achieve excellent outcomes for patients. However a number of funding, structural and organisational difficulties embedded in the system can result in a less than satisfactory experience for some.
- 2.3** The establishment of this Committee represents a major opportunity to make a declaration of intent on the introduction of a universal, single-tier, public health service, where both access and quality are guaranteed regardless of income. It is imperative that over time the existing two-tier health system - with contradictory incentives and ability to pay guaranteeing faster access to diagnostics and interventions - is replaced by a single-tier, equitable, quality service.
- 2.4** Over the last three decades successive governments have proposed, and implemented, various organisational reforms. However real, transformational, change has not occurred, to the detriment of many who rely upon a public health service. The Committee must acknowledge that a meaningful transformation of Ireland's public health services will require far more than a decade of planning and implementation and as such, its deliberations should not be limited to addressing developments that may be completed within the next ten years.
- 2.5** In this submission Congress has sought to identify:
  - The guiding principles that should inform any programme of reform;

- The measures required across the key pillars of the public health service: primary and community care, public hospitals, care of older people, the mental health service, care of people with disabilities; and
- The human resource issues arising from the implementation of a new vision for the public health service.

**2.6** Congress is uniquely placed to provide the Oireachtas Committee with a view on a reformed public health service given that our affiliated unions represent well over 90% of all employees in the service. The views expressed in this submission have been developed in consultation with both the unions in the sector and the wider trade union in Ireland. However the Irish Medical Organisation (IMO) has independently developed a strategy for the organisation of the health services in Ireland over the next ten years and beyond, which is the subject of that union's separate submission to the Committee on the Future of Healthcare.

**2.7** In our view an essential component of a single tier public health service is that all staff will be directly employed. Critically, any such service must function on a 24/7 basis, where required, and, at a minimum, on a 7/7 basis, in both the primary and secondary care services.

### **3. Guiding Principles for a Reformed Public Health Service**

**3.1** In the following paragraphs we set out the principles that Congress believes should guide the transformation of the public health service.

**3.2** In the first instance, there should be an immediate declaration of intent to create a fully integrated, universal, single-tier public health service. Clearly, a considerable transition period will be required - probably in excess of a decade - and this should be acknowledged at the outset. It will be vital to secure citizen and stakeholder support for the process and the difficult decisions it may entail. This will require active consultation with those immediately affected *and* a commitment that no service will be discontinued until an alternative service is in place. Likewise, any proposed changes to employment contracts or other contractual arrangements must be the subject of consultation with recognised trade unions, acknowledging that significant red-circling of some current arrangements will be required. Although change will be gradual the transformation envisaged must be clearly set out, along with a timetable for implementation.

- 3.3** There should be a long-term, multi-annual commitment to provide ring fenced core-funding for the public health service at a minimum level of 10% of GDP per annum. This funding should be provided through a system of progressive general taxation.
- 3.4** Building a single tier health service will involve significant capital expenditure to provide the necessary infrastructure. The funding must be allocated, in any given year, in addition to, and separate from, the minimum expenditure of 10% of GDP on current service provision. All health spending must come as a result of realistic budgeting, which can adequately provide for the delivery of planned services and the development of infrastructure.
- 3.5** As we transition to the desired single tier system, parallel funding will be required as we reconfigure and develop new services, while maintaining existing service provision.
- 3.6** A further cornerstone of this transformational programme should be a declaration that the State will, over time, cease to fund or subvent any form of private healthcare provision. This will entail the phased elimination of all tax reliefs for private healthcare insurance and direct subventions, i.e. to existing private nursing homes. This funding should be redirected to specific programmes, required for, or linked to, the implementation of the reform programme for the creation of a single-tiered service.
- 3.7** Essential to a reformed public health service must be an appropriate remuneration system aimed at attracting the most talented. If we are to attract and retain the required number of additional staff, recognising the expansion of services that will be required, the change process must include a significant personnel component. This must recognise that Ireland will be competing with other countries for well qualified health professionals and significant ongoing training and professional development opportunities should be available. Ultimately a transformed public health service must be viewed as an employer of choice.
- 3.8** Organisational restructuring, planned or under way, will need to be reviewed in order to reflect the structures necessary to deliver the single tiered accessible healthcare service. The final organisational structure that emerges must be simple, integrated and readily understood by the general public. This is necessary to ensure efficiency and effectiveness, minimise duplication and, most fundamentally, to secure the confidence and support of the general public for the transformational programme.

**3.9** Congress further calls for improved planning and expenditure on public health initiatives. The current population health strategy - *Healthy Ireland* – can be of considerable importance in lowering future disease burden. However it must be supported with a detailed implementation plan, ring-fenced funding and improved staffing of public health provision.

#### **4. Primary Care: Local Health Services to Meet Local Need**

**4.1** The delivery of public health care should be designed to ensure that the first, and, for the most part, the continuing point of contact for most citizens, will be a community-based, publicly owned and managed primary health care facility.

**4.2** A cornerstone of this enhanced system must be universal eligibility for all primary care services, to be provided by directly employed health professionals.

**4.3** The range of services offered in these primary care centres is a matter for detailed consideration and may differ based upon urban/rural locations and population density. Staffing should be on the basis of 7/7 opening and centred on a team approach, providing direct access for the public to health professionals together with the provision of cross referral from one health professional to another.

**4.4** These Primary Care Centres must offer sufficient diagnostic and support services to ensure that patients can access services at the most appropriate location, thus reducing the burden on acute and secondary services.

**4.5** In that context any current or future discussions with regard to expanding or altering existing contracts or arrangements, must recognise the potential for significant change and not, in any way, inhibit or restrict the changes necessary to transform the provision of primary care services.

**4.6** As suggested services should operate to direct patients to receive care at the most appropriate location. However, as patients will still need to attend public hospitals for particular treatments it is important that appropriate technology is utilised to ensure seamless transmission of patient information between the local facilities and public hospitals. This will require separate, ongoing, capital funding.

**4.7** In paragraph 2.3 above we referred to once off capital costs that will be incurred as part of the required reforms. It will be necessary to expand the current programme to develop primary care facilities to ensure access to such centres countrywide. The development of community based health facilities is critical to the creation of a universal, single tier public health service.

## **5. Our Public Hospitals: Acute Care & More**

- 5.1** Devolving some services from public hospitals to community based facilities, provides an opportunity to assess which services will remain with public hospitals and how they will be delivered.
- 5.2** However in any reform of the role of public hospitals we must ensure that there are sufficient beds in appropriate locations to meet expected demand.
- 5.3** It is widely accepted that there are insufficient available beds in our public hospitals. This is evidenced by the waiting times experienced in emergency departments and the severe and growing waiting lists for inpatient and/or diagnostic services.
- 5.4** Research carried out by the OECD<sup>375</sup> shows that in 2006 the number of hospital beds per 1000 of the population stood at 5.3. However by 2012 this had fallen to 2.8. If public hospitals are to be capable of responding to the needs of a growing and ageing population the number of available public beds will have to increase significantly to bring it into line with the OECD average of approximately 5 beds per 1000 of the population.
- 5.5** It is also accepted that significant change is required in how public hospital services are delivered. Fundamental to this is recognition of the leadership role played by consultants in hospital settings. In order to ensure the effective functioning of a single tier public health service it will require that patient care is delivered by consultants employed and working exclusively for the public health service. It will also require that consultants are rostered over an extended day and on a seven day a week basis. This will require a significant number of additional consultant posts in the core specialisms of medicine, surgery, paediatrics, obstetrics and emergency medicine.
- 5.6** Moving to a consultant-delivered service in public hospitals - to include a review of the existing ratios between qualified staff and professionals in training - presents an opportunity to create a system of team working where the role played by all working in the hospital is valued and recognised. It also presents an opportunity to assess how vital work is carried out. Most people working in the health service would agree that the quality of patient care could be improved by ensuring that tasks are carried out by the appropriate person in the most efficient way. It is further recognised that many staff in our hospitals are now trained to a level that would allow them to perform an enhanced role in patient care. In the move to a consultant-delivered

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<sup>375</sup><http://www.oecdilibrary.org/docserver/download/190800051e1t008.pdf?expires=1470239242&id=id&accname=freeContent&checksum=5EF2A2E6A34320414A2E6101A298CAF2>

service the duties currently performed by all those working in this vital part of our health service should be scrutinised and tasks allocated on the basis of achieving the highest possible standard of patient care.

- 5.7** Congress requests that the Committee note that our affiliates have, particularly in recent years, engaged in very constructive discussions with regard to the reallocation of work, task transfers and the provision of frontline services to patients/client. This must be constantly reviewed during the transformation programme, as a properly staffed health service, with appropriate ratios of professionals to support staff, greatly enhances the patient/client experience and accelerates the return to full health.
- 5.8** Congress broadly welcomes the recent establishment of the seven Hospital Groups, including the Children's Hospital, as it has the potential to improve co-ordination of service delivery. However past experience with regard to reconfiguring acute hospital services is one of failure, with increased overcrowding, loss of public confidence and huge frustration amongst health service staff. However, Congress, as referred to in paragraph 4.1, continues to believe that the move to an integrated single tier public health service presents an opportunity, on a planned and agreed basis, to transfer some of the procedures, performed in hospitals, to more locally based public health facilities.
- 5.9** A fundamental requirement of any further reconfiguration of acute hospital services, as part of this transition must be to ensure the maintenance of all existing services in their current locations, until the alternative service is established, properly staffed, funded, and, most importantly, enjoys the confidence of the community it serves.
- 5.10** Where appropriate and proven effective, public hospitals should provide other services critical to the care of patients, necessary for the continuing improvement and development of the public health service. An example would be for major public hospitals to continue to provide advanced diagnostic tests for patients following referral from partner hospitals and/or locally based primary care centres. Public hospitals should also continue to play a key role in the education and ongoing professional development of those working, or seeking to work, in the public health service. It is also vital that our public hospitals are involved in advanced research and development thus ensuring ongoing improvements in patient care. When our public hospitals have the capacity to provide world class care and are recognised as leaders in education and research, the public health service is more likely to attract and retain the most talented staff.

## **6. Care of Older People: The Biggest Challenge Facing our Public Health Service.**

- 6.1** While there has been an increase in both the birth rate and in the population, the long term trend shows a significant increase in number of older people who will live longer. While obviously welcome, this poses a considerable challenge to our public health service.
- 6.2** As our population ages, there will be an exponential rise in the incidence of chronic disease, and it is imperative that we radically reform the manner in which we deliver healthcare services to those affected. An expanding and ageing population places significant demands on the healthcare system with the incidence of chronic conditions expected to increase by 4% to 5% per annum during the next decade. Many services addressing chronic disease could be better delivered in a community setting and such services must be expanded accordingly.
- 6.3** Older people who live in their own homes will doubtless benefit from an expanded, locally based network of primary health care facilities. The development of these facilities will reduce their requirement to be admitted to public hospitals and the requirement to travel to avail of services currently provided in public hospitals.
- 6.4** Older people who do live at home will require support. The home help service currently provides such assistance and the provision of these crucial services are very often the reason why older people can continue to live independently. Close to 50,000 people availed of this service in 2015. It is therefore imperative that adequate funding and professional staffing are provided for the continued and improved running of this service.
- 6.5** For a growing number of older people the reality is they are unable to live independently. Most will require full time residential care. To date official policy has been to privatise this care through state subsidisation of private nursing home beds run by for profit businesses.
- 6.6** Congress believes it is vital for the State to declare that, over time, it will become the main direct provider of long term residential care for older people. This will require significant state investment in the development of facilities that will provide single room accommodation in residential settings. It will involve the construction of such facilities and the redevelopment of the existing public, long term bed stock to bring it up to the standards required by HIQA. An extended home help service can address the needs of those who can and wish to remain in their homes despite being unable to live independently.

**6.7** As we have mentioned the move to a fully integrated single tier public health service will take a number of years to implement. In the transition the private sector will continue to be a provider of care to older people. However, there will be greater certainty and security for older people with the State moving to become the main care provider.

**7. Mental Health: Removing the Stigma & Providing Effective Treatment.**

**7.1** In 2006 the then Government published a comprehensive policy on mental health entitled *A Vision for Change*. The key feature was to be the transfer of services to community settings. However in the ensuing decade there has been slow progress in implementing what constituted a transformational shift in the treatment of mental health disorders.

**7.2** The proposal to move to a community setting is still relevant and this service should be fully integrated into the locally based primary health care services, referred to earlier.

**7.3** However funding for the treatment of mental health disorders is drawn from the main budget, with no certainty about the availability of resources in the longer term.

**7.4** Congress believes that mental health requires a dedicated, multi- annual budget. This would facilitate the integration of this important element of the public health service within the locally based primary care service, with the capacity to plan for the treatment of children and adolescents, along with planning for the treatment of adults presenting with mental health disorders.

**7.5** Arising from the provision of this dedicated, multi-annual budget, specific goals and objectives must be set for the rapid development of mental health services. These must include significant investment in capital infrastructure (again through a separate capital budget) the provision of specialist services, universally available, and the employment of additional allied health professionals and nursing staff. Access to acute/supportive mental health services must be available, on a 24/7 basis, either through the primary health care centres, or dedicated staff within emergency departments in major urban areas.

**7.6** An effective means of reducing the incidence of mental health disorders is through preventative programmes that seek to lessen the prevalence of risk factors, including: substance abuse, social isolation, economic disadvantage or family conflict. The dedicated budget for mental health referred to in paragraph 7.4 above should provide resources for the implementation of such programmes.

## **8. Disability Services**

- 8.1** The funding of health services for people with disabilities dramatically reduced during the economic crisis and this must be reversed.
- 8.2** The delivery of these services is primarily carried out by not for profit voluntary organisations working nationally or locally. In the vast majority of cases the services provided are to the highest standard, given the resources made available to them.
- 8.3** However a small number of highly publicised failures in service provision highlights the necessity to ensure that quality assurance and patient care are at the heart of service delivery to people with disabilities. It must also be acknowledged that the provision of disability services, through numerous small, not for profit agencies has led to a lack of consistency, in terms of service location and access. Congress therefore proposes that the services be delivered, through direct provision and directly employed staff, and in a manner which ensures that access to necessary supports is available regardless of income and location.
- 8.4** Equally we must continue to relocate services, where appropriate, from existing residential type accommodation to more appropriate community based homes. While this is existing policy it has not been properly funded and, quite frequently, the infrastructure within the community home location is inappropriate for the needs of the client. It must also be recognised that there will be many occasions when the individual continues to enjoy a better quality of life by remaining in their current location, receiving the required level of supports.
- 8.5** The reform process must ensure that we fully utilise the skills and competencies of all staff working in the area of disability services. As part of the transition to this single tier system we must, without exception, maintain standards and practices and ensure respect for the human rights of the individual with a disability. The provision of such a service will require legislative changes to guarantee the rights of the disabled person, including the provision of all services necessary to optimise their lives, potential and overall well-being.

## **9. The Ambulance Service**

- 9.1** The National Ambulance Service plays a critical role in connecting the community with hospital and other key health care services.
- 9.2** Due to changing demographics citizens dependent on community medical services will require support in the home. Citizens will require social support which is already

provided by Home Help Services and as such it is imperative that adequate funding and qualified personnel be provided. It is therefore crucial that Government commits to adopting a strategic plan for care of citizens in the community which ensures the highest standards are maintained and that those who provide and manage the service are regulated. It is also vital that the workers in this sector are protected and remunerated in line with their counterparts who provide similar services in institutional settings.

## **10. Regulation & Standards**

**10.1** As an integral part of this transformation programme Congress supports strong regulations to govern how all health professionals practice. If the public is to have confidence in those providing care it is essential that very clear regulations remains in place to ensure high standards.

**10.2** As we move to a single tier publicly provided, health system it will be necessary to ensure that a full independent inspectorate is established and properly funded, charged with the task of constantly challenging the health service to be world class in all facets of its operation.

## **11. Future Workforce Planning**

**11.1** There are significant workforce planning issues to be considered as part of the transition to a fully integrated single tier public health service.

**11.2** It is our view that in the transition period all future recruits to the public health service will be direct employees working exclusively for the public health service.

**11.3** Remuneration, reward and recognition systems and quality continuing professional development systems must be put in place, with the aim of attracting and retaining the most talented staff.

**11.4** If the ambition of a fully integrated, single tier public health service is to be realised and if it is to operate across all settings in a timely and responsive manner, it will require significant investment in staff at all levels.

## **12. Conclusion**

**12.1** The establishment of the Committee on the Future of Healthcare presents a significant opportunity to develop a new, all-embracing and transformative vision for the future of our health care system.

- 12.2** It is the view of Congress that the Committee should clearly state that an overarching goal of this process is to move to a universal, fully integrated, single tier public health service, that guarantees access and quality care, regardless of income.
- 12.3** The public health service must be properly resourced through the taxation system to a minimum of 10% of GDP per annum, with acknowledgement that additional capital funding will also be required over time. This will also see the State cease funding for all forms of private health care.
- 12.4** A network of Primary Care Centres will act as the first point of contact for many accessing the health service, with the centres providing a range of key services and leading local health promotion campaigns. Service provision in the public hospital network will be refocused to reflect this change, but the network will continue as the cornerstone of the health care system.
- 12.5** At the heart of a transformed health service will be a consultant delivered, team-based approach to patient care, with all staff carrying out tasks appropriate to their qualifications.
- 12.6** The biggest challenge facing our public health service is the increase in the number of older people living longer. This will require the state to become the principal provider of health care for older people.
- 12.7** The growing incidence of mental health disorders demands the full implementation of the proposals contained in the 2006 *Vision for Change* strategy.
- 12.8** Moving to a universal single tier public health service presents major workforce planning challenges. Any new system must put in place conditions of employment that will make our health system the employer of choice for the most talented staff.

**Irish Congress of Trade Unions.**

<http://www.ictu.ie/>

## Irish Dental Association

The Irish Dental Association is the professional, educational, scientific and advocacy body for over 1,800 dentists in Ireland. Our mission is to promote the interests of the dental profession and to promote the well-being of our country's population through the attainment of optimum oral health.

Oral health forms an integral part of general health and wellbeing. Oral diseases also share common risk factors with chronic diseases such as heart disease, obesity and diabetes. In our experience, oral health is not prioritised in terms of promotion, funding or service delivery. We are now calling for the integration of oral health into the wider healthcare delivery system, whilst also respecting the independence of the profession. The approach to prevention and treatment of oral and 'general' healthcare should therefore be closely connected and should be achieved through individual, professional and community-level approaches.

### **IDA priorities for the future of the Health Service are as follows:**

A **new national oral health strategy** must be developed and properly resourced, with a focus on prevention that ensures oral health care is better integrated and given priority in any overall health care strategy. A full-time Chief Dental Officer should be appointed on a permanent basis to lead the development and implementation of a new oral health strategy.

The role and expertise of dentists at community / primary care level in the **management and prevention** of chronic disease must be developed.

Any state dental schemes must be properly funded and operated. They must be fit for purpose and have a focus on prevention.

There needs to be **elimination of the barriers between primary and secondary** oral and dental health care.

**A national model of publicly delivered dental care for children and patients with special care needs** is needed and must be adequately resourced and staffed.

We recommend implementation of the recommendations as they relate to **paediatric dentistry** contained in the National Clinical Programme for Paediatrics and Neonatology model of care for paediatric healthcare services in Ireland.

There must be a concerted plan to tackle the crisis in **Orthodontics**. We need to see publication and enactment of a new **Dental Act**.

## **Introduction and Background**

The Irish Dental Association is the professional, educational, scientific and advocacy body for over 1,800 dentists in Ireland. Our mission is to promote the interests of the dental profession and to promote the well-being of our country's population through the attainment of optimum oral health.

There are approximately 2,000 active dentists in Ireland with a further 2,500 technicians, hygienists and dental surgery assistants employed in the delivery of dental care (O'Neill, 2010). As such, dentistry represents a small but significant sector of the Irish economy.

Oral health forms an integral part of general health and wellbeing. Diseases of the mouth and oral cavity have a significant impact in terms of pain, suffering, impairment of function and reduced quality of life. Oral diseases also share common risk factors with chronic diseases such as heart disease, obesity and diabetes. To a large extent, oral diseases are entirely preventable. Yet when they occur, they can be among the most expensive to treat. The approach to prevention and treatment of oral and 'general' healthcare should therefore be closely connected and should be achieved through individual, professional and community-level approaches. Early diagnosis as with most disease is important for a successful outcome. Investment in timely and effective oral healthcare results in the enhancement of general health and wellbeing and a reduction of the financial burden on healthcare systems. Where investment is low resources are primarily allocated to emergency oral care and pain relief with under-privileged groups being the most vulnerable.

Currently, oral healthcare in Ireland is provided through a mix of publicly funded schemes, fully private provision, a public dental service and specialist / hospital services. The majority of dental services are provided by dentists in the private sector, while the HSE is responsible for providing dental services to children and adults with special needs. However, there are a number of problems with the current model of care including lack of funding and resources, savage cuts to funding and the scope of treatments covered that were implemented during the crisis along with bureaucratic and administration issues.

## **Strategy**

### **IDA priorities for the future of the Health Service are as follows:**

A **new national oral health strategy** must be developed and properly resourced, with a focus on prevention that ensures oral health care is better integrated and given priority in any overall health care strategy. A full-time Chief Dental Officer should be appointed on a permanent basis to lead the development and implementation of a new oral health strategy.

The role and expertise of dentists at community / primary care level in the **management and prevention** of chronic disease must be developed.

Any state dental schemes must be properly funded and operated. They must be fit for purpose and have a focus on prevention.

There needs to be **elimination of the barriers between primary and secondary** oral and dental health care.

**A national model of publicly delivered dental care for children and patients with special care needs** is needed and must be adequately resourced and staffed.

We recommend implementation of the recommendations as they relate to **paediatric dentistry** contained in the National Clinical Programme for Paediatrics and Neonatology model of care for paediatric healthcare services in Ireland.

There must be a concerted plan to tackle the crisis in **Orthodontics**.

We need to see publication and enactment of a new **Dental Act**.

The IDA, as a lead partner in the National Oral Health Forum (2013), also endorses the Forum's key recommendations as follows:

There must be absolute clarity on the responsibilities and relationships of all key stakeholders in oral health. In particular, the roles of the Department of Health and the Health Service Executive (HSE) in the delivery of oral and dental care must be clearly defined.

Delivery decisions need to be matched to clinical needs and prioritised in line with the available resources. The role and responsibilities of the HSE in this process requires detailed clarification.

Primary dental care should mirror the Primary Health Care Strategy. In order to ensure a dental service with patients at its heart, primary dental care should act as the hub and provide continuity and clear lines of responsibility for oral health outcomes for both the patient and the dental team.

Securing and maintaining oral health early in life is an urgent concern (0-5 age group) and consideration should be given to how this can be achieved in an Irish context.

There is a clear business case for Foundation Training in Dentistry. This is urgent and critical for the development of clinical patient services, better quality care and patient safety as well as both the education and retention of dental professionals.

A copy of the Report will be supplied separately.

The key challenges and actions to be taken are set out in the next section.

## **Integrated Primary and Community Care**

### **Recommendation 1**

**Publish a national oral health strategy with a focus on prevention that ensures oral health care is better integrated and given priority in the overall health care strategy. Appoint a permanent, full-time Chief Dental Officer.**

The National Oral Health Policy is over 20 years old and we have been waiting a considerable time for a new strategy to be published. This is a considerable road-block for oral health care. The strategy should ensure that oral health is integral to general health in the development of policy. It should aim to improve oral healthcare knowledge and personal oral hygiene behaviour with a focus on prevention. In addition, it should ensure the effective use of fluorides through continued water fluoridation. In order to achieve buy in to the strategy there should be enhanced engagement between the HSE, the Department of Health, the Dental Hospitals and the IDA.

According to the World Health Organisation (WHO), oral health is integral to general health and essential for well-being. There is evidence to support the interrelationship between oral and general health, for example severe periodontal disease may be associated with diabetes and heart disease. Many general disease conditions also have oral manifestations that increase the risk of oral disease, which, in turn, is a risk factor for a number of general health conditions. We have found, however, that oral health often gets forgotten or is not prioritised. The IDA is calling for the integration of oral health into the wider healthcare delivery system. The independence of the profession however should be noted and maintained. This independence should not prevent co-operation with other health services in tackling oral health issues.

Best practice examples of the integration of oral health into the overall health care strategy include the 'Lift the Lip Programme' in Cork whereby public health nurses and other general health professionals are trained and encouraged to improve the early intervention, prevention and referral of dental decay in young children. Early childhood decay is one of the most common chronic disease of childhood and is a predictor of dental decay in permanent teeth. IDA believes there is huge scope for primary care healthcare staff to identify high caries risk children, long before these children traditionally access dental services. Referral pathways may also be developed from primary and secondary care institutions for high risk patients. Oral health should also form part of every care plan for adults and children with special needs. Primary and secondary care services need to be developed and expanded throughout the country ensuring equitable access to high-quality services. In addition, IDA has recently started a project involving HIQA and the Irish Gerontology Association to raise awareness of the problems associated with dental decay and oral disease in older patients in the community and in care settings. In order to promote

the message that dentists should be involved in a care plan at an earlier stage in order to avoid dental crises.

A further key area whereby oral health can be integrated into the wider healthcare system is in terms of the risk profiling of patients by dentists to identify and to significantly reduce the impact of systemic disease on oral health and improve general health by reducing the effect of common risk factors. An integrated treatment programme which addresses chronic diseases such as diabetes or other inflammation based chronic conditions and gum disease will lead to better outcomes for the patient. This approach is consistent with the philosophy of the Healthy Ireland policy and would require very limited funding, but we believe it could help achieve transformative improvement in the nation's oral and general health and help achieve unprecedented financial and economic savings.

Significantly greater emphasis on oral health and its link to systemic illness is required in the training of doctors, nurses and related healthcare professionals. There would be considerable benefit to having a mandatory oral health -medicine module on these courses to improve the awareness of systemic links to oral disease and the need for collaboration with in the overall management of patients. Similarly dentists need more training in nutrition, dietary counselling and liaising with medical colleagues. The possibility of making every encounter with a healthcare profession matter in terms of advancing overall health is an achievable one with more interdisciplinary collaboration.

After almost two decades without any Chief Dental Officer (CDO) in office, the Department of Health appointed a half-time CDO on a three year contract in 2013. This post must be filled permanently on a full-time basis to provide advice and leadership in developing and implementing a new oral health strategy which enjoys the support and confidence of dentists, patients and their elected representatives.

## **Recommendation 2**

### **Utilise the role and expertise of dentists at community / primary care level in the management and prevention of chronic disease.**

The mouth is a gateway to the body and is an early warning system for health practitioners. Signs in the mouth indicate trouble in other parts of the body. An oral examination can reveal diseases, general health status and habits such as tobacco and drug use.

Oral diseases share common risk factors with chronic diseases such as heart disease, obesity and diabetes. The Government has stated that tackling chronic diseases is a priority. The evidence to date highlights the need for greater integration of oral health preventive programmes with general health promotion. Dentists are in an ideal position in the

community to diagnose health problems and offer patients advice on reducing the risk factors.

The *Platform for Better Oral Health in Europe* recently issued the following key policy recommendations:

- Recognise the common risk factors for oral disease and other chronic diseases;
- Develop the role of oral health professionals in generic health promotion to address risk factors such as cigarette smoking, poor diet, high alcohol consumption, and sedentary lifestyles.

The World Health Organisation recommends, that when looking at the role of the dental profession in the management of chronic disease, particular emphasis should be placed on the following elements:

- Promotion of a healthy diet, particularly lower consumption of sugars and increased consumption of fruits and vegetables;
- Prevention of oral and other diseases related to tobacco use by involving oral-health professionals in tobacco cessation programmes;
- Prevention of oral-cavity cancer and oral pre-cancer by training oral health professionals in screening, early diagnosis and referral for care, and appropriate interventions on the risks of tobacco use and excessive consumption of alcohol;
- Building of capacity in oral health systems oriented to disease prevention and primary healthcare, with special emphasis on meeting the needs of disadvantaged and poor populations;
- Promotion of oral health in schools, aimed at developing health lifestyles and self-care practices in children and young people;
- Promotion of oral health amongst older people, aimed at advancing oral health, general health and wellbeing into old age.

According to the Central Statistics Office, **43% of adults visit a dentist once a year**. The highest incidence of visits occur in the age groups 34 to 44 (48% attendance rate) and 45 to 54 (47% attendance rate).<sup>376</sup> Dentists are therefore well in an ideal position in the community to play an important role in chronic disease management.

Dentists are usually the first to see the effects of tobacco in the mouth. Dentists are therefore in an ideal position to reinforce the anti-tobacco message, as well as being able to motivate and support smokers willing to quit.

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<sup>376</sup> Central Statistics Office, Quarterly National Household Survey, 2010 Health Module

Dentists can also play a valuable role in health promotion campaigns with respect to the following conditions: osteoporosis, diabetes, renal disease as well as the fact that dentists are often in a position to detect symptoms of many other general health conditions, drug use and a variety of disorders when examining patients.

The key challenges to the move towards comprehensive oral health care are agreeing on a strategy with all the interested parties, the considerable level of funding needed as we are starting from such a low base, driving the momentum to include the necessary interdisciplinary collaboration and the timely training and up-skilling of the professionals involved in implementation.

There needs to be a multi-faceted approach to planning for future national health care including the establishment of an overseeing body or commission concerned with nutrition and lifestyle comprising which would take responsibility for disease prevention in the population focusing heavily on the management of the obesity and sugar epidemic and other related chronic diseases.

This body would have a significant health promotion remit and could be given a legislative arm informing labelling, distribution of calorie -dense products / outlets especially to the younger cohort and a role in overall planning for healthier environments to facilitate the public to take more exercise through e.g. walking and cycling.

A simple example of this would be to put a responsibility on all those receiving State funding e.g. schools, colleges, hospitals, sporting organisations , public amenities to comply with a healthy eating / lifestyle policy and effect this by measures such as removing vending machines or curbing sponsorship by bodies whose product labelling is not consistent with the recommendations of this new body or commission.

This body could be part funded by any sugar taxes should they be enacted.

### **Recommendation 3**

#### **Urgently renegotiate and adequately resource State Dental Schemes**

IDA believes that into the future, eligible adults should continue to have access to dental services through private practitioners. However, the Government must now enter talks with the IDA on a new State dental scheme that is fit for purpose. It is essential that discussions commence sooner rather than later given the great harm that is being done to the oral health of the nation because of the maladministration and inadequate funding of the Schemes at present. We believe a new approach is required and we have outlined this in our recently published report 'Unfit for Purpose' (copy enclosed).

## Background

### Medical Card Dental Scheme

This scheme is currently operated by the HSE and private dentists contract with the HSE to provide care in their own self-funded dental practices. Currently, there are over 1.7 million adults entitled to treatment under the scheme. The scheme was dramatically altered in April 2010 when the HSE suddenly announced crippling restrictions to the Scheme. Up to then, a range of routine treatment was available and studies showed the oral health of patients availing of the scheme had significantly improved since its introduction in 1994.

Treatment available prior to 2010	Treatment Available 2010 Onwards
Biannual Scale and Polish	Suspended
Extended gum cleaning	Suspended
X-rays	Suspended
Fillings	2 per annum in an 'emergency situation'
Root Canal Treatment	In 'emergency circumstances' only
Dentures	In 'emergency circumstances' only
Denture repairs	In 'emergency circumstances' only
Miscellaneous items	In 'emergency circumstances' only
Extractions	<b>Unlimited number provided!</b>

There has been a very significant increase in eligible medical card patients in recent years. As at 31<sup>st</sup> December 2009, the number of patients for dental care stood at 1,478,560, representing 34.87% of the population. As at 31<sup>st</sup> December 2015, the number of patients eligible for dental care stood at 1,734,853, representing 37.43% of the population. So between December 2009 and December 2015, we have seen an increase in eligible patients of 256,293 (17.33%).

Yet while the number of eligible patients has increased by over 17% the amount of treatments funded by the HSE has fallen by 20%. Included amongst the findings below, we see that while the number of patients attending for examinations has increased by 34.6%, the amounts of scale and polish treatments has fallen by 97%, fillings have fallen by up over 33% while surgical extractions have increased by 53% and routine extractions have increased by over 14%. The number of protracted periodontal treatments funded by the HSE has fallen by 80% while the numbers of dentures funded by the HSE has fallen by 15%.

Furthermore, the administration of the DTSS has major difficulties under a range of headings, including reclaim lists, validity of medical cards, validation requirements, administration of claims where 'clinical necessity' is involved, etc. An IDA survey of members who hold DTSS contracts, carried out in March / April 2016, found that 80% of dentists had experienced problems with the operation of the DTSS in the past 5 years, with

35% saying they had experienced considerable or huge amounts of problems. The main problems cited by dentists include:

- Dentists not paid for treatments carried out.
- Patient expecting basic treatment which is no longer available to them.
- Lack of treatments covered under the scheme results in under-treatment of patients.
- The length of time taken to get approval for treatments.
- Not getting paid for pre-approved claims / treatments.
- Refusal for necessary treatments.

In addition, over one-third (36%) of contractors found communication between the HSE and dentists to be poor or very poor.

Two-thirds of dentists have changed the way they are practising dentistry due to the current operation of the DTSS. Explaining the way that their dentistry practice has changed, respondents stated:

- *Emergency patch-up jobs only for DTSS patients, no comprehensive care and this is very damaging to long term health.*
- *Increased extractions because only 2 fillings covered.*
- *Prioritising most decayed teeth over treating caries.*
- *More or less just doing extractions now.*
- *Treatment leaning more towards extractions and provision of dentures than conserving teeth.*
- *Inability to provide the correct treatment.*
- *I'm practising old-style dentistry, extractions, dentures, amalgam etc.*

### **PRSI Dental Scheme**

This scheme is currently operated by the Department of Social Protection. Private dentists contract with the Department to provide the treatment to eligible patients. Currently, 2 million taxpayers are currently entitled to the scheme. The Dental Treatment Benefit Scheme was availed of by 312,659 people during 2015 at a cost of €10.3 million. In 2009, the last year the scheme operated unrestricted, the cost of the scheme was €62.3 million.

The scheme is funded by the Social Insurance Fund which all taxpayers contribute to. In the Budget of December 2009, this scheme was restricted to one item only – the annual oral examination. The contracting dentist is paid €33 for this treatment. There is no charge to the patient. Prior to these cuts, the range of treatment consisted of routine preventive and restorative dental treatment required to achieve and maintain good oral health.

Treatment available prior to 2010	Treatment Available 2010 Onwards
Annual oral examination	Annual oral examination
Biannual Scale and polish	No longer available
Extended gum cleaning	No longer available
Fillings	No longer available
Extractions	No longer available
Root Canal Treatment	No longer available
X-rays	No longer available
Dentures	No longer available
Denture repairs	No longer available
Miscellaneous items	No longer available

### **Absence of State Support for Dental Care**

Dentists are one of the only health professionals that do not receive any financial support from the state. Dentists rely solely on their own self-generated funds to set up in practice and adhere to increasing regulatory costs. Before a penny is spent on caring for medical card patients, GMS doctors in general practice can receive up to €100,000 per annum in grants towards employing nurses, secretaries, practice managers and where they are located in remote rural locations while pension payments are also available to doctors.

Massive state support is provided to dentists in Northern Ireland in the form of grants and pensions which leaves dentists in this state, particularly those close to the border, at a significant disadvantage. To reiterate, dentists in the Republic of Ireland do not receive a single cent toward the running of their practices.

### **Legal Issues**

There are important legal issues which need to be addressed, having regard to competition law, in order for the State Dental Schemes to renegotiated. The Framework of Agreement and Memorandum of Understanding reached between the Department of Health and the Irish Medical Organisation needs to be replicated with the IDA, the sole representative body serving the dental profession.

### **Recommendation 4**

**Eliminate the barriers between primary and secondary oral and dental health care.**

Both the Public Dental Service and dentists in private practice are involved in the delivery of primary care services but due to 'barriers' between primary and secondary care, patients are experiencing problems and delays in accessing services. These barriers include:

- Lack of capacity
- Access issues

- Lack of / confusion surrounding referral / treatment pathways between the private practice dentist and secondary care services
- Lack of clinical protocols
- Lack of structured communications between dentists and the HSE  
IT problems e.g. dentists are not currently involved in the roll-out of 'Healthmail' which is a HSE service that allows health care providers to send and receive clinical patient information in a secure manner. IDA has formally requested that the HSE would roll out the service to dentists to enable them, when the need arises, to securely share patient records with clinicians in the HSE or Voluntary Hospitals.

Currently, the vast majority of Public Specialist care is only available in the area of orthodontics. Other specialist services are delivered to varying degrees throughout the country, but there are severe difficulties in delivering these services (i.e. oral surgery, special needs dentistry etc.) due to the lack of resources. Patients requiring other specialist services are usually referred to the dental schools where there are lengthy waiting lists.

One possible area for future development of the service is the development of specialist care services in areas such as paediatric dentistry, special care dentistry, oral surgery and dental public health, which must be done on a nationwide level. This would lead to simpler journeys for patients as they would not need to leave the service for continued care.

It would also improve the status and profile of the service and aid in the recruitment and retention of staff by providing career pathways in many areas of dentistry. The current burden on the dental schools would also be alleviated, and referral to dental schools could be reserved for the management of more complex cases requiring tertiary care.

For the private patients access to specialist services needs to be improved. The IDA suggests that the number of specialists and specialties needs to be considered as part of a dental manpower review.

## **Recommendation 5**

### **Establish a national Public Dental Service that is adequately funded and staffed**

The HSE Public Dental Service is responsible for children and those with special care needs. It operates the Schools Screening Service which aims to provide targeted screening to children at three intervals during national school (in 2<sup>nd</sup>, 4<sup>th</sup> and 6<sup>th</sup> classes).

IDA believes a properly resourced Public Dental Service should continue to provide dental care to children, adolescents and special needs patients. A properly funded public dental service has the potential to provide excellent value for money.

The PA Consulting Report (2010) commissioned to review the delivery and management of HSE dental services, found:

- The public dental service is essentially 32 local dental services with significant variations in priorities and service interventions... the level of variation in practice means that the service does not add up to a coherent national model of public service.
- It is very difficult to get an accurate picture of what the Public Dental Service (salaried service) is delivering and for whom.
- The service operates with significant operational discretion at local level... public dental services operate as a parallel service stream to other health and social care services; referral pathways between services are unclear in particular between primary and secondary / tertiary services; the patient is not at the centre of how the service is planned and delivered.
- The imminent appointment of a new Oral Health / Clinical Lead is therefore an important development.
- The salaried service is delivering what it can deliver based on current resources rather than what it should deliver based on an agreed national service model.
- There is a strong sense among stakeholders consulted that oral health policy is not prioritised and not on the national radar in the same way as other health and social care services.
- The service is not planned or delivered to reflect evidence-based practice... the service is not delivered on the basis of agreed oral health outcomes.

The Irish Dental Association supports the establishment by the HSE of a national model of publicly delivered dental care and treatment. We don't believe publicly delivered dental care fits within a primary care network structure; instead we believe dental services should be organised on a national basis. This is acknowledged in the PA Consulting.

A national model is favoured rather than a model based on locally managed services with national leadership, subject to the vagaries, whims and preferences of local managers. This model has merely served to exacerbate huge variations in access and extent of dental care and service delivery.

The HSE Public Dental Service is, uniquely, a surgical service. It has specific needs in relation to infection control, radiation safety etc. and with an important acute emergency service component.

The eligibility criteria for dental patients are very different to those employed for medical and other services. Efficient delivery of the dental service cannot be achieved within individual networks though we acknowledge the importance of maintaining and growing links with the other disciplines locally within the network.

There are a number of areas of responsibility where, for example, Principal Dental Surgeons are given devolved authority to ensure compliance with statutory legislation relating to fluoridation and radiology as well as management of the DTSS. These are critical responsibilities which need to be managed in a national model.

For many reasons, we believe that dental care should be arranged as a national oral health service (like mental health, environmental health, ambulance services etc.), comprising primary, secondary and tertiary referral components, and with links to regional networks.

Integration of and within all aspects of oral health is what is required rather than integration with administrative structures though we would envisage formal links with other professions and local managers at a regional level. If there are to be any changes in HSE structures they should only happen when new arrangements are clearly structured and established with appropriate resources.

### **Link to Hospitals**

Also, it is critically important that dental care must have a link to acute hospitals – this has been a huge deficit which has been exacerbated by regionalisation.

Patients will benefit from a national dental service with clear treatment pathways (e.g. oral cancer, oral surgery, latex allergy cases, orthodontics, tertiary referrals to Beaumont and other relevant specialist centres) and better risk management and governance.

We believe that in each tier three acute hospital, there should be a dental department established to manage care and treatments requiring general anaesthesia and also to cater for in-patients requiring dental care and treatment (e.g. patients admitted primarily for cardiology, oncology or orthopaedic care and treatment). This hospital-based service would address the difficulties being experienced nationwide in providing timely treatments for children and special needs patients under general anaesthesia.

In addition, there would undoubtedly be gains in managing the orthodontic waiting list nationally rather than on a regional basis as is the case at present. Operational management on a national level is required to progress and develop these gains for the service and for patients in addition to the strategic direction provided by the national oral health office.

It is essential that the national oral health office is developed to ensure operational management and strategic leadership of the dental service.

We believe there is ample evidence of significant cost savings and efficiency gains where dental care is managed on a national basis and we have highlighted previously many instances of such gains where procurement, dental education and training and ICT roll-out

have been organised on a national basis. There should be no extra cost with any move towards national model but big gains for patient care.

### **Staffing in the Public Dental Service**

The HSE has accepted that the current staffing levels in the public dental service of around 300 are well below levels of up to 387 which pertained in 2008. Increased dental employment levels and appropriately directed staff resource allocation are urgently required in order to achieve a complement of 400 whole time equivalent posts in the HSE public dental service by the end of 2018 in order to address the difficulties apparent in the service and to enable the service deliver on its stated objectives of preventing dental health difficulties, caring for and treating children and other vulnerable groups.

It is commonly accepted that there has been a significant deterioration in the level of service provided and particularly the extent to which preventative care and screening is taking place in schools, with the consequence that children are seeing their dentist for the first time at far too late a stage in their development. International guidelines suggest that children should have their first dental examination by their first birthday. For most children in Ireland, their first scheduled encounter with the public dental service is at age seven or eight and for many, they are seen by a dentist for the first time, under the school screening programme, in sixth class; age twelve. This absence of a preventative strategy in the critical early years means that for many children their first encounter with a dentist is in pain at an emergency visit.

The services for patients with special needs are similarly under severe pressure. Many of these patients require treatment to be delivered under general anesthetic. In some areas, the waiting list for treatment under general anesthetic is two years or more.

### **Recommendation 6**

**Implement the recommendations contained in the 'National Clinical Programme for Paediatrics and Neonatology model of care for paediatric healthcare services in Ireland' as follows:**

- There is a significant unmet dental treatment need for severely medically compromised children, children with significant intellectual / developmental / behavioural / psychosocial disabilities, children with complex inherited and acquired dental conditions and children with complex dental trauma who require treatment in a paediatric hospital. An increase from 2WTE to 6WTE consultant paediatric dentists is required at the new children's hospital.
- The appointment of consultant paediatric dentists at secondary care level in the regional paediatric units is strongly recommended to allow planning, organisation and provision of a coordinated paediatric dental service for children throughout the country in collaboration with the community primary care dental services.

- To support this model, the training of paediatric dentists should be prioritised.
- The integration of primary, secondary and tertiary care dental services with the National Clinical Programme for Paediatrics and Neonatology would be envisaged as an important component of the design of such a multidisciplinary team service model.
- Data concerning all children who are awaiting, and who have, dental treatment provided under GA in public hospitals must be recorded on the inpatient and day case waiting lists and on the HIPE system.
- Data concerning the number of children who are treated under GA in the private sector on referral (with funding) from the HSE dental services, and procedures undertaken, should be recorded to inform future development and planning of a national dental service for children.

### **Background**

According to HIPE figures from the draft 'National Clinical Programme for Paediatrics and Neonatology model of care for paediatric healthcare services in Ireland', in 2012 there were 8,601 inpatient dental procedures carried out on children under 15 years of age. The number of procedures carried out on children is second only to ENT surgery. However, the report states that the dental figures do not count minor surgical procedures under local anaesthetic, many GA dental procedures that are not recorded on HIPE (such as the 3,000 plus children treated each year in the St James' Clinic prior to its closure) or about 1,000 children per year who are treated in the private sector.

The draft report states: "Unfortunately, much dental activity under general anaesthesia (GA) is not recorded on HIPE, so the recorded figure likely represents a gross under-representation... The lack of accurate HIPE data leads to underfunding of services".

In a survey carried out in October 2015, difficulties in arranging access to secondary care emerged as the single greatest cause of stress to IDA members employed by the HSE. The shocking nature of many of the individual case histories highlighted at the 2015 IDA Public Dental Surgeons conference, including stories of delays in treatment for very young children in extreme pain and with severe infection, explained this anxiety amongst dentists trained to care for and to treat children. Figures sourced by IDA, estimate that there were 2,500 children and special needs patients on waiting lists for dental procedures - mainly extractions under general anaesthetic – in October 2015. Most were waiting in excess of six months and many had been waiting for around 12 months. The closure of the out-patients GA Extraction Clinic at St James' Hospital in Dublin on 1st October 2014 has had a significant impact on this issue. Over 3,000 children were treated in this clinic annually. The problem is further compounded by the fact that dental cases are not included on hospital priority lists, and this results in theatre slots for dental cases being cancelled on a regular basis in favour of other paediatric cases.

While a limited number of theatre slots have been sourced in the private sector, there are hundreds of children awaiting "emergency" treatment. These children are suffering needless hardship, pain, enduring ongoing sepsis, requiring repeated courses of antibiotics and are at risk of serious, potentially life threatening complications. It is incomprehensible that a so called first world country allows its youngest and most vulnerable citizens to suffer in this way.

**Recommendation 7**

**Tackle the crisis in Orthodontics.**

**HSE Orthodontic Service**

The Orthodontic Service in the HSE is hugely suffering as a result of the cutbacks and the moratorium on recruitment which have led to the creation of long waiting lists for screening and for treatment. In some areas hundreds of patients have been waiting for treatment for more than four years.

**Orthodontic Waiting List Q4 2015**

Waiting time from assessment to commencement of treatment	Less than 2 years	2 to 4 years	More than 4 years	TOTAL
HSE Dublin Mid-Leinster	3,174	1,577	447	5,198
HSE Dublin North East	1,707	1,327	466	3,500
HSE South	2,483	1,364	164	4,011
HSE West	2,193	901	27	3,121
Total	9,557	5,169	1,104	15,830

We believe there is a clear need to publish in the first instance the report commissioned by the HSE on Orthodontic Care and Treatment as an important first step in debating how best to tackle these persistent difficulties.

**Recommendation 8**

**Urgently publish the new Dental Act.**

The imminent drafting of the new Dental Bill represents an opportunity to make a meaningful difference to the lives of patients by ensuring oral health is made a priority in this country. The continued delay and lack of action regarding publishing the new Dental Act is a road block to achieving the highest standards of modern dentistry. We support the introduction of the types of changes introduced for medical, pharmacy and nursing professions. However, lessons need to be learned from the changes introduced for the

medical profession and the mistakes evident in the legislation introduced for other professions should not be repeated.

We would emphasise that urgent attention is required to address the following:

- **CPD** – To enhance patient protection we call for the introduction of a mandatory CPD Scheme – with appropriate supports and protected time - similar to most other professions.
- **Inspection and standards** – we support the introduction of licensing of dental practices. Support for practices will be needed and the model of inspection should be the subject of extensive discussion with the profession. We believe that the power of any inspections to be introduced should be held by the Dental Council rather than having a second regulatory body given regulatory authority to uphold and enforce standards.
- **Foundation Training** – we call on the Minister for Health to support a properly resourced Foundation Training Scheme in Dentistry. This needs to be afforded priority to ensure graduates from the Irish dental schools are not disadvantaged in seeking access to practice in the UK where a Foundation Scheme is being introduced and which will be a pre-requisite for NHS practice.
- **Incorporation** – we support the repeal of the current prohibition on the incorporation of dental practices. This would allow a level playing pitch with dentists in Northern Ireland.
- **New roles for Hygienists and Therapists** – we recognise the role that can be played by hygienists and therapists but we believe that clear understandings must be set out as regards the scope of practice for hygienists and therapists. Direct access to hygienists does not make sense.
- **Recognition for Dental Specialists** - recognition of a greater number of specialist divisions beyond oral surgery and orthodontics. In all the other common law jurisdictions where medical and dental professionals commonly pursue their training and travel to practice and advance their knowledge (UK, US, Canada, Australia and New Zealand), the number of dental specialities ranges between nine and thirteen. Equally, in all these jurisdictions there is a recognition of the continued entitlement of general dental practitioners to provide aspects of care which are provided by Specialists provided they possess the necessary skills, expertise and experience.
- Recognition of dental specialties encourages scientific advancement, promotes innovation and the highest standards of care and rewards education and achievement; all of which serve to promote the highest standards of dentistry.

## **Models of Funding**

The Association does not have any preference as regards the health service funding model deemed best suited to Ireland. We would draw the Committee's attention to the comprehensive analysis contained with the report of the Expert Group on Resource Allocation and Financing in the Health Sector (July 2010) published by the Department of Health & Children.

The three key messages in the report are –

1. Ireland needs a system of integrated planning for all aspects of healthcare covering National Policy setting and local delivery, standards of care and clinical pathways, capital and current spending, public and private delivery in the Primary, Hospital and Community and Continuing Care sectors.
2. Our current Medical Card System could be developed in a matter which would increase systematically equity of access, and promotes the use of safe and cost effect care. The pace of development depends on the rate on which resources can be made available.
3. It is possible to improve resource allocation within and across the Primary, Hospital and Community/Continuing care sectors, supporting cost effectiveness and improved quality of care. Central to this is the incentives of both patients and providers are in line with stated healthcare objectives.

The Report goes on to say that changes could be made to the current system which could do more to promote equity and fairness, support quality of service, generate clear accountability and facilitate a greater focus from the patient. **We believe that the analysis and approach set out in this report still holds.** Furthermore, the Report identified the main characters of a quality healthcare financing system as equity and fairness, transparency, promotion of good attitudes to care, consistency with policy objectives and sustainability.

In more recent times, we have seen advocacy of the introduction of Universal Health Insurance. It is clear that the cost implications of introducing Universal Health Insurance were significantly greater than anticipated and we believe the appetite at political level for such an approach has been severely diminished in recent times.

However, it is interesting and worth bringing to the attention of the Committee that in fact a Universal Health Insurance model has been in operation for over half a century in regard to dental care and treatment. Specifically, we refer to the Dental Treatment Benefit Service (DTBS), or the PRSI dental care system as it is more popularly known. Until 2010, this model offered access to prescribed dental treatments for over 2million eligible citizens and their dependants according to clearly set out criteria. It operated on the basis of the State fully meeting the costs of certain treatments, offering grand in aid for other treatments, while it also involved a form of co-payment by patients. We believe that this model operated far more successfully in dentistry than the alternate medical card system, i.e. the Dental

Treatment Services Scheme, or Medical Card scheme, albeit that the DTBS was subject to brutal assault with the wipe out of all benefits other than the annual examination in 2009. We believe that the DTBS model is one which deserves careful scrutiny and suggest that this could be usefully examined further with a view to its more widespread application within and beyond dentistry.

It is clear to the Association that any suggestion of expansion of publicly managed and delivered dental care in primary care i.e. the concept of general practitioners becoming employees of State agencies, is neither feasible nor desirable. The complexity of treatments and the significant cost of treatments provided to the population generally and the paltry support offered by the State at present are such as to render such a concept redundant, absent a huge increase in direct taxation to the extent that we believe would not carry public support.

Equally, we believe that the independent contractor model operates successfully in private practice rewarding as it does significant innovations and productivity and without being subject to excessive operating costs which can apply in a direct employment model.

As regards the entitlements that patients ought to be provided in the funding model we refer you to the treatments which were previously available and covered fully or partially under the DTBS up to 2009 and which are listed elsewhere.

<http://www.dentist.ie/>

## Irish Farmers Association

Timely access to healthcare services is critical for rural areas as it is for urban areas. Rural populations should be able to conveniently and confidently use services such as primary care, dental, emergency, and public health services. However, those living in rural areas have seen a significant decline in health service provision in recent years.

Geographical remoteness must be considered in making decisions regarding service delivery. Service needs must be evaluated in the context of required travel time under varying and sometimes less than ideal seasonal weather conditions. Planning for either local provision of care or rapid patient transport must be guided by medically accepted standards for timely intervention.

### Key Issues

#### Private Health Care

General practice is the corner stone of primary health care in rural Ireland. The reduction in the number of rural GPs, as older GPs retire and are not replaced, is having significant implications on access to healthcare for rural populations. There is strong evidence to suggest that increased distance to health services has a profound effect on utilisation, which would reduce identification of risks and put increase pressure on the healthcare system in the long-term. Also research shows that older rural people will visit their GP more often than older urban people, whereas they are less likely to visit hospital as an outpatient.

***IFA propose that measures are introduced to support rural general practice to ensure that further inequality of access and quality of healthcare is not created.***

#### Service for Older People in Rural Ireland

Older people in rural areas are particularly disadvantaged in accessing health care services in comparison to urban areas. Day care, long-term care, and longer waiting times for emergency ambulance services are all core issues for older rural residents. For those with ill health and low income, lack of transport to services can be a barrier attending health appointments and means they rely more heavily on their local GP.

#### Home Care Package

The Home Care Package is providing a valuable support and social contact that allows older people to stay in their own homes for longer.

***IFA proposes that there is a review of the Home Care Package to increase the number of hours allocated and to expand times to include evening and night support to help to prolong living at home.***

#### Accident and Emergency

There is a serious concern amongst older people about attending A&E, due to fear of being overlooked or abandoned

#### Integration of Health Care Services

Health Service plans need to engage with communities to identifying priority health service gaps. Service plans must be integrated across the current silos of services, and designed to meet the health care needs of rural areas. The best and most cost-effective outcomes for patients are achieved when health care professionals work together and learn together to ensure progress in practice and service.

Technology needs to be adopted to develop a “one person, one record” health record to reduce inefficiency and risk of error in patient care.

***IFA proposes that rural communities are engaged to develop a cohesive and integrated management system, which uses technology to deliver a cost effective and efficient health service.***

#### Mental Health Services

Accessing mental health services is a major challenge for many rural community. There are limited mental health services available locally both in primary and acute health care settings. Rural families have difficulty accessing services particularly in the crisis and often have to travel to find mental health therapists or psychiatrists available.

Suicide is a major public health issue in rural Ireland. It is estimated that 13% of those who die from suicide in Ireland come from an agricultural background.

There is a pressing need to develop early identification and intervention capabilities, particularly for young and elderly people. Mental health services are especially important where elderly people suffer from dementia and other mental health illnesses that require complex support.

***IFA proposes increased access to counsellors and psychiatry services in rural communities, either by resident or visiting service providers or via increased use of tele mental health services.***

#### **Funding Model**

##### The Fair Deal Scheme – Removing the discrimination against farm enterprises

IFA recognises the very positive aspects of the Nursing Home Support Scheme, but has concerns about the negative impact on farm families in meeting the costs of care, in particular the potential impact on the viability of the farm business for the next generation. IFA strongly supports and encourages the lifetime transfer of family farms; however, it is clear since the implementation of the scheme that there are difficulties arising with the costs of care where the asset has not been transferred, or where it has been transferred, but within the previous 5 years. The assets farmers and other self-employed family businesses have are productive assets and are required to generate income. They are not a measure of additional ability to pay.

The current financial assessment system has the greatest negative impact on lower income farms, where any further dilution of the asset value could render the farm business asset non-viable for future generations.

***IFA is very supportive of the Fair Deal Nursing home scheme but is clear that the contribution to the cost of care must be immediately reviewed and amended to reflect the ability to pay of the family farm. This would allow farm families to make the most appropriate decisions in meeting the cost of care.***

##### Extending the Fair Deal Scheme to community based services

IFA welcomes the proposal to extend the ‘Fair Deal’ Scheme to home help packages, which could potentially enable people to stay for longer within their own home, with outside assistance. The majority of people and their carers would find this situation preferable. The proposal to extend the Fair Deal scheme to Community Based services could result in an improved model of care, and in potential savings for both the individual and State.

However, in advance of this, a resolution must be found to remove the discrimination against farm enterprises and other small businesses that arises from the existing asset test in the financial assessment for the Fair Deal scheme.

***IFA is clear that the private contribution to the costs of care, whether for nursing home or community-based care, must be proportionate to the ability to pay, and must not result in the future viability of the family farm being undermined.***

<https://www.ifa.ie/>

## Irish Heart Foundation

The Irish Heart Foundation (IHF) welcomes the establishment of the Oireachtas Committee on the Future of Healthcare to support the Oireachtas adopting a 10-year plan for healthcare. The development of a 10-year plan is an important opportunity to end the two-tier health system and move Ireland towards a health and social care system based on need and not on ability to pay.

The IHF is a founding member of the Health Reform Alliance. Alliance members share a common belief that reform is needed to create a more equitable system. We have developed a consensus on the five principles<sup>377378</sup> to underpin reform. The IHF supports the submission made by the Alliance to this consultation. While all patients would be better served by a universal system, which reflected the HRA principles, this submission comments on issues of particular relevance to people with cardiovascular disease (CVD).

As a patient organisation our only interest is in the outcome and experience of patients using the health and social care system. Many CVD patients use medical, rehabilitation and social care services concurrently. Currently, different cost structures for different elements of care lead to complicated patterns of use and unintended interactions between different elements of the system, for example between primary and hospital care.<sup>379</sup> If the objective is to achieve equitable access determined by need, then complex eligibility criteria must be avoided in the future system.

### Summary of issues addressed in this submission

- Chronic disease management, which will be the primary task of the system, requires integration of health and social care.
- It is essential to review the gaps in current chronic disease service provision and develop these services. In particular, develop a network of step-down, social care and community services adequate to meet demand.
- The primary task for reform is to define the system of universal access and define what services will be provided. The financing system is secondary to the objective of delivering universal access but is an important tool to develop integrated services.

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<sup>378</sup> The five key principles set out by the Health Reform Alliance for reform of our health and social care systems are:

1. The health and social care system treats everyone equally.
2. The health and social care system is focused on the needs of all social groups in society.
3. People have an entitlement to health and social care, free at the point of access.
4. The different elements of the health and social care system work together and are connected.
5. The health and social care system is a universal, publicly funded system.

<sup>379</sup> Smith, S. (2009) Equity in Health Care: A view from the Irish health care system. Dublin: The Adelaide Health Foundation.

## Recommendations

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- Begin by focussing on the outcome to be achieved - the healthcare system to be delivered by 2026 and the level of universality which the system will deliver. The financing system is secondary to the objective of universality.
- There is a need to fully articulate the vision for healthcare to the public who will be the users and the payees for the system. To achieve public buy-in at an early stage for reform, the Oireachtas should clearly set out the reasons why the final selected model of universality and funding best fits Irish needs and its advantages over alternative approaches.
- Protect the health budget in the short term and return to pre-crisis funding in the medium term.
- Assess the cost of introducing health reform and set aside a reasonable set-up budget.<sup>380</sup>
- Prioritise integrated care to ensure proper management of chronic diseases, including CVD, as chronic diseases will increasingly be the main focus of the system. The system of chronic disease management must be carefully designed, with reference to patient needs and to a system of financing which will support integrated care.
- Review gaps (including geographical and by population) in current service provision and develop these services. In particular, develop a network of step-down, social care and community services adequate to meet demand. Continue the focus on reducing the waiting lists to access community and acute services. Rehabilitation is an important service for patients following a stroke or a cardiac event and the IHF would welcome universal access to these services, which are currently under-funded or unavailable in many parts of the country.
- Include a strong patient advocacy element in the reform programme to ensure all reforms focus on the quality of care.
- Ensure regulators (HIQA, Patient Safety Agency, etc.) are properly resourced and provide quality standards for the full range of care.
- Use existing and forthcoming research on the Irish health and social care system, particularly the Economic and Social Research Institute's (ESRI) health systems research and Trinity College Dublin's 'Mapping the Pathways to Universal Health Care in Ireland' project.

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<sup>380</sup> The lack of set-up funding for health reform to date can be compared with the reported €180 million provided for the establishment of Irish Water (for example, see Irish Independent, 14 January 2016 <http://www.independent.ie/blog/irish-water-total-set-up-costs-will-be-180m-29916070.html>).

## Cardiovascular disease and the current health system

Recent developments in healthcare treatments and our ageing population mean that healthcare provision now primarily focuses on the management of chronic diseases and particularly on older patients with a combination of chronic diseases. It is essential that the reformed system is built around a proper system of chronic disease management. The IHF is primarily concerned with how the CVD patients we represent, many of whom have multiple care needs, will be served by the reformed system.

Between 1985 and 2000, deaths from CVD in Ireland almost halved, with 44% of the reduction attributed to more effective treatment and a greater impact from improvements in population-level risk factors.<sup>381</sup> However, the prevalence of CVD risk factors continues to change, including obesity rates. The Institute of Public Health has estimated that due to the ageing population and increases in population overall there will be considerable increases in CVD by 2020.<sup>382</sup> Further, as life expectancy increases, people are living longer with CVD, requiring community-based care and supports.

The OECD (2015)<sup>383</sup> has identified a number of significant challenges for countries seeking to reduce CVD: rising levels of CVD risk factors, including obesity; delays in diagnoses of CVD risk factors; lack of adherence to treatment; ageing population leading to more complex health needs; and gaps in timely access to specialised care. All of these challenges are apparent within the Irish system. In Ireland, the Expert Group on Resource Allocation for the Health Sector<sup>384</sup> outlined the conditions required to establish integrated care for chronic diseases in Ireland, including: formal links [which would likely include formal financing mechanisms] between the primary care system and wider healthcare system; primary care would be seen as a core component of healthcare, rather than as a parallel system to hospital care; primary care would become the centre of chronic disease management, with patients only engaging with hospital for short periods as required; and patients would be incentivised (through free primary care at the point of access) to default to primary care for their health needs. For cardiovascular patients, the *National Cardiovascular Health Policy*<sup>385</sup> makes a number of recommendations in relation to chronic disease management, including the requirements for primary care, the need for implementation of the ESC Clinical Practice Guidelines, information systems, audit and development of cardiac rehabilitation.

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<sup>381</sup> Bennett, K., Kabir, Z., Unal, B., Shelley, E., Critchley, J., Perry, I., Feely, J., Capewell, S. (2006). Explaining the recent decrease in coronary heart disease mortality rates in Ireland, 1985–2000. *Journal of Epidemiology and Community Health*, Vol 60, pp322-327. <http://jech.bmj.com/content/60/4/322.abstract>

<sup>382</sup> For example see, Institute of Public Health (2012) 'Chronic Heart Disease Briefing'. [http://www.publichealth.ie/sites/default/files/documents/files/CHD\\_Briefing\\_26\\_Jun\\_2012.pdf](http://www.publichealth.ie/sites/default/files/documents/files/CHD_Briefing_26_Jun_2012.pdf)

<sup>383</sup> OECD (2015) *Cardiovascular Disease and Diabetes: Policies for Better Health and Quality of Care*. Paris: OECD Health Policy Studies, Publishing. DOI: <http://dx.doi.org/10.1787/9789264233010-en>

<sup>384</sup> Department of Health and Children and ESRI (2010) *Report of the Expert Group on Resource Allocation and Financing in the Health Sector*. [http://health.gov.ie/wpcontent/uploads/2014/03/resource\\_allocation\\_report\\_hiRes.pdf](http://health.gov.ie/wpcontent/uploads/2014/03/resource_allocation_report_hiRes.pdf)

<sup>385</sup> Department of Health (2010) *Changing Cardiovascular Health - National Cardiovascular Health Policy 2010-19*. [http://health.gov.ie/wp-content/uploads/2016/04/changing\\_cardiovascular\\_health.pdf](http://health.gov.ie/wp-content/uploads/2016/04/changing_cardiovascular_health.pdf)

## Experience of stroke survivors to illustrate issues experienced by CVD patients in current system

This section briefly outlines how stroke survivors currently fare in accessing essential medical, rehabilitation and ongoing care services. Their experience are likely to be similar to other patients with chronic diseases.

In the acute setting many stroke patients are faced with under-resourced acute stroke services. The 2015 national audit of stroke services<sup>386</sup> shows that only 29% of stroke patients are admitted to a stroke unit and almost half do not receive any treatment in a unit during their hospital stay. Nearly a quarter of hospitals providing acute care do not meet minimum organisational standards and three of these do not have any of the infrastructure in place required for a stroke unit. In addition, there are staffing deficits of 50% for physiotherapists, 61% for occupational therapists and 31% for speech and language therapists, whilst only 44% of hospitals have any access to a medical social worker and 19% have access to a neuropsychologist.

Rehabilitation after stroke is insufficient for the vast majority of patients, resulting in disability that is unduly severe or prolonged for many people trying to rebuild their lives after stroke. The 2014 Stroke Rehabilitation in Ireland report<sup>387</sup> conducted for the IHF and HSE found poor resourcing of inpatient and community rehabilitation for stroke survivors in Ireland. There is great variability in the availability of therapy staff and the intensity with which therapy is delivered across regions, hospitals and residential and community care settings. The report estimated that over half of all stroke survivors – more than 3,000 people a year – could benefit from Early Supported Discharge (ESD), a six week programme providing therapy in people's own homes rather than hospital. Such programmes represent a basic form of care internationally and would free up 24,000 bed days, resulting in annual net savings of from €2 to €7 million. Implementing ESD would require a substantial increase in the resourcing of community therapists, community nurses and other community care above current levels. However, savings from the reduced cost of acute bed days could fund this increase in resourcing.

When stroke patients leave hospital they are faced by a widespread dearth of vital services to support them to continue their recovery, including community rehab teams, homecare packages, housing adaptations and ongoing care. The *National Survey of Stroke Survivors*<sup>388</sup> conducted by the RCSI and IHF showed major deficits in community rehabilitation services to help survivors overcome the physical impact of stroke with just half having access to any speech and language therapy, or occupational therapy and one in three survivors who require physiotherapy getting none at all.

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<sup>386</sup> McElwaine, P., McCormack, J. and Harbison, J. on behalf of the National Stroke Programme Audit Steering Group. *Irish Heart Foundation/HSE National Stroke Audit 2015*.

[http://www.stroke.ie/media/pub/strokereports/ihf\\_hse\\_national\\_stroke\\_audit\\_2015\\_\\_web\\_version.pdf](http://www.stroke.ie/media/pub/strokereports/ihf_hse_national_stroke_audit_2015__web_version.pdf)

<sup>387</sup> Wren *et al.* (2014) *Towards Earlier Discharge, Better Outcomes, Lower Cost: Stroke Rehabilitation in Ireland*. Dublin: ESRI / Irish Heart Foundation.

[https://www.esri.ie/publications/latest\\_publications/view/index.xml?id=4071](https://www.esri.ie/publications/latest_publications/view/index.xml?id=4071)

<sup>388</sup> Horgan, F., M. Walsh, R. Galvin, C. Macey and C. Loughnane (2014). *National Survey of Stroke Survivors 2013: Experiences and long-term needs reported by stroke survivors living in the community in Ireland*. Dublin, National Disability Authority/ Irish Heart Foundation.

## Consultation questions

### Strategy

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#### What are the key strategies for inclusion in a ten year plan for the health service?

The IHF recommends the Committee initially focuses on the content of the ‘universal single tier service’ to be achieved. The first step must be a clear definition of universality for the Irish system. To achieve a universal system for Ireland the plan should focus on: removing financial barriers to care through use of pooled funds; defining the services which will be financed by the fund and the breadth of coverage of the population; and defining the limits placed on out-of-pocket payments.<sup>389</sup> The funding model is the vehicle through which the universal system will be delivered.

#### What are the key challenges, in your view, to achieving a ‘universal single tier health service where patients are treated based on health need, rather than ability to pay’?

The key challenge will be to develop a definition of universality for the Irish system. The WHO framework<sup>390</sup> defines universality in terms of three dimensions – population coverage, service coverage and cost coverage (proportion of costs covered) – and is rooted in the use of pre-paid pooled funds to remove barriers to care at point of access. Reflecting the position of the Health Reform Alliance, we consider that the services covered should include curative, rehabilitative, long-term nursing, ancillary and prevention services as well as medical goods. The services should be free at the point of access, of good quality and measured against agreed quality indicators.

#### What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?

In order to meet the needs of our ageing population and the number of people living with CVD and other chronic diseases, social care must be integrated with the health system so that people can be treated in the most appropriate setting.

Reform of the health system should put health promotion and prevention of CVD and chronic disease at its core. The 10-year plan should incorporate targets for health status, risk factors, mortality, morbidity and increases in healthy life years.

Commit to addressing health inequities as part of the Committee’s 10-year plan. Currently, there is no reference to reducing health inequities within the Committee’s terms of reference. Reducing health inequities should be a major target of the 10-year plan. Poverty directly effects health, reduces access to healthcare services and makes it harder for people with low incomes to lead healthy lives. As a result, people in the most deprived areas have the lowest life expectancy (CSO,

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<sup>389</sup> See WHO re movement to universal health coverage - WHO (2015) *Health System Financing - the path to universal coverage*. [http://apps.who.int/iris/bitstream/10665/44371/1/9789241564021\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/44371/1/9789241564021_eng.pdf)

<sup>390</sup> World Health Organisation - universal coverage - three dimensions. [http://www.who.int/health\\_financing/strategy/dimensions/en/](http://www.who.int/health_financing/strategy/dimensions/en/) (Accessed 23 August 2016).

2010).<sup>391</sup> In relation to CVD, coronary heart disease is almost 2.5 times more prevalent and stroke 2.2 times more prevalent in the most deprived areas than in the least deprived areas.<sup>392</sup>

## **Integrated primary and community care**

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**What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?**

Following years of policy commitments, primary care services need to be developed and resourced. Eligibility for primary care services should be universal.

The Adelaide Health Foundation's analysis on Integrated Healthcare<sup>393</sup> makes a number of recommendations about how better integration may be achieved between different levels of the health and social care systems. Many of these recommendations particularly relate to the care of chronic diseases.

**What are the key barriers to achieving this, and how might they be addressed?**

One of the major barriers to chronic disease care in the current system is the separation of the health and social care systems with entirely separate budgetary and decision-making processes. While health need is to some extent met in the public system, social care is primarily viewed as an individual responsibility subject to heavy means-testing. Access to social care systems is mixed with some services being free, some being charged for and some being means-tested. Consequently, vital social care services are increasingly available only to those with the highest needs and lowest incomes, rather than as a universal service supporting the whole population.

**In your experience, what are the key roadblocks you encounter in your particular area of the health service?**

The fundamental building blocks of a primary care-led single tier system, community and continuing care, have significant gaps in their infrastructure.

In the current system a person's diagnosis often determines the financial support received for their care. For example, if you require rehabilitation after stroke, or social care supports for your dementia, this is not as available as medical care would be for other conditions, even though your need for care is equivalent. This is particularly the case for people whose disease requires social care input - such as home care packages - to stay well.

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<sup>391</sup> Life expectancy is correlated with a person's social class, the affluence of the area in which they live and educational attainment. People with disabilities and carers also die younger, as do single persons and those who are widowed and divorced.

<sup>392</sup> Balanda, K. *et al.* (2010). *Making Chronic Conditions Count: Hypertension, Stroke, Coronary Heart Disease and Diabetes*. Dublin: Institute of Public Health in Ireland.

<sup>393</sup> Darker, C. (2014) 'Integrated healthcare in Ireland – a critical analysis and a way forward'. Dublin: Adelaide Health Foundation. <http://www.adelaide.ie/files/Integrated%20Healthcare%20in%20Ireland.pdf>

Further, people are treated differently depending on their insurance/medical card status. Patients going through the public system are often subjected to waiting lists and delays, while those with greater resources and health insurance get faster treatment often on public hospital sites. As the medical card system has developed it has become a 'passport' required for people to access certain entitlements, including health (e.g. primary care therapists, public health nurse, etc.) and non-health services. A medical card gives access to many services which are unavailable to patients without a medical card, such as public health nurses. These services should be available to all those who have medical and/or income needs. This blockage can be overcome through provision of universal access to healthcare, as is envisaged by the Committee.

Access to social care supports (e.g. home-care packages, home help and meals on wheels) is subject to budget caps. This means that access to social care will depend on the resources that are available locally.

Receiving care in the community is the preference of most people and is also the stated policy of Government. The statutory provision of Fair Deal, in tandem with the 'discretionary' basis of home care supports, has inadvertently prioritised long term residential care over home and community care.

Cuts in funding have further restricted access to health services through the closure of hospital beds, longer waiting lists and reductions in frontline staff. Austerity has also led to significant increases in the charges patients must pay to access health and social care.<sup>394</sup>

There is a lack of data on quality measures and patient outcomes, which is vital to ensuring quality of care, monitoring costs and planning for future health needs. Patient registries which operate across all healthcare settings are required to ensure effective service planning and quality care for patients across the healthcare system. Given the volume of CVD patients in the system there is a pressing need for the establishment of either a combined CVD register, or separate registers for acute coronary syndrome, stroke and heart failure. The current stroke register in hospitals receives no dedicated funding and operates in about two-thirds of hospitals in addition to the official duties of overworked stroke care teams. Meanwhile national stroke services have recently been audited for just the second time ever. On both occasions the national audit could not have been undertaken without funding from the IHF.<sup>395</sup>

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<sup>394</sup> Thomas, S., *et al.* (2014) 'The Irish health-care system and austerity: sharing the pain'. *The Lancet*, 383 (3), 1545-6.

<sup>395</sup> Irish Heart Foundation (2008) *National Audit of Stroke Care*. Dublin: Irish Heart Foundation [https://www.irishheart.ie/media/pub/strokereports/ihf\\_stroke\\_audit\\_final.pdf](https://www.irishheart.ie/media/pub/strokereports/ihf_stroke_audit_final.pdf) and McElwaine, P., McCormack, J. and Harbison, J. on behalf of the National Stroke Programme Audit Steering Group. *Irish Heart Foundation/HSE National Stroke Audit 2015*.

## 1. Funding model

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Do you have any views on which health service model would be best suited to Ireland?

A universal system free at the point of access paid for by all through pooled funds. All those using the system would contribute to costs through taxation or social insurance but would receive care free at the point of access. The ESRI's 2015 review of UHI<sup>396</sup> estimated that 77% of healthcare expenditure came from general taxation in 2013; 9% from insurance and 12% from out-of-pocket payments.

**Specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating**

The funding model must be progressive, based on ability to pay and the State, through transfers, must ensure that healthcare is affordable for low income groups.

The IHF would caution against the use or retention of co-payments within the reformed system. Equity in healthcare provision comes from the separation of payment from the receipt of care. Co-payments are a regressive form of financing and are damaging to health because they discourage necessary use by patients. Co-payments put the focus for overuse of care on the patient, rather than on the medical professionals, who should be in a position to properly apportion care according to medical need. Co-payments can also increase the administration costs of a system.

**What are the main entitlements that patients will be provided under your funding model?**

Design a system which responds to the health and social care needs of people with chronic disease. People with chronic conditions and older people need access to care, whether that care be for medical services, or care to live in their own home with dignity. In a society where we are increasingly called to care for people with multiple morbidities the differences in entitlement to health and social care services no longer appear appropriate, or fair.

We would advise that the mechanism used to define the services covered in the universal system be carefully considered. The development of a 'health basket' is a just one approach which can be taken. Some argue that having a set package from the outset is a limiting approach which may not be responsive to patient's needs. For example, the NHS does not have a formalised 'basket' of care, instead the National Institute for Clinical Excellence (NICE) develops evidence-based practice guidelines to guide NHS service delivery.<sup>397</sup> Setting out a defined universal health basket would be a

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<sup>396</sup> Wren, M.A., Connolly, S. and Cunningham, N. (2015) *An Examination of the Potential Costs of Universal Health Insurance in Ireland*. Dublin: ESRI. <https://www.esri.ie/pubs/RS45.pdf>

<sup>397</sup> See National Institute for Clinical Excellence <https://www.nice.org.uk/about/what-we-do> and <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/types-of-guideline>. In Ireland, the National Centre for Pharmoeconomics plays a role in terms of determining which drugs are cost effective. Further, the National Clinical Effectiveness Committee is developing national clinical guidelines for healthcare in Ireland. <http://health.gov.ie/patient-safety/ncec/> and <http://health.gov.ie/patient-safety/ncec/national-clinical-guidelines-2/>. HIQA also develops guidelines for certain service types <https://www.hiqa.ie/standards/healthcare>.

major exercise and would need to be continually updated to consider changing technology and evidence.

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**For further information contact:**

**Cliona Loughnane, Policy and Research Manager**  
**Irish Heart Foundation, 50 Ringsend Road, Dublin 4**  
**[cmccormack@irishheart.ie](mailto:cmccormack@irishheart.ie) (01) 6685001**  
**<https://www.irishheart.ie/>**

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## Irish Hospital Consultants Association (IHCA)

The Irish Hospital Consultants Association (IHCA) represents 85% of hospital consultants working in Ireland. The Association welcomes the opportunity to make a submission on the future provision of healthcare in Ireland and looks forward to further engagement with the Oireachtas Committee in this regard.

The necessity to comply with the Committee's deadline for receipt of submissions means that this document and its contents have not yet been approved by the IHCA National Council. The National Council will review the submission at its next meeting and the Association will correspond with the Committee thereafter as necessary.

### Executive Summary and Recommendations

The existing governance arrangements in the health service need to be strengthened significantly to be fit for purpose and to enable the development of an integrated, effective and efficient health service in Ireland. To be successful the long term plan and strategy must be properly resourced taking account of present and future anticipated levels of demand.

Appropriate governance together with proper resourcing can eliminate the existing critical capacity constraints that are restricting the provision of timely, high quality healthcare to an increasing number of patients.

The following summarises this submission's key recommendations. The first five bullets address strategic priorities. The remainder address the other questions set out in the consultation guideline.

- **Strengthened Governance:** A clear set of measures are required to strengthen hospital, hospital group, CHO, HSE, corporate and clinical governance arrangements to ensure that they represent best practice and are fit-for-purpose. In particular, it is essential that the current focus of governance is rebalanced to facilitate increased clinical governance input at organisational board levels to prioritise the delivery of safe, high quality, timely care to patients. In addition, CHO and the Hospital Group geographic coverage must also be aligned without delay.
- **Realistic Resourcing:** Realistic funding is required to end the under-resourcing of public hospital and mental health services that is preventing the delivery of timely care to patients. This must provide for the requirement to increase public hospital and mental health service capacities through increased investment to address the growing physical infrastructure, equipment and frontline staffing deficits.
- **Proper Planning and Demographic Pressures:** Future resourcing must take full account of the existing unfunded and unmet patient care needs together with projected future demographic and other pressures which will increase the demand for care. This requires realistic, verifiable projections which take account of the increased numbers of patients awaiting care, the rising prevalence of chronic disease, an ageing population and other demographic pressures.

- **Capacity Constraints:** Significant investment is required to address the critical capacity constraints that are preventing the provision of care to patients as needed. In particular, the effectiveness of our acute health services depends on an immediate increase in the number of acute, ICU and rehabilitation beds together with increased endoscopy, diagnostic imaging, operating theatres and outpatient clinic capacity. In addition, there must be an immediate increase in the availability of step down care and other facilities without delay to support timely discharge of patients from acute hospitals.
- **Consultant Recruitment Crisis:** The filling of hundreds of vacant permanent consultant posts requires the restoration of trust through the State ending the discrimination against new entrant Consultants, honouring the 2008 Consultant Contract, reversing austerity imposed salary cuts to improve Ireland's international competitiveness in the global marketplace for Consultants.
- **Universal Single Tier Health Service:** The key challenge is to clarify and determine the scope, effectiveness and cost of the proposed universal single tier health service in contrast with the improved health service that would arise by addressing the priorities, challenges, roadblocks and issues which are preventing the current health service from delivering timely, high quality care to patients. The priority should be to definitively address the current unacceptable waiting lists.
- **Demographic Pressures:** Key actions include the development and implementation of properly resourced strategies, plans and budgets based on realistic, verifiable projections which take account of demographic pressures and real demand levels. This requires that the long term plan provides a blueprint for the next 10 to 15 years outlining the increased capacities in acute hospital, mental health and other services that will be in place to care for the increased number of patients.
- **Integrated Care:** Steps to integrate primary, secondary and community care include addressing the lack of alignment between CHO's and Hospital Groups in terms of geographic coverage and co-ordination, the need for more integrated governance and management and the need for improved ICT systems, referral guidelines, and front line resourcing.
- **Key Barriers and Roadblocks:** In day to day practice, the provision of high quality care to an increasing number of patients is hampered by a range of factors which need to be resolved including governance, bureaucracy, infrastructure, equipment, front line staffing and other capacity deficits.
- **Healthcare Professional Support:** The medical profession is keen to engage collaboratively in the development of strategies and plans that will enable the provision of high quality, safe, timely care to patients.
- **Examples of Best Practice:** Nationally best practice examples include the governance model in voluntary maternity hospitals, Clinical Directorships with responsibility, authority and accountability, Clinical Care Programmes, Acute Medical Units that are properly resourced and improved chronic care services in the community.

- **Overall Funding Model:** It is questionable if significant changes in the sources of funding for health care services, which are broadly similar to those used in other countries, are practical in the current economic situation or whether they would deliver sustainable benefits in terms of improved patient care given the risks in changing the model while substantial operational and service delivery issues and problems need to be addressed.
- **Specifics on Financing, Payment and Service Delivery:** Funding of public hospitals should be based upon an Activity Based Funding model (ABF) using a simplified Diagnosis Related Grouping (DRG) system whereby episodes of patient care are classified into a unique DRG category (approximately 750 in number) and costed accordingly.
- **Patient Entitlements:** In line with existing entitlements, all patients should continue to be entitled to receive care and treatment in public hospitals and mental health services. The range of services should be maintained and improved from existing levels and keep pace with medical advancements and developments in best practice. In particular, they should be supported by appropriately resourced and funded primary and community health services.

## Strategy

In determining key priorities, it is important to avoid confusing symptoms with the fundamental underlying problems. For example, growing waiting lists must be addressed to ensure that patients are treated within medically acceptable timeframes. However, a narrow focus along these lines may not address the underlying factors that create waiting lists in the first instance, e.g. capacity constraints which are preventing the treatment of patients.

In conducting its analysis for recent submissions on maternity, cancer and trauma services and its Pre-Budget Submission in July 2016, the IHCA has identified common themes and key issues that are relevant. The vast majority of existing difficulties in the Irish health service can be traced back to a deficit in governance, underfunding and a lack of basic resources including capital investment, physical infrastructure, equipment and medical manpower.

### 1.1. Priorities for inclusion in the ten year strategy

#### Priority 1: Strengthened Governance

The existing governance and management of public hospital and mental health services in Ireland has undermined the trust of patients, consultants and other healthcare staff. Restoring that trust will require substantial improvements in governance. The governance structures in many hospitals, Hospital Groups and Community Health Organisations (CHOs) are overseen by a small group of non-clinical executives, who are not accountable to a board of directors. Likewise, it is a significant concern that the HSE operates without a board as it was abolished a number of years ago. Governance must be substantially strengthened to ensure that high quality safe, timely care can be provided.

Clinical governance in the majority of public hospitals and the CHOs is constrained due to the limitations on the authority of Clinical Directors and Executive Clinical Directors. This and the failure to facilitate the required clinical governance input at organisational board levels is adversely impacting on the prioritisation of the issues that need to be addressed on an ongoing basis to delivery safe, high quality care to patients on a timely and consistent basis. Public hospitals should

replicate the key elements of the model that has worked very effectively for over 100 years in the voluntary maternity hospitals whereby the governance structure is headed up and directed by a Master (CEO), who is a Consultant in the hospital, and reports to the hospital board.

In addition, there should be alignment in geographic coverage and other respects between CHOs and the Hospital Groups without delay. The current failure to align the organisation of public hospital and community services is impacting adversely on efficient and effective service delivery.

**Strengthened Governance:** A clear set of measures are required to strengthen hospital, hospital group, CHO, HSE, corporate and clinical governance arrangements to ensure that they represent best practice and are fit-for-purpose. In particular, it is essential that the current focus of governance is rebalanced to facilitate increased clinical governance input at organisational board levels to prioritise the delivery of safe, high quality, timely care to patients. In addition, CHO and the Hospital Group geographic coverage must also be aligned without delay.

### **Priority 2: Realistic resourcing for public hospital and mental health services**

Years of underfunding in public hospital and mental health services has resulted in significant capacity, resources and physical infrastructure deficits that have impacted adversely on the provision of timely care to patients. Appendix 1 includes supporting data and detailed analysis in this regard.

While revised estimates and supplementary budgets have been allocated in recent years to address shortfalls in funding for day to day spending, these have not been sufficient to address the significant infrastructure and capacity deficits as demonstrated by growing waiting lists, ED overcrowding and unmet demand. Additional funding for the NTPF and other waiting list initiatives operate as stop-gap measures without tackling the underlying capacity deficits which are causing growing waiting lists. Current waiting list targets for day-case and inpatient procedures include reference to an outer limit of 18 months which is unacceptable and represents an excessive delay for patients awaiting treatment. Instead the health service must be resourced to provide care with minimal delay in order to reduce the number of patients on waiting lists. Hospitals must be sufficiently funded so that they are not operating above recommended bed occupancy levels. Many hospitals currently operate at maximum capacity on an almost continuous basis. There must be sufficient scope and flexibility within the system to adapt to and cope with fluctuating demand at different stages of the year based on seasonal and other factors.

**Realistic Resourcing:** Realistic funding is required to end the under-resourcing of public hospital and mental health services that is preventing the delivery of timely care to patients. This must provide for the requirement to increase public hospital and mental health service capacities through increased investment to address the growing physical infrastructure, equipment and frontline staffing deficits. Appropriate funding is also required for teaching, training and research.

### **Priority 3: Proper planning to address predictable demand arising from demographic pressures**

Increased demand for care is partly attributable to demographic changes. Ireland's population is growing and ageing having particular regard to the increase in the population aged over 65 years. This cohort is associated with medical needs that are especially complex, time consuming and resource intensive. Appendix 2 includes supporting data and detailed analysis in this regard.

**Proper Planning and Demographic Pressures:** Future resourcing must take full account of the existing unfunded and unmet patient care needs together with projected future demographic and other pressures which will increase the demand for care. This requires realistic, verifiable projections which take account of the increased numbers of patients awaiting care, the rising prevalence of chronic disease, an ageing population and other demographic pressures.

#### **Priority 4: Address the capacity constraints that restrict the provision of timely, high quality healthcare**

International comparisons confirm that Ireland's health services have:

- One of the lowest numbers of practising doctors
- A relatively low number of acute hospital beds
- An excessively high acute bed occupancy rate
- Significant capacity deficits in terms of acute hospital beds and ICU beds
- Restrictions on timely access to endoscopy, diagnostic imaging, operating theatres and outpatient clinics
- An unacceptable number of patients being treated on trolleys
- A significant number of clinically discharged patients needlessly occupying acute hospital beds due to a failure to provide step down home care and other supports
- Significant problems with outdated, malfunctioning and obsolete equipment

Appendix 3 includes supporting data and detailed analysis in this regard.

**Capacity Constraints:** Significant investment is required to address the critical capacity constraints that are preventing the provision of care to patients as needed. In particular, the effectiveness of our acute health services depends on an immediate increase in the number of acute, ICU and rehabilitation beds with increased endoscopy, diagnostic imaging, operating theatres and outpatient clinic capacity. In addition, there must be an immediate increase in the availability of step down care and other facilities without delay to support timely discharge of patients from acute hospitals.

#### **Priority 5: Resolve the Consultant Recruitment and Retention Crisis**

One in four advertised hospital Consultant posts received no applicants in 2015 and a significant percentage of posts received only one eligible applicant. There are now hundreds of approved Consultant posts which are vacant or not filled on a permanent basis. Appendix 4 includes further analysis in this regard. In summary, the crisis has been caused by a combination of:

- The State's failure to implement the recommendations of the 2003 Hanly Report. Ireland has around two thirds the number of hospital consultants recommended in the Report.
- The imposition of discriminatory terms and conditions on new entrant consultants since 2012.

- Breaches by the State of the terms of the 2008 Consultant Contract since 2009.
- Loss of competitiveness in attracting internationally mobile highly trained specialists.
- Inflexible work practices that fail to recognise modern workforce needs and do not assist with the retention of highly trained specialists and doctors.
- Under-resourcing of public hospital and mental health services with consequent unacceptable working conditions for consultants and doctors. Scapegoating and unwarranted attacks on consultants and doctors for systems failures undermines morale and impacts on recruitment. Restoration of trust is key to addressing the recruitment crisis.

There is an urgent need to develop career structures and recruitment processes that ensure a stable consultant and doctor workforce that can deliver safe, high quality health services. There should be a detailed examination of consultant and NCHD staff, with a particular emphasis on the percentage of posts which are filled by locum or temporary staff and, in the case of NCHDs, the percentage of posts which are included in a national training programme.

The consultant recruitment and retention crisis can be addressed comprehensively by engaging with the IHCA which represents 85% of all hospital consultants working in Ireland.

**Consultant Recruitment Crisis:** The filling of hundreds of vacant permanent consultant posts requires the restoration of trust through the State ending the discrimination against new entrant Consultants, honouring the 2008 Consultant Contract, reversing austerity imposed salary cuts and other actions to improve Ireland’s international competitiveness in recruiting and retaining Consultants.

## **1.2. Key challenges to achieving a universal single tier health service.**

The State’s persistent failure to adequately fund and resource public health services has undermined the trust of the population, patients, consultants, doctors and other healthcare staff. This constitutes the central obvious impediment to developing an effective health service be it single tier or otherwise. The key challenge is to develop a health service that provides sustainable access to timely high quality safe healthcare to patients when required. As matters stand, this is not possible because existing services are not adequately resourced to meet current levels of patient demand for care, expected increases in demand and unmet demand for care.

Existing public health services are comprehensive in scope and they do not impose an excessive financial burden on end users. Insofar as universality is concerned therefore, the real deficits in the existing system are not related to the range of services or affordability but rather the significant delays and waiting times that patients experience in trying to access the health services that they require. The priority should be to address the unacceptable waiting lists that currently exist.

Universal health coverage (UHC) is defined by the World Health Organisation (WHO) as meaning that “all people can use the promotive, preventive, curative, rehabilitative, and palliative health services that they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship”.

In many countries healthcare is funded and delivered through a number of different channels and

not through a monolithic institution or single tier. They utilise a combination of public and private hospitals, clinics and facilities that rely predominantly on a mix of public funding and private health insurance income. For decades, a significant proportion of the population in Ireland has held private health insurance (currently 46%), endorsing an alternative to a single tier system.

The adoption of a single tier approach is unlikely to lead to an efficient, effective and sustainable public health service, in view of the existing capacity, demographic, funding and other challenges impacting on the delivery of health care services. In fact, it may be counterproductive in terms of negating the benefits associated with having complementary and competitive networks of public and private healthcare providers. In general public hospitals provide care to patients with more complex conditions than private providers and they play a central role in education, training, research and innovation. There is a high level of synergy and complementarity associated with having a private service that operates in parallel. Private hospitals provide 40% of surgical procedures requiring anaesthesia. This capacity is essential in providing care to patients and in reducing waiting lists. Private hospitals also translate some improvements and medical advancements with greater speed into day to day practice due to their focus on investment in equipment and infrastructure. As a result they are part of the drive to improve standards which can be replicated in the public service to the benefit of all patients and the population at large.

In the absence of a competitive private service, there is a significant risk that a monolithic or single tier service would not increase the efficiency and effectiveness of delivering care to patients to keep pace with international and other developments. The UK's Mid-Staffordshire Trust debacle bears testimony to the dangers of an excessive reliance on a single tier or monolithic approach.

**Universal Single Tier Health Service:** The key challenge is to clarify and determine the scope, effectiveness and cost of the proposed universal single tier health service in contrast with the improved health service that would arise by addressing the priorities, challenges, roadblocks and constraints which are preventing the current health service from delivering timely, high quality care to patients. The priority should be to definitively address the current unacceptable waiting lists.

### **1.3. What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?**

See Priority 3 above. Detailed commentary and analysis is also included in Appendix 2.

**Demographic Pressures:** Key actions include the development and implementation of properly resourced strategies, plans and budgets based on realistic, verifiable projections which take account of demographic pressures and real demand levels. This requires that the long term plan provides a blueprint for the next 10 to 15 years outlining the increased capacities in acute hospital, mental health and other services that will be in put in place to care for the increased number of patients.

- There is an immediate need for an expanded capital budget for investment in physical infrastructure and to replace obsolete and malfunctioning equipment.
- The establishment of a Standing Committee within the Department of Health/HSE with responsibility to assess demographic trends and statistical data from health services on a continuing basis so that strategies, plans and budgets are formulated on a realistic basis. The

Committee must have representatives from the key staff and patient stakeholder representative organisations including the IHCA.

- An increase in the number of acute, ICU and rehabilitation beds to provide the healthcare and treatment needs of the population including the expanding cohort of patients aged over 65 years together with guaranteed commitments for further phased increases as needed.
- Immediate additional investment in step down care and other facilities, including homecare support and the Nursing Home Support Scheme, to ensure the timely discharge of patients from acute hospitals. There must be guaranteed commitments for further phased increases in this regard as needed.

## 2. Integrated Primary and Community Care

### 2.1. What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?

**Integrated Care:** Steps to integrate primary, secondary and community care include addressing the lack of alignment between CHO's and Hospital Groups in terms of geographic coverage and co-ordination, the need for more integrated governance and management and the need for improved ICT systems, referral guidelines, and front line resourcing.

- Devise and implement increasingly integrated primary, community and acute services where the GP is the first point of contact, except in cases involving an obvious emergency which necessitates an ED attendance.
- Align geographic coverage of the CHOs and the Hospital Groups without delay as it is preventing efficient and effective service delivery.
- Improved integration between primary, community and acute services in terms of governance, budgets and administration/management. While these are mainly HSE managed services, there is a lack of integration, as demonstrated by the high number of clinically discharged patients in hospitals awaiting step down homecare or nursing home supports.
- Increased emphasis on the improvement of direct clinical care, rather than repeated reorganisation of administrative and managerial tiers.
- Provide sufficient funding for home care packages and nursing home placement thereby reducing the excessive number of long stay clinically discharged patients who are resident in acute hospitals.
- Once the misalignment between Hospital Groups and CHOs is resolved, Hospital Groups should be established on a formal and statutory basis, otherwise the hospital group strategy needs to be reviewed.
- Improve communications and relationships between primary, acute and community

services. This will require greater investment in information and communication technology (ICT) systems. Existing systems are inadequate for the purpose of efficient information sharing and monitoring of patient care.

- Improved engagement and interaction between primary and acute services in terms of agreeing and formulating guidelines on referral thresholds having particular regard to referrals to outpatient clinics and Emergency Departments.
- Formulate Integrated Care Pathways (ICPs) for patient groups with specific medical conditions. This requires multi-disciplinary and multi-agency input and co-operation.
- Caution must be exercised to ensure that the costs of implementing increased integration are managed and controlled so that they do not reduce the net benefits.

## 2.2. Key Barriers and Roadblocks

**Key Barriers and Roadblocks:** In day to day practice, the provision of high quality care to an increasing number of patients is hampered by a range of factors which need to be resolved including governance, bureaucracy, infrastructure, equipment, front line staffing and other capacity constraints.

**Governance issues:** Organisation and corporate governance structures need to be strengthened to ensure that the quality and safety of care provided to patients is not restricted by budget, staffing and other limitations as outlined in the earlier sections of this submission.

**Bureaucracy and red tape:** Multiple tiers of overlapping bureaucracy absorb valuable time and resources thereby obstructing the development of the public health service. Health care administration is focussed excessively on budgets and head counts instead of ensuring that optimum resources are directed to the treatment of patients. The focus must be on outcomes rather than inputs.

**Deficits in acute hospital and ICU bed stock:** Ireland has one of the lowest numbers of acute hospital beds in the OECD.<sup>398</sup> There is also an insufficient number of ICU beds despite a HSE commissioned report which recommended substantial increases. Appendix 3 includes supporting data and detailed analysis in this regard.

**Restricted access to diagnostics:** Access to diagnostic imaging is a significant and growing problem due to underinvestment and insufficient numbers of consultant radiologists and radiographers. At a very basic level, the inadequacy of essential hospital equipment impedes access to diagnostic investigations. Appendix 3 includes supporting data having particular regard to MRI and CT Scanners.

**Restricted access to operating theatre facilities:** Essential surgery required even for cancer patients is being cancelled on a regular and repeated basis throughout the acute hospital network due to a mismatch between capacity and demand. In addition, other scheduled surgical appointments are also being cancelled leading to growing waiting lists.

**Insufficient number of consultants:** Most hospital departments have a severe shortage of permanent and locum consultants. Problems in this regard are exacerbated by the consultant

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<sup>398</sup> Ireland has 2.4 beds per 1,000 population, which is 33% below the OECD average of 3.6. Source: *OECD Health Statistics 2016*

recruitment and retention crisis and a lack of funding to provide required locum cover when consultant colleagues are absent on leave.

**Malfunctioning, outdated and obsolete equipment:** This represents a major problem in acute services and is attributable to steep cuts in capital budgets since 2008.

**Lack of office space, secretarial and administrative support:** Many consultants do not have access to appropriate facilities and secretarial supports to carry out administrative and other activities including filing of reports, letters to consultant colleagues, GPs, etc. Gaps in the chain of communication lead to delayed diagnosis and/or treatment with consequent implications for patient care.

### **2.3. How would you ensure buy-in from health care professionals to progress towards an integrated health care model?**

**Healthcare Professional Support:** The medical profession is keen to engage collaboratively in the development of strategies and plans that will enable the provision of high quality, safe, timely care to patients.

Consultants and other doctors will support changes that facilitate and enable timely treatment of patients. In contrast, time-consuming administrative practices that do not benefit patients should be questioned where they reduce the efficiency and effectiveness of care delivery. Evidence should be provided on how each specific proposal will facilitate patients being seen by appropriate healthcare professionals in appropriate settings at appropriate times.

It is essential that authority and decision-making are delegated away from the increasing layers of centralised bureaucracy to the patient/doctor interface together with increased resourcing freed up through the reduction in centralised administration. Clinicians must be given autonomy and facilitated in their efforts to treat their patients to the highest possible standards without delays.

It is essential to guard against centralised administration of an integrated health care model that is far too distant from patients and, as a result, inefficient and ineffective. The management and administration of integrated health care needs to be based at the point where the care is delivered in terms of primary, acute and community services.

Health service human resource management must ensure that best practice is adhered to at all times. There should be no repeat of past episodes where clinicians have been scapegoated for the failures of under-resourced and under-staffed frontline services.

As with the acute hospitals, the clinical governance of an integrated health model is the key to success. In the absence of effective clinical governance, mistakes of the past will be repeated with the ever-present risk of creating additional tiers of autocratic bureaucracy that obstructs progress. The majority of consultants have worked in very effective functional health services abroad. Their collective efforts to reform the organisation and decision making processes of the public hospitals and mental health services are usually frustrated by administrative and management structures that restrict change and stymie innovation. This must be addressed as a matter of priority.

**Examples of Best Practice:** Nationally best practice examples include the governance model in voluntary maternity hospitals, Clinical Directorships with responsibility, authority and accountability and Clinical Care Programme

- Clinical Care Programmes developed and implemented by consultants since 2010.

- Masters' management structure and board governance in voluntary maternity hospitals.
- Clinical Directorships in acute hospitals albeit they are restricted due to the failure to provide the appropriate authority and governance structures.
- Executive Clinical Directors in Mental Health, although in the past year a decision by the HSE and Mental Health Directorate has undermined their effectiveness though organisational changes which are in breach of "Vision for Change" and the CHO Policy Guidelines.
- Acute medical units that are appropriately staffed and resourced and linked with primary care and community services.
- Improved chronic care services in the community.

## Funding Model

### 2.4. Views on health service funding model

Ireland is not unusual in that its current model is based on a combination of funding from general taxation, social insurance, private health insurance and out of pocket payments - similar to the model employed in many other OECD countries (see Appendix 5). Extensive changes to any healthcare financing or delivery systems is a challenge which runs substantial risks even in a stable, well-functioning system. The risks are much higher where operational and service delivery problems exist such as capacity, staffing, waiting lists, etc.

Regardless of the funding model that is employed, there needs to be adequate funding and resourcing of public hospital and mental health services so that patients and the population at large have confidence and trust in the capacity of the system to provide timely care as required. A key question is the extent to which an alternative funding model can deliver significant improvements over the existing model while also safeguarding the ability of the service to maintain and expand its capacity to provide care in the coming years.

Participation in private health insurance provides significant additional funding which underpins acute capacities that would otherwise have to be funded through general taxation. The treatment of private patients in public hospitals is beneficial in that it generates income for the public system while closing the gap between standards in public and private hospitals as patients compare service provision and outcomes across all settings

Private hospitals and facilities operate to a business plan and they are appropriately financed in that the levels of available funding and resources are set in anticipation of increases in service demand. Hospitals and staff have an incentive to ensure the provision of efficient and effective care to an optimal number of patients. The same is not true of public hospitals where a top down funding model applies with several tiers of bureaucracy between the provision of health services and funding. Especially in recent years, public hospitals have not had the manpower or physical resources necessary to deal with increased demand which has impacted adversely on the capacity to provide high quality safe care to patients on a timely basis.

**Overall Funding Model:** It is questionable if significant changes in the sources of funding for health care services, which are broadly similar to those used in other countries, are practical in the current economic situation or whether they would deliver sustainable benefits given the risks in changing

the model while substantial operational and service delivery issues and problems need to be addressed.

## **2.5. Specifics of financing, payment method and service delivery**

Under an Activity Based Funding (ABF) model, it is in the hospital's financial interest to optimise the number of patients it treats. Under the current model, no such incentive exists. In fact, hospital services/units that treat larger numbers of patients while optimising utilisation of available resources and staying within budget tend to be penalised in subsequent budgets which fail to take account of excellent past performance.

The proposed ABF model should be implemented initially in simplified form with a view to evolving into a more sophisticated model over time. In implementing such a model, it is essential to ensure that the associated administration and related costs of operating the system do not undermine the potential benefits. To achieve this, the model should be developed in conjunction and with the guidance of consultants and other doctors to ensure it is user friendly without excessive administration requirements.

The effective implementation of an ABF model utilising DRG categories also requires that cases are accurately costed to ensure that hospitals are appropriately funded for the delivery of each episode of care. The model should be underpinned by appropriate structures for clinical, hospital and corporate governance to ensure the funding is expended and employed appropriately.

Extreme care must be taken to avoid or eliminate the potential negative or unintended consequences of an ABF model including transfer or avoidance of unprofitable cases, inappropriate early discharge, withholding necessary services, etc. Consultant input will be essential to ensure that unintended consequences are avoided and that the ABF model is implemented effectively.

A question arises in relation to emergency services and whether they should be funded through an ABF model. These services differ fundamentally from inpatient and day-case services as they need to maintain certain minimum levels of capacity regardless of actual demand. In circumstances where a significant amount of inpatient activity is undertaken in the Emergency Department setting, it is vital that they are properly financed and are not disadvantaged through non-inclusion.

**Specifics on Financing, Payment and Service Delivery:** Funding of public hospitals should be based upon an Activity Based Funding model (ABF) using a simplified Diagnosis Related Grouping (DRG) system whereby episodes of patient care are classified into a unique DRG category (approximately 750 in number) and costed accordingly.

## **2.6. Main entitlements that patients will be provided with under the funding model**

As highlighted above, the WHO defines universal health coverage as access to healthcare services without exposing the user to financial hardship. It should be noted that no country has perfected a system where literally every person immediately receives every health service that they require without incurring individual charges. Committing to provide free healthcare is an ineffective strategy if services are not already of a consistently high standard and accessible on a timely basis.

It is important that Ireland adopts an approach of incremental healthcare reforms in which the aim is to make continuous progress towards a properly resourced public health system that ensures

timely access for all patients with a guaranteed level of healthcare services that can be expanded over time. As outlined previously, the real deficits in the existing system are not related to the range of services or affordability but rather the significant delays and waiting times that patients experience in trying to access the health services that they require.

**Patient Entitlements:** In line with existing entitlements, all patients should continue to be entitled to receive care and treatment in public hospitals and mental health services. The range of services should be maintained and improved from existing levels and keep pace with medical advancements and developments in best practice. In particular, they should be supported by appropriately resourced and funded primary and community health services.

**Signed and submitted by:**



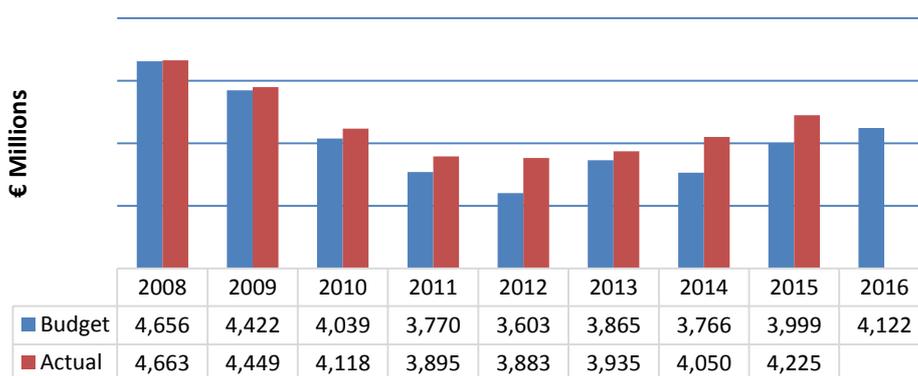
**Mr Martin Varley, Secretary General as an authorised officer of the Irish Hospital Consultants Association**

#### **Appendix 1 – Under-funding, under-resourcing and budget deficits**

Years of significant underfunding of acute hospitals, with an average annual deficit of €215m between 2012 and 2015, have resulted in gaping capacity deficits undermining the basic resources and physical infrastructure required to meet the increasing demand for care.

It is clear that increases in the frontline acute hospital budgets in recent years were inadequate to fund patient demand for care. The acute hospital funding deficit for the first four months of 2016 was €112.1m<sup>399</sup>. It should be noted that the 2016 acute hospital budget is 11.4% below the budget in 2008.

#### **Acute Hospital funding 2008 – 2016 (€millions)**

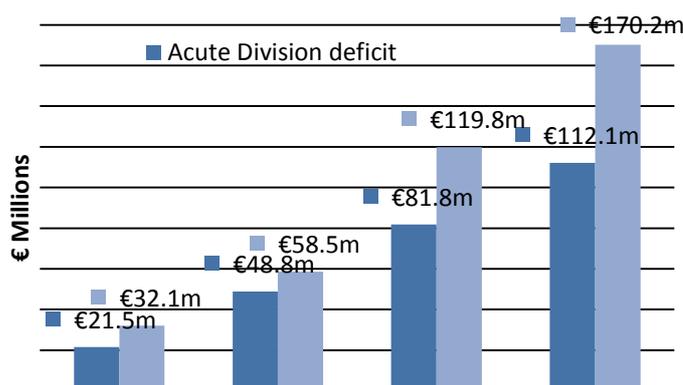


**Source: HSE Performance Reports and HSE Annual Reports and Accounts (2007 -2016)**

The April 2016 HSE Performance Report confirms that acute hospitals were 8.28% over budget at the end of April.

<sup>399</sup> April 2016 HSE Data document

## HSE and Acute Hospital funding (January to April of 2016)



Source: HSE Performance Reports (January – April 2016)

All but two of the country's 49 acute hospitals reported budget overspends at the end of April 2016. Fifteen acute hospitals were over budget by between 10% and 27%.<sup>400</sup>

In terms of capital budgets, between 2008 and 2016, there have been cumulative cuts of €1,700m and €530m in the overall health budget and the acute hospital capital budget respectively, resulting in overwhelming restrictions on essential infrastructure and equipment investment.

### Health and Acute Hospitals Capital Expenditure/ Budgets

	Health Capital Expenditure /Budget Totals (€m)	Acute Hospital Capital Expenditure/ Budget Totals (€m)
2008	598	273
2009	447	209
2010	366	220
2011	347	202
2012	350	208
2013	347	203
2014	386	197
2015*	382	178.3
2016*	414	234.7
<b>Cumulative reduction in Capital Expenditure</b>	<b>1,745</b>	<b>532</b>

<sup>400</sup> April 2016 HSE Data document

**Source: Revised Estimates for Public Services (2008 – 2014) and HSE Reports on Capital Programme cited in DOH Key Trends 2015 and Revised Estimates for Public Services (2015 – 2016).**

**\*Figures for 2015 and 2016 refer to budgeted capital amounts rather than expenditure data.**

The 2016 Mental Health budget was €215m (21%) below 2009 expenditure even allowing for increases in 2014 and 2015. At €791.6m, it equates to 5.8% of the total health budget, which is low by international standards and in comparison with the NHS which spends 11% of its total health budget on mental health services.

## Appendix 2 – Demographic Pressures

Increases in the demand for care are partly attributable to demographic changes in society. Between 2006 and 2015, there has been an increase of 143,600 (31%) in the population aged 65 and over. By 2021 it is projected that there will be a further increase of 107,600 aged 65 years and over, representing an increase of 53% compared with 2006.

### Population aged over 65 (2006 – 2015)



**Source: CSO statbank population aged 65 and over by age group (2006 – 2015)**

This cohort is associated with medical needs that are especially complex, time consuming and resource intensive. It is worth noting that patients aged 65 and over<sup>401</sup>:

- Account for 91% of delayed discharges.
- Have an average length of stay of 12.3 days compared with 6.0 in general.
- Account for over 50% of all in-patient bed days despite making up 12.7% of the overall population.
- Approximately 90% of our total healthcare costs are expended on 30% of the population with chronic disease and this demographic is expanding.
- By 2021 it is projected that there will be another 107,600 people aged 65 years and over, representing an increase of 17% compared with 2016.
- In the same period there will be an additional 15,200 people aged 85 years and over.

<sup>401</sup> HSE Report: “Planning for Health: Trends and Priorities to inform Health Service Planning 2016”

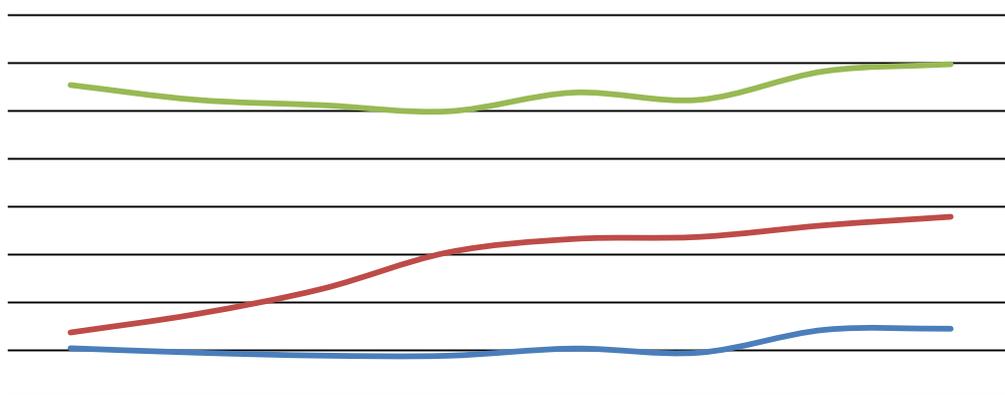
The population growth of 3.7% between 2011 and 2016, as confirmed in the 2016 census results, further highlights the increased demand which must be taken into account in deciding the Future Healthcare Plan.

Despite the significant increase in the number of patients being treated in acute hospitals, waiting list numbers continue to increase. These unmet and other medical needs can only be fulfilled by effectively addressing the underlying capacity deficits in terms of acute and ICU beds, theatre facilities, and the Consultant recruitment and retention problems.

Continued failure to invest in physical capacity and human resources as the population increases and ages will lead to increasing inefficiency, poorer patient outcomes and unnecessary costs.

Overall, the number of inpatients and daycase patients treated in acute hospitals has increased by 282,434 in the seven year period to 2015, an increase of 22.8% during a time of steep budget cuts and reductions in acute hospital staff numbers.

#### Inpatient and Daycase totals (2008 to 2015)



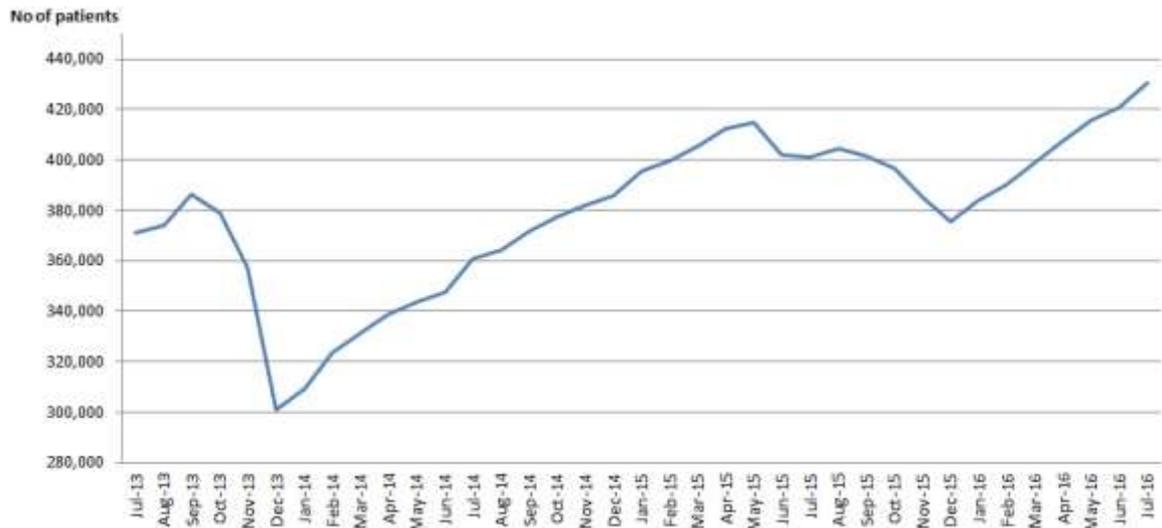
	2008	2009	2010	2011	2012	2013	2014	2015
— Inpatient	604,239	595,022	588,860	588,623	603,579	595,109	642,812	644,990
— Day case	637,138	675,611	728,269	804,274	832,476	836,789	861,138	878,821
— ED Attendances	1,154,004	1,123,068	1,111,964	1,098,956	1,138,152	1,123,083	1,182,947	1,197,343

Source: HSE Performance Reports (2008 – 2015)

Along with these increases are increasing inpatient, day case and GI waiting lists as the number of patients requiring acute care far exceeds the existing capacity.

The total numbers of patients waiting on the outpatient waiting list have increased from 401,060 to 430,573 (7%) in the year to July 2016.

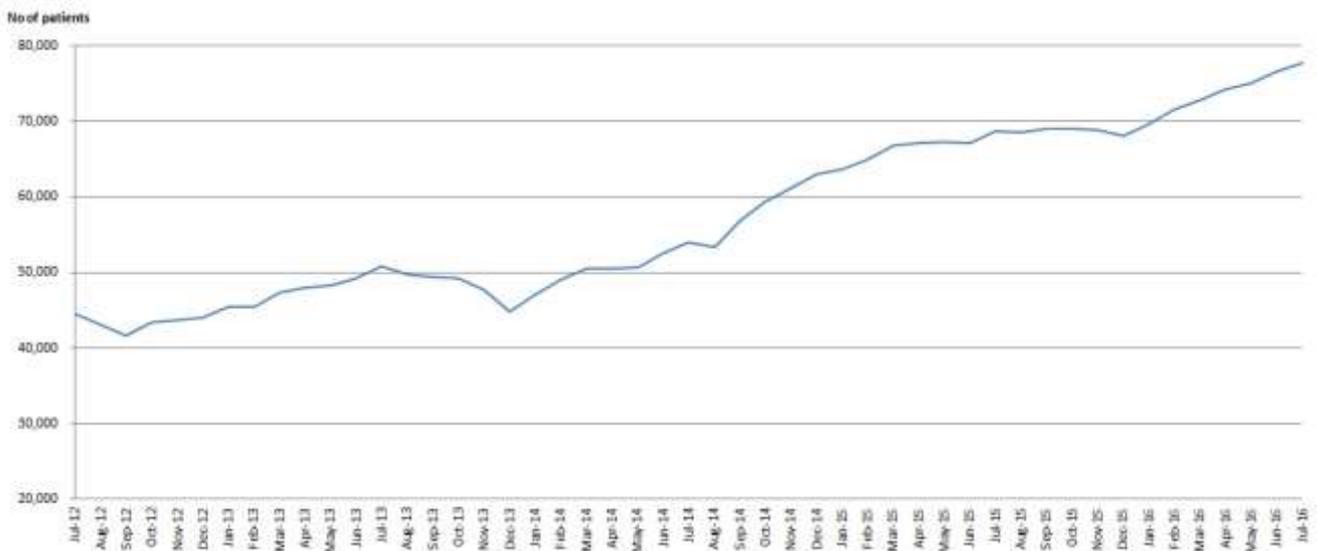
**Number of patients on the outpatient waiting list (Jul 2013 – Jul 2016)**



Source: NTPF

The total number of patients waiting on the inpatient and daycase waiting list has increased from 68,786 to 77,810 (13%) over the same period.

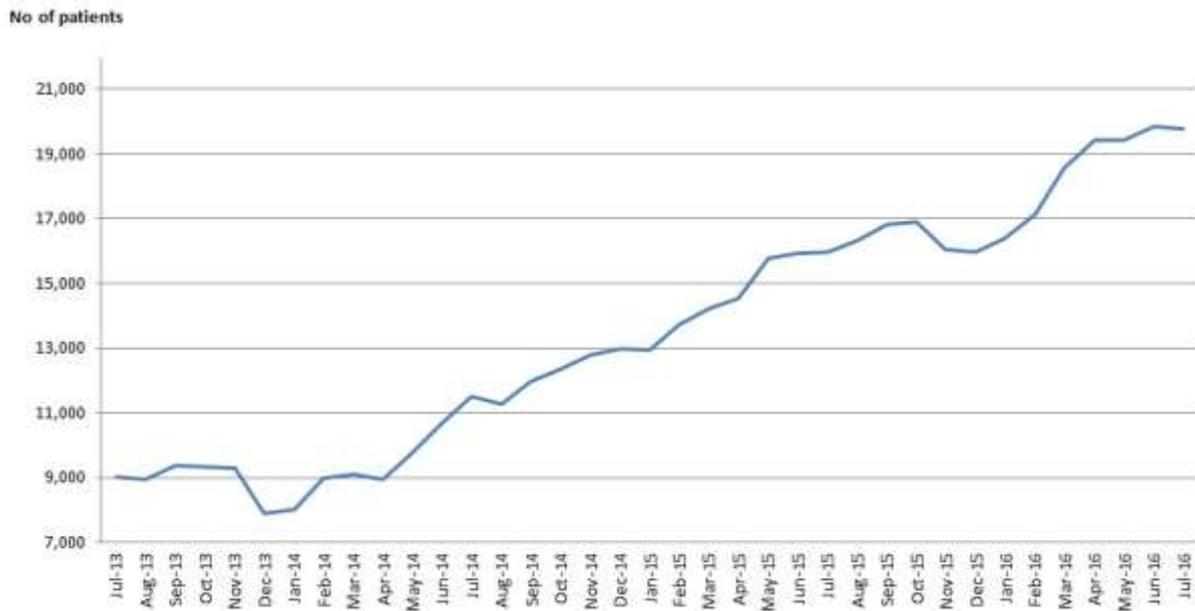
**Number of patients on the inpatient and daycase waiting list (Jul 2012 – Jul 2016)**



Source: NTPF

The total number of patients waiting on the GI endoscopy waiting list has increased from 15,986 to 19,761 (24%) over the same period.

### Number of patients on GI waiting list (Jul 2013 – Jul 2016)

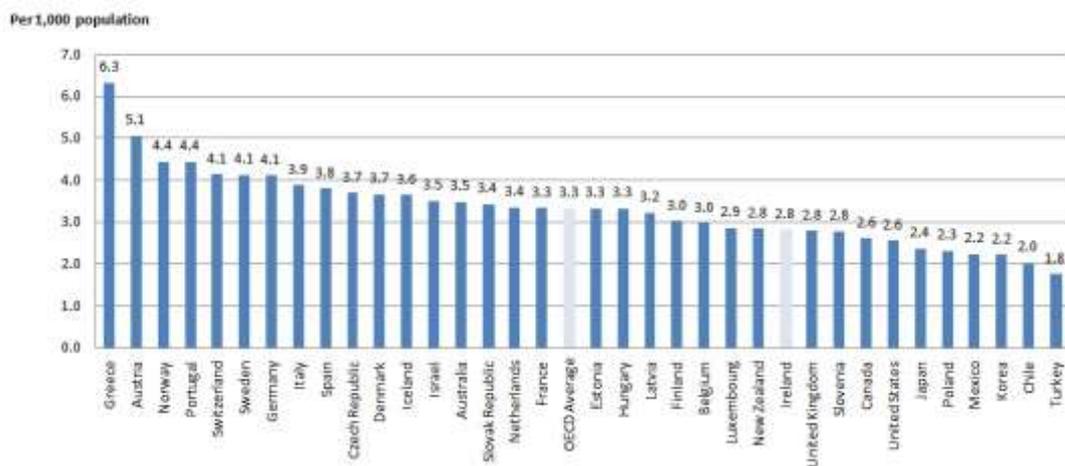


Source: NTPF

### Appendix 3 – Capacity Constraints

International comparisons confirm that the Irish health service has one of the lowest numbers of practising doctors in the OECD on a population basis. Due to the lower number of doctors and consultants on a population basis, the workload of consultants in Ireland is much higher than their peers elsewhere as demonstrated by comparisons of the number of patients to be assessed in outpatient clinics which are often multiples of the numbers in clinics in other developed countries.

### Doctors per 1,000 of population (2014 or nearest year)

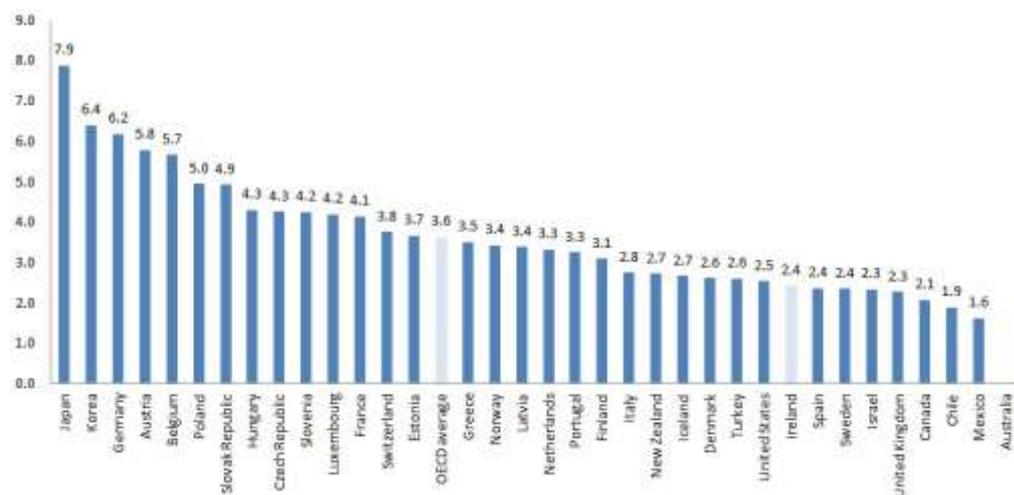


Source: OECD Health Statistics 2016

Between 2007 and 2014, the number of acute public hospital beds was cut by 1,643 (14%) from 12,123 to 10,480 at a time when the population increased significantly. At 2.4 beds per head of population, Ireland has 33% less beds compared with the OECD average (3.6).

In 2009, the HSE’s commissioned Prospectus Report recommended an immediate increase of 45% in ICU beds from 289 to 418 in 2010 alone, to be followed by a further increase to 579 by 2020. The report has not been acted upon and instead the number of ICU beds has actually declined.

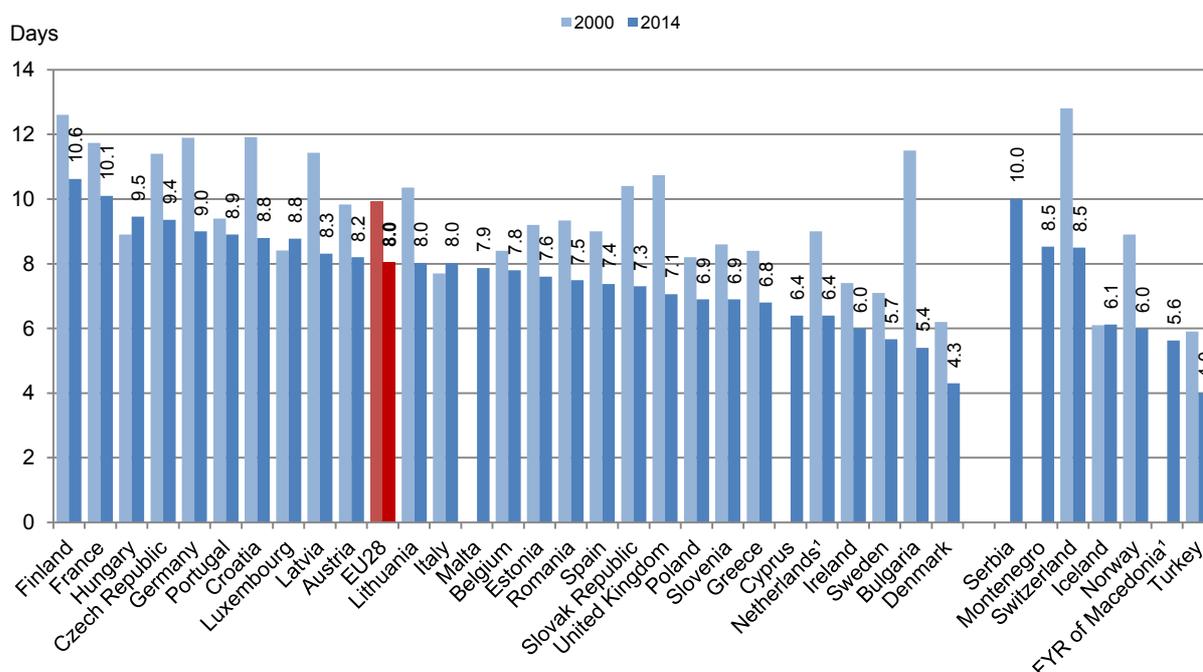
### Hospital Beds per 1,000 of population (2014 or nearest year)



Source: OECD Health Statistics 2016

The average length of stay in Ireland’s acute hospitals is 5.6 days, which is 25% below the OECD average of 7.5. This is being achieved despite the fact that Ireland has one of the lowest numbers of practising doctors. In addition, a large number of acute hospital beds are occupied on an ongoing basis by clinically discharged patients who are awaiting step down homecare or nursing home supports.

### 8.10. Average length of stay in hospital, 2000 and 2014 (or nearest year)

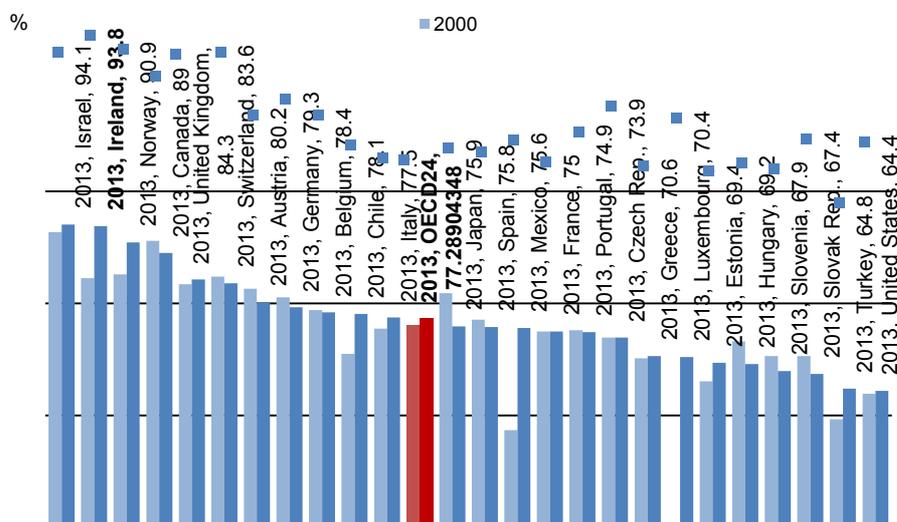


1. Data refer to average length of stay for curative (acute) care (resulting in an under-estimation).

Source: OECD Health Statistics 2016; Eurostat Database.

Ireland's bed occupancy rate at 94% compares unfavourably with the OECD average (77%) and the UK (84%). This occupancy rate is far in excess of the recommended 85% occupancy rate.

### Bed occupancy rate of curative (acute) care beds, 2000 and 2013

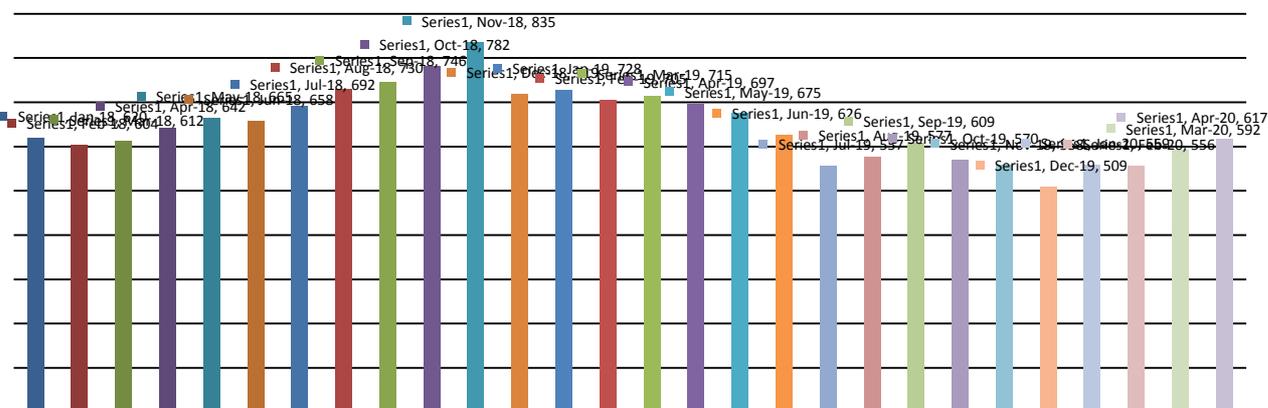


Source: OECD Health at a Glance 2015

Research has confirmed that bed occupancy rates above 85% are associated with poorer outcomes, increased rates of hospital associated infection, negative impact on staff health, and poorer performance as assessed by Emergency Department admission and discharge targets<sup>402</sup>.

At any given time, there is a significant number of clinically discharged patients residing in acute hospitals which impacts adversely on the optimal use of the existing inadequate bed capacity. In April on average 617 acute hospital beds per day were occupied by clinically discharged patients and unavailable to new admissions. This is the equivalent of a large teaching hospital being closed throughout the year.

### Clinically discharged patients by month (Jan 2014 – Apr 2016)



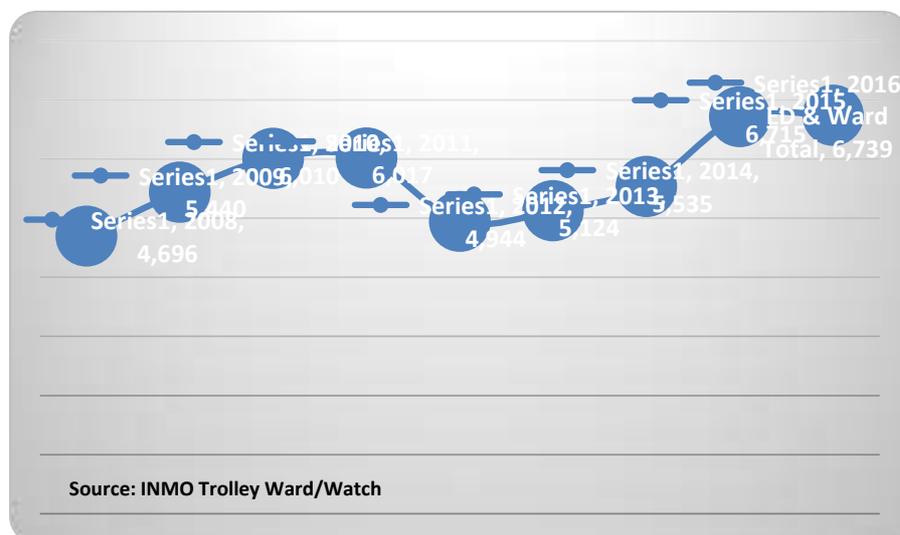
Source: HSE Performance reports (January 2014 – February 2016)

<sup>402</sup>Keegan, AD, (2010), "Hospital bed occupancy: more than queuing for a bed", *Medical Journal of Australia*, Volume 193, Number 5, 6 September 2010

The treatment of large numbers of patients on trolleys is no longer a seasonal problem but a year round capacity problem which highlights the extreme nature of the acute hospital capacity shortage.

The lack of sufficient bed stock has led to hundreds of patients being treated on trolleys every day. In July 6,739 patients were treated on trolleys, 22% and 44% above the July 2014 and July 2008 levels respectively.

### Monthly Trolley Analysis (July 2008 – July 2016)



Source: INMO Trolley Ward/ Watch (July 2008 – July 2016)

Access to diagnostic imaging is a perennial problem in the acute health service. At a very basic level, the inadequacy of essential hospital equipment impedes access to diagnostic investigations. The average number of MRI Units per million of population in Ireland was 13.4 compared with an OECD average of 14.9 in 2014. The equivalent average for CT scanners was 16.7 compared with an OECD average of 25.3.<sup>403</sup>

### Appendix 4 – Consultant recruitment and retention

Acute hospitals have around two thirds the number of Consultants recommended in the Hanly Report over 13 years ago. In the interim, the demand for care has grown substantially due to the country's increasing and ageing population. In some specialties, the country has around one third to half the number of hospital consultants compared with the recommended international norms. Under these circumstances it is not surprising that the public health system is failing to provide the quantum of care that the public deserves.

It is essential that the health service recruits and retains the number and calibre of Consultants that are needed to deliver safe high quality care to patients. There is a continuing failure to fill Consultant posts due to the State's blatant and repeated breaches of Consultant Contract terms. Combined with frontline under-resourcing, the failure to honour contract terms has undermined the attractiveness of the Irish health service to highly trained internationally mobile specialists. Ireland is suffering a damaging medical brain drain. It is not competitive in recruiting and retaining Consultants because the terms and conditions on offer in Ireland are not competitive with the other English speaking countries which include North America, Australia and the UK.

<sup>403</sup> OECD Health Statistics 2016

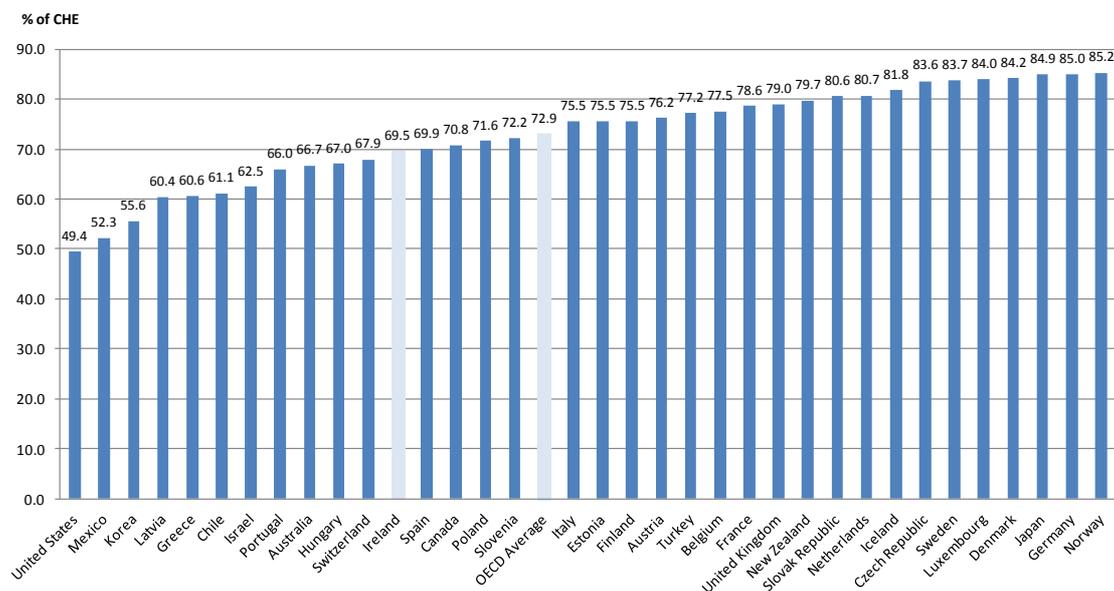
The State’s refusal to provide parity for new entrant consultants in terms of salary, and the failure to restore basic trust risks the loss of a generation of highly trained specialists and consultants who are emigrating to pursue their careers in other countries. The continued failure to take corrective action along these lines is having serious consequences. One in four advertised hospital consultant posts received no applicants in 2015 and in addition a similar number had only one applicant per post. There are now hundreds of approved consultant posts which cannot be filled on a permanent basis some of which have been vacant for several years. These vacancies are exacerbating the delays in treating patients and impacting adversely on patient outcomes.

It is clear that the health service is no longer competitive in attracting and recruiting the number of high calibre consultants required to deal with current service levels let alone the significant unmet needs of Irish patients. In this regard, it is important that the health service recognises that remuneration for doctors and specialists in other countries have been increasing each year at a time when hospital consultants in Ireland have suffered severe salary cuts and pension levy increase totalling between 30% to 40%.

### Appendix 5 – UHC and Funding Models

Government and compulsory health insurance schemes represented 69.5% of current health expenditure in 2015 somewhat below the OECD average of 72.9%. Increased public healthcare funding will be necessary to improve access and quality to healthcare in line with international standards.

#### Government and compulsory health insurance schemes, % of current health expenditure (2015)

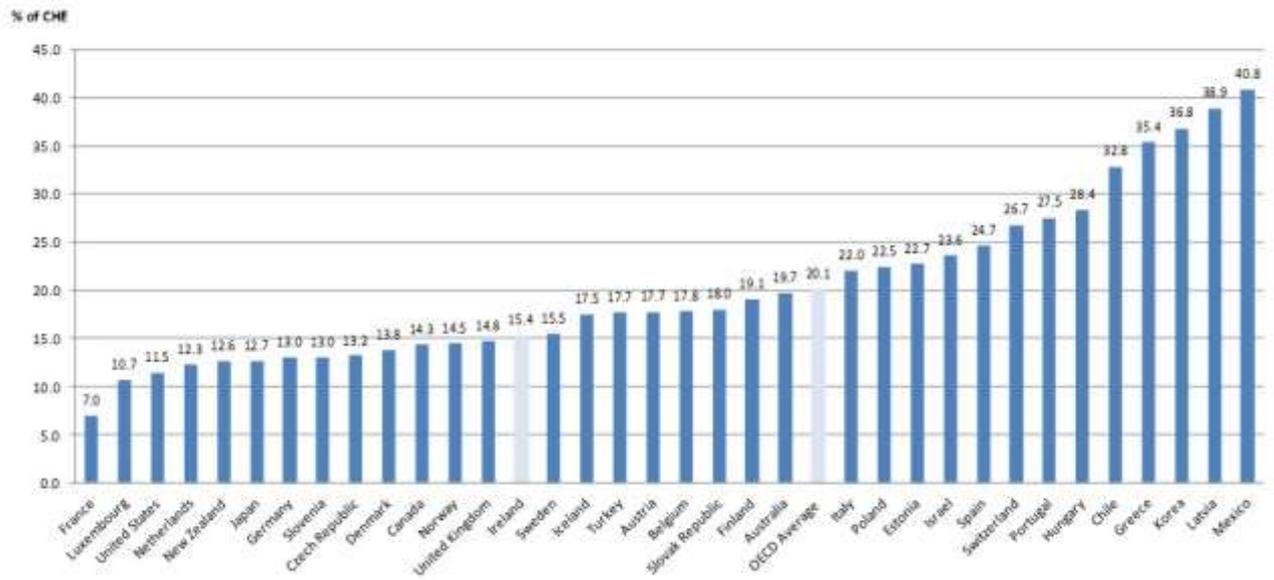


Source: OECD Health Care Statistics 2016

*Delivering Universal Health Coverage – A Guide for Policy Makers* states that “to truly reach UHC, coverage of the whole population needs to be achieved while minimizing out-of-pocket expenditure by individuals.”<sup>404</sup> It is worth noting that at 15.4% Ireland’s Out of pocket expenditure as a % of current health expenditure is well below the OECD average of 20.1%.

<sup>404</sup> Report of the WISH Universal Health Coverage Forum 2015

**Out of Pocket expenditure, % of current health expenditure (2014 or nearest year)**



Source: OECD Health Care Statistics 2016

<http://www.ihca.ie/>

## Irish Hospice Foundation

In the next 10 years 300,000 people will die in Ireland and over 3 million people will be bereaved. Many of those who die will not die in their place of choice.

Dying, death and bereavement are not confined to any one area of the health services but are the business of all sectors – and of the whole of society. Each year up to 10% of the healthcare budget is spent on end of life care – much of it unplanned – up to €13 billion over 10 years.

The IHF believes that with strategic support, better coordinated end-of-life care can make a real difference to both the quality of healthcare provided to the patient and the cost of healthcare to the State.

One of the main challenges is to “join the dots” – to coordinate, replicate, progress and embed innovative, evidence-based solutions to issues which arise in care of the dying and the bereaved, whether these solutions are provided by the statutory or voluntary sector. Many of these are instanced in this document.

Our overarching recommendation is:

- That the state should develop an end-of-life and bereavement strategy to cover all aspects of dying, death and bereavement in Ireland. This should include appropriate health and social care provision in all care settings.
- This strategy should be multi-sectoral, supported by all Departments and Agencies of State since dying, death and bereavement affect all aspects of people’s lives and the State should take a lead role to drive change across all sectors.

The health service has primary but not sole responsibility for issues arising in dying, death and bereavement and should be supported in their role. The state must not engage in death denial but must actively encourage and enable people to think and talk about their end of life needs. One of our recommendations calls for this to be formalised.

Other specific recommendations recognise that end-of-life care encompasses primary, secondary, tertiary and community care settings, all diagnoses, all ages and involves the majority of healthcare professionals and care staff. They cover policy, infrastructure and development for pivotal specialist palliative care services, as well as support for their colleagues in primary and acute care and in the community.

The current restructuring of the health service offers a strategic opportunity to focus on end-of-life care and ensure that people can ‘die well’ in Ireland. It must be stressed that dying, death and bereavement cannot be neatly packaged and handed over to palliative care services as their unique remit and responsibility. They are the business of the whole health service, each part of which requires attention and support. We recommend a public health approach to dying, death and bereavement.

### SUBMISSION TO THE OIREACTHAS COMMITTEE ON THE FUTURE OF HEALTHCARE

#### End-of-Life Care - Why it matters

Death is an inevitable and universal experience. A fact of life. While most people will experience 'death denial', it is not appropriate that the State should adopt the same attitude. Dying, death and bereavement present myriad challenges to a health service which is largely focused on cure. It follows that since death is a whole-population experience, it requires a whole population approach. It also requires a whole health service approach since death can occur at any time, in any care setting, at any age, in any circumstances.

#### The facts.

In the next 10 years<sup>405</sup>:

- Almost 300,000 people will die in Ireland
- Over 3,000 of those deaths will be of children
- Over 240,000 will be of people over 65 years of age
- Almost 3 million people will be bereaved<sup>406</sup> and up to 150,000 of these will encounter significant difficulties or 'complicated grief'<sup>407</sup>

If current trends continue:

- Each year 10% of the national healthcare budget will be spent on end of life care - €13 billion over 10 years<sup>408</sup> - much of it unplanned
- Each year only 0.55% of the national healthcare budget will be spent on Specialist Palliative Care Services (SPC) - €710.9 million over 10 years<sup>409</sup>
- 74% of people will want to die at home<sup>410</sup> but only 26% will do so<sup>411</sup>

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<sup>405</sup> Figures estimated from CSO statistics of 2015: Vital Statistics 2015 Yearly summary (29,952 deaths in 2015)

<sup>406</sup> Estimate based on 10 people directly affected by each death

<sup>407</sup> Kersting A, Brähler E, Glaesmer H, Wagner B. Prevalence of complicated grief in a representative population-based sample. *J Affect Disord* 2011;131:339-43 and [Newson RS<sup>1</sup>, Boelen PA, Hek K, Hofman A, Tiemeier H](#). The prevalence and characteristics of complicated grief in older adults. *J Affect Disord*. 2011 Jul;132(1-2):231-8. doi: 10.1016/j.jad.2011.02.021. Epub 2011 Mar 12.

<sup>408</sup> Research evidence (Gray 2004; Polder et al 2006; Ezekiel 2002 and Raitano 2006) summarised in *Access to Specialist Palliative Care services and Place of Death in Ireland: What the data tells us*, IHF Perspectives Series Number 2; Irish Hospice Foundation May 2013

<sup>409</sup> Calculation based on 2015 HSE SPC budget of €71.9m in 2015

- 43% will die in hospital and 26% in long-stay care<sup>412</sup>
- 6% will die in a hospice<sup>413</sup>
- 5% of grieving people will require specialist mental health services/psychological intervention<sup>414</sup>

Given this evidence, it is essential that the healthcare system meets the needs of people facing dying, death and bereavement and ensures that everyone gets equal access to good care. By careful planning, we can make the best use of the substantial funds that we directly and indirectly invest in the care of the dying and, crucially, that this planning includes helping people to live well until they die.

This subject has been and remains the focus of a number of investigations, reports, and research and development projects. Particular attention should be paid to the submissions to the then Oireachtas Joint Committee on Health and Children which held a series of hearings on end of life issues in 2013 and reported in 2014<sup>415</sup>.

Despite this attention, coordinated, seamless care of people at end of life remains a largely elusive goal with many pockets of progressive good practice and development isolated by location and not mainstreamed, or hampered by deficits in infrastructure, staffing or training.

One of the main challenges is to “join the dots” – to coordinate, replicate, progress and embed innovative, evidence-based solutions to issues which arise in care of the dying and the bereaved, whether these solutions are provided by the statutory or voluntary sector.

High quality end-of-life care – which includes supportive and palliative care – encompasses primary, secondary, tertiary and community care settings, all diagnoses, all ages and involves the majority of healthcare professionals and care staff.

In the context of end of life care, the Irish Health System is facing major challenges:

- an ageing population with increasing cultural diversity;

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<sup>410</sup> Weafer, J. (2014) Irish attitudes to death, dying and bereavement 2004-2014. Dublin: Irish Hospice Foundation

<sup>411</sup> Irish Hospice Foundation: *Enabling More People to Die at Home*. (supported by a research paper from Dr. Kieran McKeown) Irish Hospice Foundation Perspectives Series Number 3; December 2014

<sup>412</sup> Ibid

<sup>413</sup> Ibid

<sup>414</sup> Aoun SM et al. A public health approach to bereavement support services in palliative care. Australian and New Zealand Journal of Public Health. 2012; 36: 14–16. doi: 10.1111/j.1753-6405.2012.00825.x. pmid:22313700

<sup>415</sup> <http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2014/End-of-Life-Vol-1.pdf>

- the need for protracted end-of-life care as people live longer with chronic diseases, including dementia, cancer and heart failure
- growing demand for services;
- increasing public expectation and strong demand for responsive, patient led and personalised health care;
- a move from predominantly hospital based delivery to care at /or close to home;
- an immediate requirement to progress the development of integrated chronic disease management and care delivery models;
- Significant structural change to the health delivery model including: development of Hospital Groups and Community Health Organisations; and development of new funding model-concepts, particularly “*money follows the patient*” and ‘*universal health care*’
- increasing co-dependency between the voluntary and statutory sectors to develop and maintain responsive and appropriate services for dying, death and bereavement.

### **Strategic approach**

Any element of a national healthcare system that cares for a significant proportion of the population, expects client numbers to continue to grow, and commands a significant direct and indirect budget, must plan effectively for the future delivery of services. This is particularly the case with end-of-life care. People are living longer with life-limiting conditions and multiple morbidities and will have specific and growing palliative care needs.

Palliative care is a distinct care approach which helps people with life-limiting conditions to live life as well as possible. Specialist palliative care services are concerned with the delivery of palliative care, and guidance of other professionals. Generalist palliative care is often provided within other areas of healthcare, including primary care.

This submission sets out some of the key priorities.

### **Our overarching recommendation is:**

**That the state should develop an end-of-life and bereavement strategy to cover all aspects of dying, death and bereavement in Ireland. This should include appropriate health and social care provision in all care settings.**

**This strategy should be multi-sectoral, supported by all Departments and Agencies of State since dying, death and bereavement affect all aspects of people’s lives and the State should take a lead role to drive change across all sectors.**

## Planning for end of life

Increasing longevity does not bring immortality but it may distance us from the inevitability of our demise – so much so that two thirds of us have never discussed our end of life care preferences and almost 40% of us have not made a will, but 57% of us say there is not enough discussion about dying and death<sup>416</sup>.

The Assisted Decision Making (Capacity) Act 2015 legislatively underpins the rights of people to make decisions for themselves. It includes provision for the making of Advance Healthcare Directives (AHD). This provision provides a useful focus for engaging in a national conversation about our attitudes to dying, death and bereavement.

Programmes such as the “Think Ahead” programme which helps members of the public talk about and record their preferences in the event of emergency, serious illness or death has been well received in civil society. It has been tested in research by general practitioners and is deemed acceptable as a forward planning tool<sup>417,418</sup>. A recent report on how the Civil Service deals with dying, death and bereavement also recommended that all Departments should make available to their staff a planning tool – such as Think Ahead – as part of their suite of staff support.<sup>419</sup>

Encouraging thought and discussion about end of life preferences is the responsibility of both the health services and wider society and can benefit both<sup>420</sup>.

### Recommendation:

**The State must support, enable and encourage people of all ages to discuss and plan for end of life needs – to Think Ahead - including the speedy commencement of the Assisted Decision Making (Capacity) Act 2015 and its provisions on Advance Healthcare Directives.**

A truly strategic approach to the care of people addresses some of the challenges set out above:

- Anticipating and planning for end-of-life care needs will ensure that they have a **better quality of life**, and increase the chance of dying in the care setting of choice.
- **Up to €1.3 billion is being spent on end-of-life care** –careful planning can ensure better patient and service outcomes

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<sup>416</sup> Weafer and IHF 2014

<sup>417</sup> O’Shea et al: Are we ready to Think Ahead? Acceptability Study using an Innovative End of Life Planning Tool: IMJ May 2014

<sup>418</sup> O’Shea et al .*End-of-Life planning with frail patients attending general practice: an exploratory prospective cross-sectional study*. British Journal of General Practice. August 2016

<sup>419</sup> Senator Marie Louise O’Donnell: Finite Lives: A study in how the State deals with issues relating to end of life. Part 1 December 2015

<sup>420</sup> See Professor Patrick Plunkett to the Oireachtas Joint Committee on Health and Children; Page 23 of Report <http://www.oireachtas.ie/parliament/media/committees/healthandchildren/health2014/End-of-Life-Vol-1.pdf>

- Anticipating needs and planning for end of life care can assist in **preventing inappropriate emergency admissions** to acute hospitals, and **facilitate discharge and the provision of care closer to home, in line with patient preferences**
- **Public interest**<sup>421</sup> in end-of-life issues is increasing and is likely to result in more public demand that everyone should be able to have a ‘good death’.
- A **public health approach** to end of life care can enable services to share expertise with the community; encourage discussion of end-of-life issues and engagement in social models of care that may **reduce healthcare costs** and provide increased support during bereavement.
- **The voluntary sector is a significant resource** - pioneering important developments in end of life and bereavement care and committed to innovation.
- Similarly, in the area of mental health the voluntary sector plays a crucial role in bereavement support for adults and children following deaths in a range of different circumstances – from miscarriage/ still birth, to child death, suicide, accidental/homicide, and illness.
- Specialist palliative care services<sup>422</sup> play a critical role in the development and provision of care for people with life-limiting illnesses **in all care settings**, which makes it an **important component of the overall health service**.

The current restructuring of the health service offers a strategic opportunity to focus on end-of-life care and ensure that people can ‘die well’ in Ireland. It must be stressed that dying, death and bereavement cannot be neatly packaged and handed over to palliative care services as their unique remit and responsibility. They are the business of the whole health service, each part of which requires attention and support.

### **The role of palliative care and specialist palliative care (SPC)**

Many international studies indicate savings when patients access hospice programmes. They also show improved length of life, better symptom control and a better patient and carer experience<sup>423</sup>.

Ensuring that patients with life-limiting conditions are cared for in the most appropriate setting for their needs is a better use of health resources and could potentially reduce unnecessary admissions to hospital as well as waiting times in emergency medicine departments.

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<sup>421</sup> The Irish Hospice Foundation’s *Forum on End of Life in Ireland* enjoyed significant public engagement during its period of public consultation in 2009-2010

<sup>422</sup> **Specialist palliative care** – Care provided by a service which has palliative care as its core specialty. It generally involves a multidisciplinary team of healthcare

<sup>423</sup> Prospectus Consulting, Acute Hospital Bed Capacity Review, 2007

In 2011, there were over half a million people aged over 65. Thirty years on, it is estimated that that number will reach 1.4 million.

A study<sup>424</sup> commissioned by the Health Service Executive (HSE) found that 40% of patients being cared for in hospitals could be more appropriately cared for elsewhere. More can be done within the health service to coordinate and deliver high quality end-of-life care.

The role of SPC in the care of people with *any* life-limiting condition – and not just cancer – is increasingly being recognised. Furthermore, it has strong roots in the community and voluntary sector, which contributes – and is willing to contribute further – both financially and in terms of experience, to service planning and development.

The care provided by specialist palliative care services draws on the expertise of multidisciplinary teams skilled in the management of pain and other complex and demanding symptoms, working in specialist in-patient units (hospices), in the community and in acute hospitals. These professionals also have a key role to play in advising and supporting colleagues in other disciplines and care settings; and are increasingly involved in education, research and community development.

Thankfully, most of us will not require ‘specialist’ palliative care, but will hopefully have our palliative and end-of-life care needs met by our GP or other clinician. But for those of us who do require specialist services, our level of access to them is currently determined by where we live.

There has been comprehensive government policy on palliative care since 2001<sup>425</sup>. Despite this there are significant gaps in specialist palliative care (SPC) services in parts of the country.

A 2013<sup>426</sup> report found that because of regional inequity in resource allocation, an estimated 2,500 patients are denied admission to hospice beds every year. Most significantly the report shows that in those areas of the country with access to a hospice in-patient unit, the number of deaths occurring in acute hospitals is significantly reduced. Most hospice patients either die at home (with the support of the hospice homecare team) or in the hospice itself.

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<sup>424</sup> Prospectus Consulting, Acute Hospital Bed Capacity Review, 2007

<sup>425</sup> Explicit commitments to address inequality in hospice/palliative care contained in a number of Government policies including: *Report of the National Advisory Committee on Palliative care, 2001*; *Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015*; *A Strategy for Cancer Control in Ireland* (National Cancer Forum, 2006); *National Development Plan 2007-2013 Transforming Ireland – A Better Quality of Life for All*; *The Joint Programmes for Government 2007 and 2009*; *Palliative Care Services – Five Year Development Framework* (2009-2013), HSE 2009; *Palliative Care for Children with Life-Limiting Conditions in Ireland, a National Policy*, 2009; *National Positive Ageing Strategy* (2012); *Future Health, 2012*; *A Programme for a Partnership Government*, Government of Ireland 2016

<sup>426</sup> *Access to Specialist Palliative Care Services and Place of Death in Ireland – what the Data Tells Us* Irish Hospice Foundation

The IHF has for many years advocated for the removal of disparities in the delivery of specialist palliative care, supported by numerous research reports and in 2015 a report by TCD and the ESRI<sup>427</sup> again shows wide variations in access to SPC services for people with a terminal illness. While all areas have access to specialist community palliative care/home care teams there are differences in service availability with some offered seven days a week, twenty four hours a day and others during office hours only. There are also variations in the availability of multi-disciplinary palliative care teams.

There is compelling evidence that the provision of comprehensive SPC services across all care settings (hospital, home, inpatient hospice and daycare) is cost effective. Where such services exist, people in those services use less acute hospital services and live longer in greater comfort and dignity. Well-developed services allow for earlier patient referral. Less well developed services are only able to offer specialist support nearer to end of life

Areas of the country remain without a specialist inpatient unit (Level 3 Hospice). The Midlands (Laois, Longford, Offaly and Westmeath) and North East (Cavan, Louth, Meath and Monaghan) regions still have no committed plan in place for an inpatient unit. Kerry, Wicklow, Waterford, Galway, Roscommon/Mayo whilst having received approval for development in principle, need to be assured that revenue for running units will be prioritised within annual budgets.

We welcome the Government's commitment to "bring into operation further hospices, the construction of which local communities have funded" and "encourage the development of a hospice in the Midlands and North-East, and home care in regions where there are no hospices."<sup>428</sup>

**Recommendation:**

**As the new Palliative Care Services Three Year Development Framework (2016-2018) is nearing completion, we call for the drawing up of a Department of Health-resourced timeline and clear process to implement the new framework.**

**Recommendation:**

**The 2001 Report of the National Advisory Committee on Palliative Care be revised to take account of developments in the sector.**

**Recommendation:**

**Gaps and inequalities in local hospice/specialist palliative care services should be bridged as soon as practicably possible.**

**Recommendation:**

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<sup>427</sup> Economic Evaluation of Palliative Care Services in Ireland ESRI/TCD

<sup>428</sup> A Programme for a Partnership Government, Government of Ireland 2016

## **Children’s palliative care services: To re-evaluate the national priorities for this service in light of development since 2009**

### **ACUTE HOSPITALS**

Acute hospitals are not necessarily geared towards the dying person. But 43% of people die in acute hospitals. There has been some welcome progress in relation to end of life and bereavement issues in acute hospitals. The Hospice Friendly Hospitals (HfH) Programme<sup>429</sup> is an evaluated initiative of the Irish Hospice Foundation in partnership with the HSE that seeks to ensure that dying, death and bereavement are considered integral to the business of the hospital as well as improve the physical infrastructure. There have been welcome developments mainstreaming this initiative within the HSE, including the appointment of end of life care coordinators to each of the hospital groups and End of Life Care Committees.

Collaborative approaches and networking (such as that in HfH Programmes) has proved to be beneficial and create staff buy-in across all disciplines. These require sustained attention and mainstreaming to maintain improvements.

#### **Recommendation:**

**Initiatives such as the Hospice Friendly Hospitals Programme and Design and Dignity schemes should be mainstreamed across the hospital networks and funding allocated to support them where necessary.**

#### **Recommendation:**

**To ensure continuing development of a culture of excellence in end of life care, ongoing training in (*inter alia*) palliative care, communications, breaking bad news, awareness of end of life issues and bereavement support should be made available to healthcare professionals, allied healthcare professionals, care and ancillary staff, and protected time to avail of such training.**

While most people express a wish to die at home, many will not achieve this. Barriers to discharging people who wish to die at home or to long-stay care from the acute hospital include the lack of available comprehensive and appropriate supports in community and continuing care, lack of access to hospice beds, the “nine to five” nature of some services and delays in the processing of Fair Deal applications. With strategic support, as well as the provision of appropriate services such as Community Intervention Teams and palliative care homecare, GPs, primary healthcare teams, carers and families may be supported in allowing people to die at home more instances.

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<sup>429</sup> Clark, D., Graham, F. (2014), *The Hospice Friendly Hospitals Programme; A Narrative History*, IHF and Walsh, K. (2014), *The Hospice Friendly Hospitals Programme; Overview 2007-2013*, IHF.

## **Primary Care**

The majority of their care in the last year of their life of the 29,000 people who die each year is provided by the GP and primary care team. However in Ireland, unlike other countries, there has been no formal framework to support community-based health care staff to assist them identify and respond to the care needs of those people who are facing death in the community.

## **Dying at home**

People who wish to die at home and those who care for them will be largely dependent on the care provided by GPs and primary care teams. In 2010 the Irish Hospice Foundation, in partnership with the Irish College of General Practitioners and the HSE established the Primary Palliative Care (PPC) programme<sup>430</sup>, in order to identify palliative care initiatives that will support primary care team's responses to adults living with advancing life-limiting diseases in the community.

One recommendation was the introduction of a formal mechanism for GPs to communicate to their local out-of-hours service providers with regard to the palliative care needs of their patients

## **Night Nursing**

Night Nursing services provide up to 14 nights of palliative care nursing for those nearing end of life who wish to die in their own home. This service plays an integral part in ensuring quality and continuity of care and reducing health care costs at end of life in acute services. In 2015, 2,812 patients with provided with 9,483 nights of care at end of life. Both demand and costs are increasing. The service is funded by the Irish Cancer Society and the IHF with the HSE beginning to give financial support this year.

A recent evaluation showed that more could be done to integrate the service with the primary care and SPC services that support people die at home.

Support is required for primary care staff to help care for their patients who are dying at home and in particular to support GP engagement to deliver end of life care in nursing home settings. Community intervention teams are critical in providing support to families caring for a person at end of life at home or in a nursing home setting.

Innovative programmes are underway to promote excellence in end of life and bereavement care in the residential care sector.

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<sup>430</sup> IHF, HSE, ICGP: Primary Palliative Care in Ireland: Identifying improvements in primary care to support the care of those in the last year of life

### **Recommendation:**

**Embed and mainstream innovative end of life care services (such as night nursing) and quality improvement and practice development initiatives to support primary care teams and those working in the residential care sector.**

### **Place of death –**

The majority of people say that they wish to die at home. This is not always possible or appropriate. There is much activity and conversation on this area but little joined up action.

### **Recommendation:**

**To ensure long term focus on care at home we advocate for a national performance indicator on place of death and place of care so that current spending on end of life care can be focused on the most appropriate and cost effective care in the primary, home care and community settings.**

This should help support the drive for change towards more care in the community.

## **BEREAVEMENT**

Just as death is inevitable it follows that bereavement is an unavoidable life experience. Over 50% of Irish people have been bereaved of someone close during the previous two year period<sup>431</sup>. Regardless of circumstance of death much bereavement support comes under a 'health promotion' banner allowing that supportive friends, colleagues and frontline professionals provide time, compassion and accurate information. However, a proportion of people (estimated to be 25%) benefit from more bereavement- focussed community interventions – often those provided through volunteer structures or voluntary groups using a counselling approach. Between 5 to 7% of bereaved people go on to develop serious disruptions and illness or 'complicated grief' and require psychological and psychotherapeutic therapies<sup>432</sup>.

Children's bereavement necessitates focussing on the whole family as well as the child, and best practice outlines roles for community education, professional education as well as investment in mental health services for the smaller proportion of children who encounter significant difficulty (reference [www.childhoodbereavement.ie](http://www.childhoodbereavement.ie))

Just as palliative care has been described above using a public health framework, so bereavement care benefits from use of the same framework.

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<sup>431</sup> Weafer and IHF 2014

<sup>432</sup> Aoun SM et al. A public health approach to bereavement support services in palliative care. Australian and New Zealand Journal of Public Health. 2012; 36: 14–16. doi: 10.1111/j.1753-6405.2012.00825.x. pmid:22313700

A strategic approach to bereavement care in Ireland would promote this understanding and ensure that people access the appropriate service for their needs; it would direct training and the regulation of counselling and volunteer support in this area as well as explicitly including grief related disorders as part of the remit of mental health services.

**Recommendation-**

**Explicit inclusion of bereavement support in an overarching end of life strategy and the development of national standards on bereavement care.**

<http://hospicefoundation.ie/>

## Irish Life Health

Irish Life Health is the new force in health insurance following the acquisition by Irish Life Group of Aviva Health and GloHealth in August 2016. Set out below are the views of both Irish Life Health and GloHealth representing over 400,000 health insurance members.

Irish Life Health welcomes the opportunity to make this submission on this fundamentally important topic for the population of Ireland but will limit its views to those pertinent to health policy which may impact health insurance consumers.

Private health insurance has formed an intrinsic part of the Irish health care system since the establishment of the VHI in 1957. The largest provider of hospital services in the State to the private sector is the HSE, which now receives in excess of €620 million<sup>433</sup> from private health insurers. In addition, to which, we estimate, consultants working for the HSE also receive in excess of €140m<sup>434</sup> income from private fees generated from private work in public hospitals.

The evolution of legislation within the health insurance market has led to private health insurers being forced to drive consumers into public hospitals, and, public bed charges have created a situation where public hospitals have a financial incentive to prioritise private patients over public patients. This has created inequity for public patients, but also for private patients who are paying twice to receive the same service (private patients are charged €813 per night for the same public bed, or in some instances even trollies, and normally attendance by the same consultant they would see as a public patient) as they have paid for through taxation.

The logic conclusion is that if equity is to be achieved within the public health system, the HSE should cease providing all private health care services and concentrate its services to public health. This would require additional funding for the HSE and a fundamental reassessment of the reimbursement model for consultants working within the HSE.

Irish Life Health thanks the Committee for the opportunity to participate in the debate on how best to shape the future of healthcare in Ireland.

### STRATEGY

#### **1. What are the key priorities for inclusion in a ten year plan for the health service?**

The key priorities for inclusion in any ten year should be to achieve a sustainable health service that provides an equitable service to everyone.

#### **2. What are the key challenges, in your view, to achieving a “universal single tier health service, where patients are treated based on health need, rather than ability to pay”?**

What constitutes a “universal single tier health service” needs to be defined. Is this where equal access is provided to all patients within a public health care system or is this equal access to all patients to all health care facilities within the country? The determination of this definition will then drive both the funding model and regulatory structure required to sustain this definition.

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<sup>433</sup> HSE Data Management Reports - December 2015- gross private charges were approximately €620 million. December 2013- prior to the implementation of new charges- gross private charges were circa €470million.

<sup>434</sup> This is estimated as being approximately 25% of total expenditure to public and voluntary hospitals, i.e. €620\*0.25/0.75

Currently access to private hospital facilities and consultants is limited by a patient's ability to either pay for health insurance or to pay directly out of pocket. Access to public health care facilities is universal to all but with extensive waiting lists for public patients.

If equity of access to public health care services is the ambition then the NHS model should be considered. Access to the NHS in the UK is only possible via the public system, the NHS does not provide private treatments nor does it allow its consultants to engage in private practise within the NHS. Private treatment if sought can be accessed through private hospitals and private consultants within the UK. Hence, a single tier with regard to public access is possible but does allow for those who can or wish to pay private to access treatment (sometimes quicker) in private facilities.

This model could be adopted within Ireland by ceasing to allow the HSE and consultants to carry out private work within public facilities. Private patients seeking treatment could gain access to private facilities within Ireland. The key challenge to the implementation of this model is that the HSE currently generates approximately €620m in income from private patients and consultants in public hospitals are provided with over €140m in additional fee income to their public hospital contract. This would leave a funding gap within the system that would need to be rectified, however, all access and treatment within the HSE would then be on a pure needs basis. Category A consultants currently within the HSE can only provide public work and a model transitioning all consultants onto this framework could also be utilized, with perhaps the option to carry out private work within private facilities once their public responsibilities had been fulfilled.

If the intent is to move to a system of equity of cover across all health providers in the country then a more fundamental change of the entire health care and funding system would need to be implemented to create parity for all through a universal health insurance or social insurance model.

### **3. What actions are needed to plan for, and take account of, future demographic pressures (population growth, ageing population), and their impact on the health system?**

Irish Life Health does not have a view vis-à-vis this question for the health system, however, this issue is also pertinent within a community rated health insurance market, where all policyholders pay the same price of the same product regardless (generally) of age or previous claims history. If a sustainable health insurance market is to be maintained (and hence keep people from utilising the public system) then measures need to be put in place to keep health insurance attractive for younger members and for those on lower incomes.

The health insurance levy is currently set as two flat rates that are applicable to each plan regardless of the premium payable on those plans. Hence currently the cheapest "non-advanced plan" which costs €433 per annum has a levy of €202 which means the levy is over 40% of the premium, meanwhile the most expensive non-advanced plan is approximately €1300 which means the levy is 15% of the premium. The cheapest advanced plan on the market is around €655 with a levy of €403 which accounts for 60% of the premium, while the most expensive plan is €6,300 and the levy is 6% of the premium.

The levy is therefore a socially regressive form of taxation whereby those on the cheapest most affordable plans are paying substantially more than those on the expensive plans on the market and only being provided with full coverage for public hospitals. While the risk equalisation scheme was designed to spread claims costs across the market it was not meant that those who could least afford it should substantially subsidise the most expensive plans on the market.

As a flat based health insurance levy currently disproportionately affects premiums of those on lower plans (which are those generally taken out by younger persons) this should be change to a more socially progressive model of a levy based on a percentage of premium.

## **INTEGRATED PRIMARY AND COMMUNITY CARE**

### **What steps are needed to move from the current model towards a model based on integrated primary, secondary and community health care?**

Irish Life Health would support a move to an integrated primary and community care model which places patients in the lowest costs medically safe setting. Both Aviva Health and GloHealth previously provided their views on primary care to the Department of Health copies of which are set out in Appendix 1.

### **What are the key barriers to achieving this, and how might they be addressed?**

- **In your experience, what are the key roadblocks you encounter in your particular area of the health service?**

Irish Life Health would endorse a move towards greater utilisation of primary care and integrated services. It should be noted when considering funding models that the experience within the private health insurance market has been that customers have been reticent to purchase any standalone primary care products and prefer instead to pay out of pocket for these expenses.

Any increase in primary care, secondary and community health care will only work where the funding model incentivise the lowest cost setting and there are penalties when this is not adhered to e.g. within the private health insurance model – insurers have been very successful in changing hospital behaviours by incentivising that procedures are carried out in the most appropriate safe clinical i.e. side-room rather than day case, or day case rather than in patient stays.

- **How would you ensure buy-in from health care professionals to progress towards an integrated health care model?**

Irish Life Health does not have a view on this matter.

- **Are there any examples of best practise that the Committee should consider? Please refer to any evidence you have to support this.**

Irish Life Health does not have a view on this matter.

## **FUNDING MODEL**

### **Do you have any views on which health service funding model would be best suited to Ireland?**

Currently the legislative structure within the Irish health insurance market pushes patients into public hospitals and incentives public hospitals to favour private patients over public patients. The government introduced a risk equalisation scheme through the implementation of a flat rate health insurance levy and age related tax credits in 2009. This levy scheme was subsequently amended in 2012 and the concept of “non-advanced” plans was introduced in order to alleviate the impact of a flat levy on plans with lower cover.

The legislation sets out on what basis a plan may be deemed an advanced or non-advanced plan. If a health insurance contract has more than 66% coverage for any private hospital it is automatically deemed an advanced plan.

The legislation therefore favours the provision of public hospital coverage over private hospital coverage in order to avail of a lower levy and pushes patients into already overcrowded hospitals. This is an artificial construction as in a number of cases public hospital charges are more expensive than private hospital charges, in particular when looking at side room procedures.

The Minimum Benefit Regulations<sup>435</sup> specify that all health insurance contracts must cover as a minimum the daily charge in a public hospital. On 1 January 2014 the Minister for Health also changed the charging structure within public hospitals for private patients. From this day forward all private patients would be charged a minimum of €813 for overnight accommodation in a public hospital even if this was provided on a chair, trolley or in a public bed in a public ward. The public hospital does not provide any additional or private services to private patients differing from those it provides to public patients. The new charges do however provide a financial incentive for public hospitals to favour a private patient (for whom they will receive €813 per night) over a public patient in the same bed where at best they will receive (€75 per day for 10 days).

Currently therefore:

- Private patients are being driven into public hospitals rather than being accommodated outside the public system;
- Public hospitals are being financially incentivised to favour a private patient over a public patient;
- Private patients are receiving the same accommodation and treatment they would receive as a public patient but being charged twice for the same – once through taxation and a second time through their insurer.

None of the above is equitable for either public or private patients within the health care system – however it does generate additional revenue for both public hospitals for no additional costs and for consultants working within the HSE.

In addition, the change in the charging structures for private patients in public hospitals has removed the previous 20% cap of use of designated beds which curtailed the level of private work consultants working within the public system could effectively utilize. The HSE has highlighted<sup>436</sup> that the rules limiting the private practice of consultants within public hospitals may have been compromised by the change in charging structures.

The logical solution to the above would be to remove the current legislative restrictions that are forcing patients into public hospitals and a gradual withdrawal of private work within public hospitals. This should be accompanied by measures to maintain the stability within the health insurance market to avoid any further pressures being placed on the public health care system.

**Please outline the specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating.**

In order to remove the challenges set out below, Irish Life Health would recommend a two-step approach to the withdrawal of private patients from the public health care system.

The following changes should be implemented:

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<sup>435</sup> SI 83/1996 Health Insurance Act, 1994 (Minimum Benefit) Regulations as amended

<sup>436</sup> <http://www.irishtimes.com/news/health/rules-limiting-private-practice-in-hospitals-a-farce-hse-chief-1.2490156>

- Change the risk equalisation scheme from a flat based levy model to a % of premium and hence remove the legislative requirement to cover public hospitals on lower based plans – with this insurers could commence to redirect patients away from public hospitals;
- Revise the Minimum Benefit regulations so that these to do not require coverage of public hospitals;
- Remove private patients from public hospital entirely and create one single public health care model.

The public healthcare model could continue to be funded directly through taxation which adjustments made for loss of income due to ceasing of private funding.

Based on experience dealing with both private and public hospital providers, Irish Life Health, would note that a reimbursement models within private hospitals where payment is based on lengths of stay, procedures undertaken and fixed priced packages are put in place are far more efficient and effective than the standard per night/day case rates within public hospitals.

**What are the main entitlements that patients will be providing under your funding model?**

Irish Life Health does not have a view in relation to this.

**Please provide examples of best practise, or estimated costs of such models if available.**

Irish Life Health would suggest that the template used within the UK for the NHS be assessed.

**Conclusion**

Irish Life Health believes that if the ambition is to create one single tier of public health care in Ireland this can be achieved by taking some difficult decisions that may impact funding within the public health sector in the short term but which would create equity of access for all.

To achieve a single tier public health care system in Ireland the support of the private health insurance market is required to alleviate pressures within the public healthcare system and to help prevent further increases in public waiting lists. As such private health insurance needs to be kept affordable for those who elect to fund their own healthcare and reduce the burden on the public healthcare system.

<http://www.irishlifehealth.ie/>

## Irish Medical Devices Association (IMDA)

The Irish Medical Devices Association (IMDA) is the business association within Ibec which represents the medical technology. IMDA's broad focus is to promote and support an environment that encourages the sustainable development and profitable growth of our multinational and small to medium size medical device and diagnostic companies. The sector in Ireland employs 29,000 people across 450 companies. We are thankful for the great work that our healthcare professionals do every day on behalf of Irish citizens, and we fully support the move towards a single long-term vision for health care and direction of health policy in Ireland, addressing the challenges that are impacting our strained health service.

Statistics show that Ireland's population is both increasing and aging and forecast to grow even further in the coming years. The Irish birth rate of 14.9 per 1,000 residents is higher than the EU average of 10.1, and Irish citizens actually live longer than the average in Europe. While this is positive for the individual, these changing demographics pose significant challenges for the health service now and in the coming years.

The primary aim of any medical technology is to improve medical care, making it easier to improve the overall health of users or patients. Working together Ireland can drive a new era in healthcare that will be good for patients, good for medtech and good for the Irish economy. IMDA's key recommendations are centered around a theme of ***working better together to deliver a modern healthcare system for everyone***. Our recommendations are:

- A. Encourage changes to make Ireland's healthcare infrastructure world class.
- B. Promote innovation in healthcare settings to deliver better patient care and drive economic success.
- C. Reduce healthcare costs by adding value and promote early adoption of new healthcare solutions.

IMDA recognises the important role our members play in contributing to a world-class healthcare system. The opportunity to examine future models of healthcare in Ireland has arrived at a time when IMDA has newly launched its strategy, which is also focused on achieving better healthcare solutions for patients and the health service.

### IMDA Strategy - 'The global medtech hub'

Earlier this year, IMDA launched its four year strategy for the medtech industry in Ireland 'The Global Medtech Hub'. This strategy set-out ambitious targets for 2020. During the recent economic crisis, the medtech industry continued to expand and experienced exports of €12.6 billion in 2015. This steady growth which accounts for nearly 10% of all Irish exports has now been bolstered as the recovery takes hold in the domestic economy. IMDA has identified key priorities to ensure Ireland is innovating for future healthcare and economic growth, including:

- **Drive our future:** Identify and influence key areas of focus such as trade barriers, skills needs, and changes to the business environment.

- **Achieve the potential of the cluster:** Assist companies utilise the cluster to expand and achieve their potential developing new technologies from concept to market.
- **Use technological innovations to help patients:** Facilitate cooperation between sectors such as pharmaceuticals, biotechnology and ICT and realise the potential for advanced, additive and cell manufacturing.
- **Nurture entrepreneurship:** Develop policies and conditions to ensure entrepreneurship can thrive, such as facilitating new funding opportunities.

### **Recommendations for The Oireachtas Committee on the Future of Healthcare.**

Like many countries, Ireland's health system faces the challenge of dealing with increased pressures with limited resources. However, there is now an opportunity for the government to build a world-class healthcare system and to attract more clinical research into Ireland. Ireland should maximise opportunities with growing demands to become major contributors to global healthcare and the global economy.

#### **A. Encourage changes to make Ireland's healthcare infrastructure world class.**

Healthcare systems globally are increasingly challenged by greater demands for healthcare services in the face of diminishing fiscal resources. The healthcare system in Ireland is no different. The medtech industry has a key role to play in addressing these challenges which the system faces and supporting its sustainable development.

The adoption of innovative processes and healthcare solutions within the health system would support better patient outcomes. Innovation in the sector will increasingly align with new care models. New digitally enabled health applications have the potential to transform healthcare delivery models and introduce efficiencies. Data will become one of healthcare's greatest resources and will drive better clinical decision making, improve outcome based accountability and promote patient empowerment. Progress can be made by working together.

#### ***IMDA recommendations:***

- Develop a more efficient Irish healthcare system. Engagement with industry will help the Irish healthcare system to identify more efficient usage of limited resources by learning from best practice in lean processes that have already been adopted by industry. Recently, IMDA and the Mater Misericordiae University Hospital have decided to work together to share best practice in lean principles. The objective is to share expertise across both sectors and to learn from each other. Over the past 5 years, IMDA have set up similar partnerships in lean (08) between companies and the results have been impressive. Should this partnership prove beneficial, the scope of the programme of work could be expanded to other hospitals and industries.
- Move towards integrated health information systems. Much of today's health information systems function as silos. We must create an opportunity for information to be globally integrated and readily available, whereby electronic

patient records can travel with the patient. Due consideration of data interoperability and healthcare data standardisation is critical to allow a platform based approach to healthcare delivery. The roll-out of the national broadband plan is essential for integration to be possible. We must recognise the importance of technology within the health services and the opportunity that technology can bring not only within the hospital, but also to care in the home, and the community. IMDA and ICT Ireland have set up an IoT for Health Forum to support the development of connected technologies that will drive better patient care and a more efficient health service and we look forward to working with the HSE in this regard.

- Build Ireland's reputation as a centre of excellence for clinical and surgical research, and for early adoption and investment in new, advanced medtech solutions.

### **B. Promote innovation in healthcare settings to deliver better patient care and drive economic success.**

Excellence in patient care is dependent on innovation, without it clinicians would not be able to build the sound evidence base needed to underpin best practice. Whilst there are excellent examples of leadership within Ireland's healthcare settings, hospitals and primary care centres, we must do more to leverage recent investments and progress made to develop a culture that values, promotes and rewards innovation and R&D practices.

The availability of state of the art research infrastructure for medtech simulation, testing and prototyping within our medical schools and teaching institutions is necessary to be able to attract global R&D and support our thriving indigenous base. Research centres will need support for investment in critical leading edge technologies such as robotics, surgery simulation, 3D printing and cell manufacturing. More companies will direct investment into clinical research in Ireland if our research centres are recognised internationally as world class.

A robust clinical research infrastructure would provide enormous value to Ireland's patient population and to the economy. The level of medtech clinical investigations taking place in Ireland is currently low considering the number of medtech companies located here. We recognised the progress that has been made in recent years with the establishment of the National Healthcare Innovation Hub and recently announced Health Research Board Clinical Research Coordination Ireland, but more needs to be done.

#### **IMDA recommendations:**

- Promote, reward, and value a culture of innovation leadership within the Irish healthcare system. Encourage engagement with industry to understand best practice in innovation. Encourage clinical-industry engagement to support commercialisation of innovative medtech therapies.
- Appoint an Executive Director with responsibility to drive innovation and R&D within the Department of Health. Set and monitor relevant metrics across the health service.

- Attract and retain globally recognised key opinion leaders and researchers.
- Invest in hospital based state of the art facilities in areas such as surgery simulation, testing and prototyping.
- Reform the medical technology ethics approval process in Ireland. Align pharmaceutical trial and device investigation approval requirements, whereby the latter would only require recognised single ethics committee approval for multi-centre investigations.
- Introduce a national credentialling system which will further improve standards of quality, safety and ethical behaviour in regard to medical technology supply and support. IMDA's Code of Ethical Business Practice guidance was developed to safeguard the important relationships that companies have with healthcare professionals with whom they work closely in developing and improving medical devices. IMDA's sees ethical compliance at the forefront of the sector's business.

### **C. Reduce healthcare costs by adding value and promote early adoption of new healthcare solutions.**

The ability to adopt new and advanced technologies is essential for best practice in patient care. The establishment of the National Healthcare Innovation Hub as a first step to enable Ireland's indigenous SMEs to introduce new product into the health system is welcomed. There is an opportunity for Ireland to be recognised as an 'early adopter' of medtech, this is a measure of international best practice in modern healthcare systems.

Ireland needs to acknowledge the transformational change that can be achieved through a pragmatic approach to public procurement. Ireland is still struggling to move procurement to a strategic activity to support innovation and adoption of new technology.

#### **IMDA recommendations:**

- Adopt best in class economic models such as a Value-based Procurement model, i.e. the Most Economically Advantageous Tender (MEAT) model for healthcare provision. The impact of new technologies on the longer term outcome and total cost of a patient's illness needs to be considered, as opposed to tendering purely on the basis of short-term prices. Value for money mechanisms should be modified to take into account other evaluation criteria such as quality and patient outcomes. Medtech Europe, the EU trade association that represents the medtech sector are currently working with EU based hospitals to pilot a new procurement model that will support value-based decision-making in healthcare procurement. (see appendix 1)
- Support clinical input as an important element of effective procurement of medtech. Early engagement with industry can be mutually beneficial.

- Simplify tendering processes to encourage greater participation of indigenous companies. In particular administration burdens and public procurement costs for SMEs should be addressed. The excessive use of centralised procurement risks impeding competition by excluding SME companies from the marketplace.
- Introduce a Small Business Innovation Research fund for health, similar to the fund set-up for energy and transport to support the adoption of new and advanced technologies into healthcare system. Similar programmes have proven to be effective in the UK and the US for medtech adoption in hospitals.

## Appendix 1:

### Value based procurement, a new model for Europe.

Value-based healthcare is a framework for achieving better outcomes that matter to patients, and optimising the cost of care delivery to the health system. This idea has been discussed for a decade, inspired by the academic work of Professor Michael Porter and others putting at the core the outcomes that matter to patient divided by the cost to deliver this care<sup>437</sup>. Others have highlighted the importance of considering the value of investment and the views of other healthcare actors – such as providers and healthcare professionals - along with societal and economic considerations<sup>438</sup>. The need for change was embraced by the MedTech sector in Europe as part of the five-year strategy set out in the *Contract for a Healthy Future*<sup>439</sup>. This document acknowledges the need to change how all actors operate in order to steer European healthcare onto a sustainable path. Now is the time to move from theory to practice. The potential of procurement in fostering value-based healthcare remains largely untapped. By choosing healthcare products, services and solutions that offer the most value, procurement has the power to move the needle towards smarter, more economically advantageous spending.

There are some excellent examples of how this has been done in ways that benefit the purchaser while incentivising innovative companies to develop healthcare products, services and solutions that offer genuine value. However, it has yet to be uniformly embraced and value-based procurement is not universally known or understood. At the same time, the need to accelerate the shift towards the value-based approach to healthcare grows ever greater. Pressure on budgets and demographic challenges are focusing minds on the need to reimagine health services. Significant variations in outcomes are seen between and within European countries. Short-term cost-cutting solutions and austerity measures have reached their limit and start to affect the quality of health and care. This is resulting in a vicious circle of increased healthcare needs and associated spending.

MedTech Europe, in partnership with The Boston Consulting Group (BCG) and procurement experts, have launched the **MEAT Value-Based Procurement** initiative. Under this framework a tool has been developed to support value-based decision-making in healthcare procurement in line with the EU public procurement directive.

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<sup>437</sup> <http://www.nejm.org/doi/full/10.1056/NEJMp1011024#t=article>

<sup>438</sup> [http://www.medtecheurope.org/sites/default/files/resource\\_items/files/BCG-Procurement-Dec-2015.pdf](http://www.medtecheurope.org/sites/default/files/resource_items/files/BCG-Procurement-Dec-2015.pdf)

<sup>439</sup> <http://www.medtecheurope.org/index.php/node/536>

The development of this tool arose from the two critical challenges that the global healthcare industry are facing; 1) large variation in patient outcomes and 2) increasing costs. It is widely acknowledged that a valued-based approach to procurement is required in order to address these challenges.

BCG and MedTech Europe's new valued-based procurement tool is aimed at breaking down organisational silos within healthcare institutions, and promote innovation amongst medtech companies. Currently this tool is being piloted across Europe, and IMDA would be happy to share the results with the Oireachtas Committee once they become available. **IMDA and IMSTA are jointly in dialogue with an Irish hospital to determine interest in participating in a Medtech Europe pilot in Ireland.**

For future information please contact [sinead.keogh@ibec.ie](mailto:sinead.keogh@ibec.ie) , Director of IMDA.

<http://www.irishmedtechassoc.ie/>

## Irish Medical Organisation

The Irish Medical Organisation (IMO) is the only body that represents all doctors in Ireland and is committed to a caring efficient and effective health service.

**The IMO believes that the primary strategic goal over the next ten years should be to develop a universal healthcare system that aims to secure access to adequate, quality healthcare for all when they need it and at an affordable cost.**

### IMO Key Priorities for the Health Service

Building a 21<sup>st</sup> century universal healthcare system requires:

- Agreement on a strategic plan for the development and resourcing of General Practice. General Practice is the cornerstone of any healthcare system. The continuity of care provided in General Practice is key to improving patient outcomes and cost-effective care;
- Building Capacity in the Public Hospital System. This will require detailed medical manpower planning to assure a consultant-delivered hospital service and an assessment of the acute bed capacity needed;
- Provision for appropriate long-term residential and community care services as well as rehabilitative care services to cater for the needs of an ageing population;
- A new mental health strategy that places mental health on a par with physical health;
- Expansion of Public Health Expertise to ensure that health service planning and prevention measures take into account the best available evidence.

### Key challenges to a Universal Health System

Ireland faces three significant challenges to achieving a universal healthcare system, as follows:

- Enhancing service provision and manpower capacity across the health system to meet the needs of a growing population and changing demographics. This requires an assessment of capital investment, manpower planning across all health professionals and the financial resources required to provide a 21st century healthcare service in line with international best-practice.
- The recruitment and retention of our highly qualified medical workforce. As key decision makers doctors are vital healthcare professionals in a 21st century healthcare system assuring the highest quality evidence-based care. Doctors undergo many years of training to become specialists in their field. Only doctors possess the clinical skills and expertise necessary to diagnose illness, recommend treatment and advise patients on the likely prognosis. No other healthcare professional is trained in this way or possesses these skills. With up to 60% of our trainee doctors planning to leave, the recruitment and retention of our medical workforce is the biggest threat to assuring a quality public universal health service.

- I. **Financing universal healthcare.** Universal healthcare will require additional capacity and resources. In order to avoid a fiasco like the water charges, open debate is required on both the future vision of our health services and the cost, as well as the most appropriate funding model.

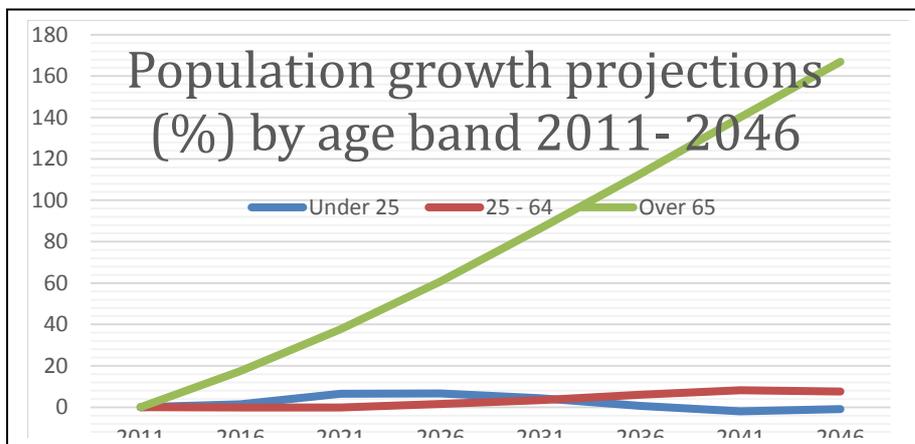
**Building Capacity in the Healthcare System**

Health services are complex and require detailed long-term planning. In order to achieve the desired goal of a universal healthcare system careful assessment is needed of the capacity, financial and manpower resources needed across the health system.

**Ireland’s Growing Population and Demographic Change**

Ireland’s population is both growing and ageing. Based on a number of different scenarios the CSO estimate that Ireland’s population will grow from 4.758 million<sup>440</sup> to between 4.85 and 5.3 million by 2026 while the population aged 65 and over will grow from 586,600 people (2014

figures) to between 850,000 and 860,000 by 2026.<sup>441</sup>



<sup>440</sup> Census April 2016 [www.cso.ie](http://www.cso.ie)

<sup>441</sup> CSO, Population and Labour Force Projections, 2016-2046 [www.cso.ie](http://www.cso.ie)

While the majority of people are healthy, an expanding and ageing population places significant demands on the healthcare system with the prevalence of chronic disease expected to increase by 4% - 5% per annum during this period.

Projected Patients with Chronic Disease Aged 65+ (2016 – 2026)

Disease	Prevalence (%)	2016	2021	2026*
Angina	10.1	63,040	73,920	86,930
Hypertension	51.4	320,830	376,180	442,400
Atrial Fibrillation	5.6	34,950	40,980	48,200
Stroke	2.9	18,100	21,220	24,960
Diabetes	10.9	68,040	79,770	93,820
COPD/Lung Disease	5.1	31,830	37,320	43,900
Arthritis	38.9	242,800	284,700	334,810

Health Service Executive, *Planning for Health: Trends and Priorities to Inform Health Service Planning 2016*, p. 37. \* 2026 patient projections achieved by applying stated prevalence rates to the aged 65+ population estimate for 2026 of 860,700 supplied in Central Statistics Office, *Population and Labour Force Projections: 2016-2046*, 2013, p. 27. Assessment based on static prevalence.

### Resourcing General Practice

GP care is the cornerstone of any universal healthcare system. Continuity of care and the patient-centred (rather than disease-focused) approach that is specific to General Practice is associated with better health outcomes, equity of access, reduced inequalities in health, more appropriate utilisation of services, long-term cost effectiveness and increased patient satisfaction<sup>442 443 444</sup>. Up to 90% of consultations are treated in General Practice without further referral to secondary hospital care.<sup>445</sup>

Extensive research by the late Barbara Starfield<sup>446</sup> found that:

- Increasing the supply of GPs is associated with better health outcomes, lower rates of all-cause mortality, lower post-neonatal mortality rates, higher numbers of people reporting good health and higher life expectancy;
- GP care is associated with more equitable distribution of health in populations.

Investment in General Practice will lead to efficiencies in the medium to long-term. The continuity of care provided by General Practice is associated with lower mortality rates in the elderly,<sup>447</sup> and decreased likelihood of future hospitalization, as well as decreased

<sup>442</sup> Starfield B, Shi L and Macinko J, Contribution of Primary Care to Health Systems and Health. *The Milbank Quarterly*, Vol. 83, No. 3, 2005 (pp. 457–502)

<sup>443</sup> Atun R, What are the Advantages and Disadvantages of Restructuring a Health System to be More Focused on Primary Care Services? Copenhagen, WHO Regional Office for Europe, Health Evidence Network report ; January 2004

<sup>444</sup> Kringos DS et al, The Strength of Primary Care in Europe, NIVEL 2012

<sup>445</sup> Gouda P. 2013 Treat or Refer? Factors Affecting GP Decisions Forum August 2013

<sup>446</sup> Starfield B, Shi L and Mackinko J. Contribution of Primary Care to Health Systems and Health, *The Millbank Quarterly*, 2005: 83:3 457-502

<sup>447</sup> Maarsingh OR et al, 2016 Continuity of care in primary care and association with survival in older people: a 17-year prospective cohort study, *British Journal of General Practice* Aug 2016

emergency department use.<sup>448</sup> GP continuity of care is also associated with time saving, less use of laboratory tests, fewer referrals to secondary care and lower health care expenditure.<sup>449</sup>

Health policy discourse that fails to mention the key role of the GP is misleading. International research into General Practice and community care<sup>450 451</sup>, firmly relates to the unique role of the General Practitioner in terms of continuity and coordination of care and the resources provided to support GP care. Countries that are considered to have a strong primary care system exhibit the following traits:

- Universal access to GP care with little to no out-of-pocket payments;
- Provide appropriate economic conditions and distribute resources equitably based on medical need;
- Have strong governance arrangements in place including compulsory registration with a GP and a GP gatekeeping role;
- Provide a comprehensive range of services in General Practice and the community;
- invest in the development of the workforce.

General Practice in Ireland has been decimated with the removal of €160 million or approximately 38% of funding through the heavy handed and arbitrary FEMPI mechanism. Ireland is facing a shortage of GPs as our newly trained GPs see emigration as the only viable option.

Proposals to address the shortage of GPs by transferring GP tasks to other healthcare professionals is not in the interest of patients or the state. In addition to interrupting continuity of care, nurse delivered care is associated with a greater use of healthcare resources<sup>452</sup> including higher number of visits<sup>453</sup>, longer consultations<sup>454</sup> and higher use of diagnostics<sup>455</sup> while commercial factors have been found to influence pharmacy prescribing above clinical evidence.<sup>456</sup> There is no evidence that patient outcomes are improved by transferring tasks to other healthcare professionals in the community.

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<sup>448</sup> Starfield B, Shi L and Mackinko J. 2005

<sup>449</sup> Mainous III AG. *Continuity of care and trust in one's physician: evidence from primary care in the United States and the United Kingdom*. In: Baker R, editor. 2000 North American Primary Care Research Group Meeting; 2001 January 2001: Fam Med 2001; 2001. p. 22-7.

<sup>450</sup> Starfield B. Primary care: an increasingly important contributor to effectiveness, equity, and efficiency of health services. SESPAS report 2012

<sup>451</sup> Kringos DS et al, The Strength of Primary Care in Europe, NIVEL 2012

<sup>452</sup> A. Hemani *et al.*, 'A Comparison of Resource Utilization in Nurse Practitioners and Physicians', *Effective Clinical Practice*, Vol. 2, No. 6, November 1999, pp. 258-265.

<sup>453</sup> E.R. Lenz et al., 'Primary care outcomes in patients treated by nurse practitioners or physicians: two-year follow-up', *Medical Care Research and Review*, Vol. 61, No. 3, September 2004, pp. 332-351.

<sup>454</sup> C. Seale, E. Anderson, and P. Kinnersley,, 'Comparison of GP and nurse practitioner consultations: an observational study', *British Journal of General Practice*, Vol. 55, No. 521, December 2005, pp. 938-943.

<sup>455</sup> K. Rosenberg, 'NPs and Physician Assistants Order more Imaging Tests than Primary Care Physicians', *American Journal of Nursing*, Vol. 115, No. 3, March 2015, p. 63.

<sup>456</sup> P. P. C. Chiang, 'Do pharmacy staff recommend evidenced-based smoking cessation products? A pseudo patron study', *Journal of Clinical Pharmacy and Therapeutics*, Vol. 31, Issue 3, June 2006, pp. 205-209; P.

### **Recommendation No. 1**

The IMO is calling on the Department of Health and the HSE to agree a strategy with the IMO for the development of General Practice in Ireland over the coming decade. To ensure the maximum benefit for both patients and the health system the Strategy must include:

- a) **A commitment to preserving the following positive traits of General Practice:**
- **Community based, same-day appointment service where appropriate;** expanding free GP care to the entire population will increase GP utilisation.<sup>457</sup> Preserving the same ratio of GPs to population will lead to waiting times of up to a week as experienced in the UK's NHS.<sup>458</sup>
  - **The independent GP contractor model;** which provides patient focused, quality of care and value for money<sup>459</sup> and is the model used in most developed health systems.<sup>460</sup> While corporate models of Primary Care may offer short-term advantages in terms of ready investment capital, in the long-term the corporate model of care leads to fragmentation and poor quality of care.
  - **The GP Gatekeeper role** which ensures more appropriate use of scarce healthcare resources.
- b) **A manpower action plan to address the growing shortage of GPs and to include an increase in the number of GP training places** - The HSE estimate that by 2025 an additional 1380 GPs are required to ensure the provision of GP services to the under 6 year olds and over 70 year olds – to expand GP care to the entire population an additional 2,055 GPs are required by 2025.<sup>461</sup>
- c) **In order to halt the exodus of GP trainees, priority must be given to negotiating a new GP contract with the IMO that is properly resourced and fit for purpose for a 21<sup>st</sup> Century Health Service to include:**
- **Terms and conditions that ensure both existing and newly qualified GPs are attracted to a career in the health service.** 17% of newly qualified GPs work

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Rutter and E. Wadesango, 'Does evidence drive pharmacist over-the-counter product recommendations?', *Journal of Evaluation in Clinical Practice*, Vol. 20, Issue 4, August 2014, pp. 425–428.

<sup>457</sup> Brick A, Nolan A, O'Reilly J and Smith S, Resource Allocation Financing and Sustainability in Health Care - Evidence for the Expert Group on Resource Allocation and Financing in the Health Sector, ESRI, Dublin: 2010 Vol II , p507

2. <sup>458</sup> **Campbell D.** Patients' waiting times on NHS 'a national disgrace' – GP leader, *The Guardian* 26 September 2014 ( <https://www.theguardian.com/society/2014/sep/26/patients-waiting-times-nhs-gps-uk> accessed 02 August 2016)

<sup>459</sup> IMO Submission to Department of Health Public on the Scope of Private Health Insurance to incorporate additional Primary Care Services. IMO: January 2015

<sup>460</sup> Ed. E Mossialos and M. Wenzl, London School of Economics and Political Science, R Osborn and D, Sarnak, 2015 International Profiles of Health Care Systems, The Commonwealth Fund. The Commonwealth Fund January 2016

<sup>461</sup> HSE HR Directorate National Doctor Training and Planning, Medical Workforce Planning Future Demand for General Practitioners 2015-2025, HSE: Sept 2015

- abroad<sup>462</sup> with many more planning to emigrate to countries where GP care is more appropriately valued
- **A working environment including an out-of-hours service that provides vital continuity of care and respects the needs of individual GPs**
  - **Investment in evidence-based Chronic Disease Management Programmes** (which newly qualified GPs are trained to deliver) **and opt-in enhanced services** (many GPs have training in other specialist areas such as minor surgery or dermatology)
  - **Allowances for the employment of practice staff** (including medical, nursing and practice support staff)
  - **Additional supports that address the real and specific needs of patients in both rural and deprived areas**
  - **Appropriate adoption of new work practices such as telemedicine that are based on international best practice and assure continuity of care**
- d) **Incentives must be provided for the development of infrastructure including premises, medical equipment, diagnostic equipment, IT (as per the recommendations in the Indecon report)<sup>463</sup>**
- e) **Access to diagnostics and allied health and social care professionals in the community (see integrated care)**
- f) **Access to GP care should be expanded on a phased basis taking into account income and medical need.**

### **Expanding Capacity in the Public Hospital System**

Access to care in the public hospital system is primarily a capacity issue both in terms of the number of consultants employed in our health services and the number of acute hospital beds available. While investment in GP care will reduce the rate of increase in demand on the hospital system it will not immediately resolve waiting lists or the crisis in our Emergency Departments.

### **Providing a Consultant-Delivered Hospital Service**

Waiting lists for specialist outpatient appointments and elective procedures will only be reduced following the introduction of a fully-resourced consultant delivered healthcare service. Hospital consultants undergo up to 15 years of medical education and training to become specialists in their field. The Hanly Report (2003) recommended a consultant delivered hospital service in which consultants have a direct involvement in the diagnosis, delivery of care and overall management of patients. This would improve quality of care and patient safety as important clinical decisions would be made faster and at a higher level.<sup>464</sup> Research shows that consultant delivered care is associated with:

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<sup>462</sup> Collins C. et al, Planning for the Future Irish General Practitioner Workforce – informed by a national survey of GP Trainees and Recent GP Graduates. ICGP 2014

<sup>463</sup> Indecon International Economic Consultants 2015 Analysis of Potential Measures to Encourage the Provision of Primary Care Facilities , Dublin 2015

<sup>464</sup> Report of the National Task Force on Medical Staffing June 2003

- marked reductions in all-cause mortality following admission with acute coronary syndromes and a significant reduction in hospital length of stay<sup>465</sup>
- improved patient outcomes and satisfaction and reduced length of stay in emergency care<sup>466</sup> without increases in adverse events or readmissions compared to consultant –led care<sup>467</sup>
- a 96.9% appropriate response rate during the first review of a trauma case.<sup>468</sup>

While there has been a gradual increase in the number of consultants and NCHDs employed in the HSE, NCHDs still outnumber consultants 2:1<sup>469</sup> and currently 1 in 8 consultant posts remain unfilled. Working conditions in over-crowded hospitals have led to unprecedented recruitment and retention issues. Many of our newly trained doctors are emigrating or planning to emigrate while we in turn are becoming increasingly reliant on foreign trained doctors.

### **Recommendation No. 2**

**The IMO recommends that integrated medical manpower planning takes place at national level which takes into account the number of consultants and specialist training posts required to deliver a Consultant delivered service.** Based on the calculations in the Hanly Report an additional 1,657 consultants are required across all specialties to ensure a consultant delivered healthcare service based on current population figures while an additional 1,920 consultants will be needed by 2026.

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<sup>465</sup> (<http://www.tandfonline.com/doi/abs/10.3109/17482941.2012.655290>)

<sup>466</sup> G.C. Geelhoed and E.A. Geelhoed, 'Positive impact of increased number of emergency consultants', *Archives of Disease in Childhood*, Vol. 93, No. 1, September 2007, pp. 62-64; A.L. White, P.A.R. Armstrong, and S. Thakore, 'Impact of senior clinical review on patient disposition from the emergency department', *Emergency Medicine Journal*, Vol. 27, 2010, pp. 262-265; J. Temple, *Time for Training: A review of the impact of the European Working Time Directive on the quality of training*, NHS Medical Education England, 2010, p. 42.

<sup>467</sup> M. Harvey *et al.*, 'Correlation of physician seniority with increased emergency department efficiency during a resident doctors' strike', *New Zealand Journal of Medicine*, Vol. 121, No. 1272, April 2008, pp. 59-68; G. Robinson *et al.*, 'The New Zealand national junior doctors' strike: implications for the provision of acute hospital medical services', *Clinical Medicine*, Vol. 8, No. 3, June 2008, pp. 272-275; A. Russell *et al.*, 'Consultant-delivered care – what is it worth?', *The Bulletin of the Royal College of Surgeons of England*, Vol. 97, No. 7, July 2015, pp. e22-e25.

<sup>468</sup> G. Finlay *et al.*, *Trauma: Who cares?*, National Confidential Enquiry into Patient Outcome and Death, London, 2007, p. 57.

<sup>469</sup> The latest HSE census report shows that there are currently 2,764 consultants and 5,762 NCHDs employed in the HSE. HSE Census Report May 2016 downloaded from [http://www.hse.ie/eng/staff/Resources/Employment\\_Reports/Census-Report-May-2016.pdf](http://www.hse.ie/eng/staff/Resources/Employment_Reports/Census-Report-May-2016.pdf)

### Hospital Consultants (Recommended vs. Currently Employed)

Speciality	Recommended Ratio of Specialists per Population*	Recommended Number of Specialists per Current Population*	Current Number of Specialists Employed by HSE*	Shortfall from Recommended to Currently Employed Specialists
Anaesthesia	1/8,300	573	358	-215 (-38%)
Emergency Medicine	1/40,000	119	87	-32 (-27%)
Medicine	1/4,700	1,012	692	-320 (-32%)
Obstetrics & Gynaecology	1/20,500	232	132	-100 (-43%)
Paediatrics	1/18,700	254	156	-98 (-39%)
Pathology	1/14,000	340	217	-123 (-36%)
Psychiatry	1/6,600	721	362	-359 (-50%)
Radiology	1/12,700	375	252	-123 (-33%)
Surgery	1/6,200	767	489	-278 (-36%)
<b>Total</b>	<b>1/1,080</b>	<b>4,406</b>	<b>2,749</b>	<b>-1657 (-38%)</b>

\* Report of the National Task Force on Medical Staffing, 2003, pp. 139-158; Current population data (4,757,976) from Central Statistics Office, *Census 2016 Preliminary Results*, July 2016; Current HSE employment figures taken from Health Service Executive, *Health Services Employment: Section 6 Grade Level Detail - Overview by Grade Group: December 2015 to May 2016*, p. 2.

### Hospital Consultants (Recommended – Report of the National Task Force on Medical Staffing)

Speciality	Recommended Ratio of Specialists per Population*	Recommended Number of Specialists per Current Population*	Recommended Number of Specialists per 2021 Population*	Recommended Number of Specialists per 2026 Population*
Anaesthesia	1/8,300	573	587	607
Emergency Medicine	1/40,000	119	122	126
Medicine	1/4,700	1,012	1037	1073
Obstetrics & Gynaecology	1/20,500	232	238	246
Paediatrics	1/18,700	254	261	270
Pathology	1/14,000	340	348	360
Psychiatry	1/6,600	721	739	764
Radiology	1/12,700	375	384	397
Surgery	1/6,200	767	786	813
<b>Total</b>	<b>1/1,080</b>	<b>4,406</b>	<b>4,514</b>	<b>4,669</b>

\* Report of the National Task Force on Medical Staffing, 2003, pp. 139-158; Current population data (4,757,976) from Central Statistics Office, *Census 2016 Preliminary Results*, July 2016; 2021 (4,875,100) and 2026 (5,042,100) population projections from *Population and Labour Force Projections: 2016 – 2046*, Central Statistics Office, 2013, using M2F2 models.

### **Recommendation No. 3**

**Measures must be taken immediately to improve training pathways, recruitment and retention of our medical workforce including the full implementation of the recommendations made in the report of the Strategic Review of Medical Training and Career Structures ('MacCraith Review') and the negotiation of a new, fit for purpose contracts for both consultants and NCHDs.** Arrangements for the training of doctors must be modernised reflecting changes in the practice of medicine and the changing demographics of doctors in training. This requires initiatives to consider the duration of training to bring arrangements in line with international norms. A differentiated model which provides clearer career paths with greater predictability of training arrangements,

responsibility, location and working conditions must be developed. Greater flexibility must be achieved to facilitate differentiated arrangements to attract the best and brightest graduates to deliver healthcare in Ireland.

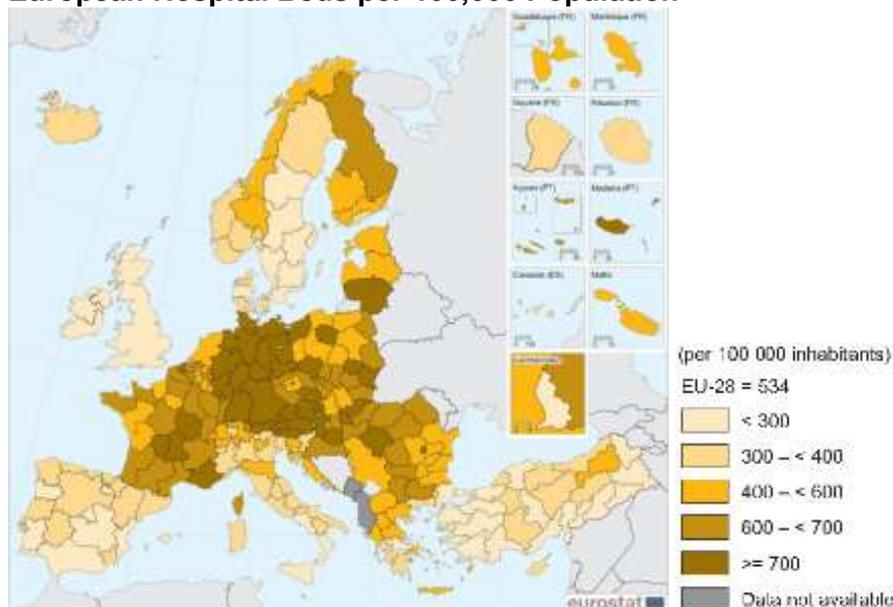
### **Acute Bed Capacity**

Hospital capacity planning requires assessment of numerous dimensions of healthcare provision, including diagnostic and therapeutic equipment and technology, the manner of delivery, and housing of medical services, and the human and financial resources required for the continuous and adequate delivery of those services. In a number of jurisdictions, hospital bed capacity has been the traditional unit by which care has been planned.<sup>470</sup> Increasingly, states are also using service volume and activity to plan for capacity. This is achieved by detailed recording of services delivered, patient discharges, and other healthcare data, as a means of predicting future demand.

### **Recommendation No. 4**

**The IMO recommends a detailed assessment of the number of acute beds needed in the public hospital system to meet current and future demand. The reinstatement of the National Treatment Purchase Fund (NTPF) is not sufficient to alleviate waiting lists nor a sustainable long-term solution. The private sector does not sufficiently cater for frail or complex patients. When we include both public and private beds the number of acute inpatient and day-case beds falls well below European averages.** Ireland possesses 276 inpatient and day-case beds per 100,000 population. This compares to a Western European average of 449 per 100,000. Again even when including private hospital beds, Ireland's figure still rises only to approximately 358 hospital beds per 100,000 population. In terms of inpatient beds alone Ireland needs an additional 3,500 inpatient hospital beds to bring us up to the West European average.

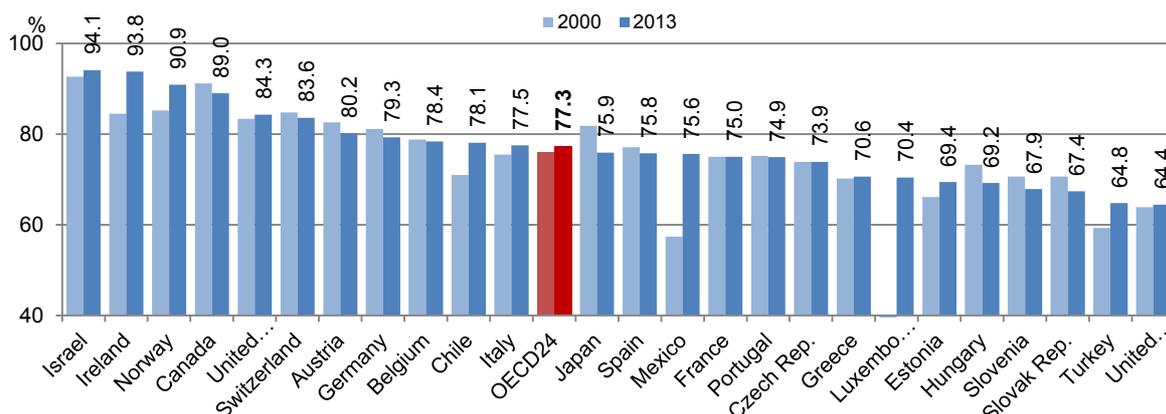
### **European Hospital Beds per 100,000 Population**



<sup>470</sup> S. Ettelt et al., *Capacity Planning in Healthcare: A Review of the International Experience*, Brussels, European Observatory on Health Systems and Policies, 2008, p. 6.

- **The assessment should be based on 85% occupancy rates to ensure patient safety and provide for seasonal increases in demand<sup>471</sup>.** OECD figures from 2013 show that Irish public hospitals operate at 93.8% capacity, a figure well over the established safe occupancy threshold of 85%,<sup>472</sup> and above the identified 92.5% tipping point that has been shown to result in significantly higher patient mortality, due to rationing of resources and elevated stress levels.<sup>473</sup>

### Acute Hospital Occupancy Rates in the OECD



- **An immediate and effective plan must be implemented to meet current bed requirements. No further beds should be taken out of the public system until appropriate community and long-term care services are in place.** The plan must include an assessment of available unused capacity in the system. 13% of inpatient beds have been withdrawn since 2009. The plan should also include potential collaboration with Northern Ireland to improve access in border regions and for rare diseases.
- **Capacity planning must include an assessment of Diagnostics, Radiology and Laboratory service requirements in both acute and community care.**

### Long-Term and Rehabilitative Care

Older people and people with disabilities have the right to equal access to and equal resourcing of health and social care services, including rehabilitative care services and long-term community and residential care.

<sup>471</sup> A. Bagust, M. Place, and J.W. Posnett, 'Dynamics of bed use in accommodating emergency admissions: stochastic simulation model', *British Medical Journal*, Vol 319, July 1999, pp. 155–158; R. Jones, 'Hospital bed occupancy demystified', *British Journal of Healthcare Management*, April 2011, dx.doi.org/10.12968/bjhc.2011.17.6.242; F. Madsen, S. Ladelund, and A. Linneberg, 'High Levels Of Bed Occupancy Associated With Increased Inpatient And Thirty-Day Hospital Mortality In Denmark', *Health Affairs*, Vol. 33, No. 7, July 2014, pp. 1236-1244.

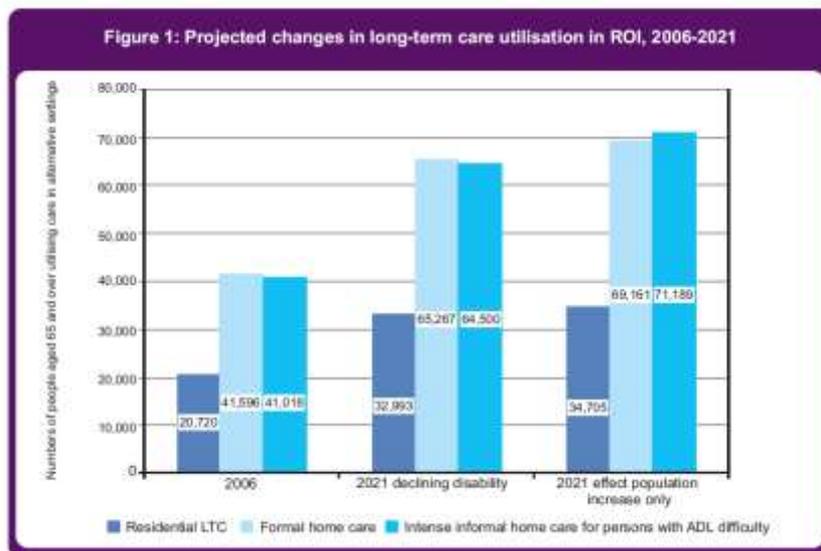
<sup>472</sup> Organisation for Economic Co-operation and Development (OECD), *Health at a Glance 2013*, Paris, 2013;

<sup>473</sup> L. Kuntz, R. Mennicken, and S. Scholtes, 'Stress on the ward: evidence of safety tipping points in hospitals', *Management Science*, Vol. 61, pp. 754-771.

## Recommendation No.5

### **Demand for community and long-term care must be properly assessed and adequate resources provided including capital investment, operational funding and manpower.**

While only a small percentage of elderly people require long-term care, the ageing population will have a significant impact on the number of long-stay beds required. Wren et al predict that based on 2006 utilisation and some decline in disability rates, by 2020 demand for long-term residential care, formal and informal home care would increase by almost 60%.



Source: Wren et al, *Future Demand for long-term care in Ireland 2012*, CARDI Research Brief

Since 2006 the number of long-term beds has fallen, as has the number of people in receipt of home help along with the number of home help hours provided. The number of home care packages provided has trebled although from a low base to approximately 15,000 packages in 2015. The HSE service plan provides for no increase in 2016 of home care packages. The additional €40m announced in June is directed simply at delivering the home care services set out in the HSE National Service Plan 2016.

### **Placing Mental Health on a Par with Physical Health**

Mental health disorders affect one in four adults in Ireland and are the leading cause of disability worldwide<sup>474</sup>, but less than 50% of people receive professional help and even less receive appropriate care.<sup>475</sup> In 2006, *A Vision for Change – the Report of the Expert Group on Mental Health*<sup>476</sup> laid out the blueprint for the transfer of mental health services from an institutional to a community-based setting over a period of 7-10 years. However progress has been slow with poor implementation and inadequate and uneven distribution of resources.

<sup>474</sup> H. Wittchen and F. Jacobi, 'Size and burden of mental disorders in Europe – a critical review and appraisal of 27 studies', *European Neuropsychopharmacology*, Vol. 15, Issue 4, August 2005, pp. 357-376.

<sup>475</sup> Tedstone Doherty D, Moran R, Mental Health and Associated Service Use on the Island of Ireland: HRB Research Series 7 HRB 2009: 13

<sup>476</sup> Department of Health and Children, *A Vision for Change*, Stationery Office, Dublin, 2006, p. 178.

## **Recommendation No. 6**

**The IMO is calling for a new Mental Health Strategy that puts mental health on a par with physical health which must be accompanied by a detailed implementation plan and an appropriate allocation of resources.** Ireland currently spends just 6% of its health budget on mental health compared with 10-11% in the UK, France and Germany<sup>477</sup> and 8.24% recommended in A Vision for Change.

### **The strategy should include:**

- **The appointment a national independent body to determine mental health catchment areas to ensure equality of services in all parts of the country;** Financial and manpower resources are unevenly distributed across mental health services with no relationship between population size or socio-economic need.
- **Urgent investment to address deficits in Child and Adolescent Mental Health Services;** With just 58 child acute psychiatric beds available out of a recommended 98, last year 95 children (26% of child admissions) were inappropriately admitted to adult psychiatric units.<sup>478</sup>
- **Direct access on GP referral to counselling and psychotherapeutic services in the community;** General practitioners (GPs) are often the first point of contact for those suffering from mental illness and 80% of GPs believe that anxiety, depression, and other similar disorders could be managed more effectively in primary care with appropriate resources and supports.<sup>479</sup>

## **Expanding Public Health Expertise**

Effective health service planning, that provides equal services to all based on need and within the available resources, requires public health medicine expertise and capacity to:

- Assess the health needs of the population in the short, medium and long term using available health data, and an epidemiological approach taking into account population distribution, including age profile and socioeconomic profile
- Develop a comprehensive evidence-base for individual services and wider programmes
- Provide health economic support to the HSE
- Give evidence-based advice to policymakers, including advice on the options available and the benefits and risks of each

Public health doctors have expertise in epidemiology, health economics, health information and planning, health protection and health improvement. They have an essential role in health surveillance, in protecting the public from infectious disease and environmental

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<sup>477</sup> M. Schultz, 'Mental health services in Germany', in N. Brimblecombe and P. Nolan (eds.), *Mental Health Services in Europe – Provision and Practice*, Radcliffe Publishing, London, 2012, pp. 97-120; The NHS Confederation, *Key facts and trends in mental health*, London, November 2009, p. 4; G. Faedo and C. Normand, *Implementation of 'A Vision for Change' for Mental Health Services*, Trinity College Dublin, March 2013, p. 14.

<sup>478</sup> Mental Health Commission, Annual Report 2015 Including Report of the Inspector of Mental Health Services, [accessed <http://www.mhcirl.ie/File/2015-Annual-Report-inc-Report-OIMS.pdf> 20 June 2016]

<sup>479</sup> A. Jeffers, *Mental Health in Primary Care – What Do Health Professionals Believe Is the Best Model of Care?*, poster presented at the Spring Conference of the College of Psychiatry of Ireland, Cork, 2010.

threats, and ensuring Ireland meets its commitments under national and international health regulations. If properly resourced public health doctors could play a pivotal role in commissioning services, analysing health data, conducting needs assessments, assembling the evidence base for interventions, monitoring services and quality assuring parts of the health service such as screening.

#### **Recommendation No. 7**

**Immediate action is needed to expand public health capacity and attract medical graduates to this discipline through consultant status and a new fit for purpose contract.**

Over 40% of specialists in public health medicine were aged over 55 in February 2014. The review of the speciality recommended by the MacCraith Review in June 2014 was scheduled to report by September 2015; the brief was put out to tender in August 2016.

#### **Recommendation No. 8**

**Health Information and Patient Safety Legislation must ensure the public health planning function has access to appropriate data while at the same time ensuring confidential patient data is protected.**

#### **Prevention – Implementing and Resourcing Healthy Ireland**

Prevention is the most ethical and cost-effective intervention. Unhealthy lifestyle choices pose significant challenges to population health, while global health threats could undermine all planning. In 2013 the Government published *Healthy Ireland - A Framework for Improved Health and Wellbeing 2013-2025* which lays out the Government's strategy to improve health and well-being in Ireland from 2013 to 2025 the goals of which are to:

- increase the proportion of people who are healthy at all stages of life;
- reduce inequalities in health;
- protect the public from threats to health and wellbeing;
- create an environment where every individual and sector of society can play their part in achieving a healthy Ireland.

#### **Recommendation No. 9**

**The IMO welcomes the goals of *Healthy Ireland* and calls on the Government to develop a detailed implementation plan supported by ring-fenced funding.** Many well-thought out strategies fail through lack of a detailed implementation plan, resources or a dedicated person with overall responsibility.

- **Health Surveillance Programmes should be enhanced.** Both public health and community health doctors have a key role to play in health surveillance and prevention assuring programmes are delivered to the highest quality evidence-based standards by appropriately qualified health professionals.
- **Immediate priority should be given to:**
  - **Developing a comprehensive multi-disciplinary programme to tackle childhood obesity**
  - **Enactment of the Public Health Alcohol Bill**
  - **Full implementation of the recommendations for a *Tobacco Free Ireland*.**

## **Integrated Care**

An integrated healthcare system can enhance quality of care and patient outcomes and has the potential to improve patient experience and lower costs. Despite some isolated examples and pilots, healthcare in Ireland is both highly fragmented and poorly coordinated.

A commercial competitive healthcare environment where healthcare professionals and corporations compete for scarce resources is not conducive to integrated care. On the other hand key enablers of, integrated care include the effective use of information and communication technology, appropriate standardisation of care through the implementation and appropriate funding of clinical guidelines, and effective management and allocation of resources.

## **Effective Use of Information and Communication Technology**

Information and communications technology (ICT) is widely considered a key tool for supporting integrated health care systems, facilitating the “seamless” transfer of patients between clinical settings and enhancing patient safety and quality of care, by reducing repetition and errors in diagnostics and treatments. The collection of data also allows for the advance of medical knowledge, management of disease and health service planning. As mentioned above issues relating to patient confidentiality, security and the secondary use of information need to be addressed through Health Information and Patient Safety legislation. Challenges can also arise if new systems are not capable of capturing clinically relevant information, cannot be easily embedded into existing ICT systems and add to the administrative workload of physicians

### **Recommendation No. 10**

**The Government must provide ring fenced funding to support the roll-out of a secure national system of electronic health records. Funding must not be diverted from patient care. New eHealth systems should be piloted to ensure they are fit for purpose, can easily be embedded into existing ICT systems and do not add to the administrative workload.**

## **Appropriate Standardisation of Care through the Implementation and Resourcing of Clinical Guidelines**

Care pathways and clinical guidelines contribute to integrated care by standardising care across services and sites, and defining roles and responsibilities of different healthcare professionals within their particular domain of competence.<sup>480</sup> However, there is a danger that, due to resource constraints or the time lag involved in the gathering of evidence and incorporating it into formal quality assured clinical guidelines, that guidelines may not be up to date or result in the optimal clinical outcome. Clinical guidelines are also usually disease focused and thus designed to be applied to population groups with similar morbidity. As a result, they may not factor in co-morbidity or the impact of individual patient characteristics or choices. While guidelines have been developed for GP management of certain chronic conditions, appropriate resources have yet to be provided.

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<sup>480</sup> Suter E. Oelke N.D. Adair C.E. Armitage G.D. Ten key Principles for Successful health Systems Integration, Healthcare Quarterly 2009 13 Special issue 16-23

### **Recommendation No. 11**

**The development of clinical guidelines must reflect international best practice, must be appropriately resourced and flexible to meet individual patient needs and choices.**

### **Effective Management of Resources**

As mentioned above integrated care systems can enhance quality of care and patient outcomes and have the potential to reduce costs. However, Integrated care will not resolve inadequate resourcing of services and new activities cannot be successfully integrated without an increase in resources<sup>481</sup>. While it is expected that integrated care systems can lead to both administrative and clinical cost savings, integration processes may not be achievable without additional initial investment before any savings become apparent.<sup>482</sup> The HSE is currently developing a large-scale programme of work to integrate health and social care services in the community. However without additional resources the HSE's integrated care programmes will not succeed. Currently waiting lists exist for all community allied health and social care services. In many areas services simply aren't available regardless of ability to pay.

### **Recommendation No. 12**

**Integrated health and social care services requires integrated manpower and capacity planning and the provision of appropriate capital and operational resources.**

### **Quality of Care and Efficiency**

#### **Recommendation No. 13**

**In addition to integrated care, there must be an on-going emphasis on improving quality of care and efficiency in the health service through a wide range of measures such as:**

- Many specialist faculties are developing and implementing national clinical quality improvement programmes of international acclaim;
- As the elderly are the main users of healthcare services, services can be more age-attuned by creating dementia friendly services;
- Efficiencies in care may be lost without reform of HSE management and administration processes;
- New technologies have the potential to improve care and disrupt work practices. The potential benefits and risks of new technologies should be explored.

### **Funding Model**

#### **Recommendation No. 14**

**The IMO believe that with significant increases in resources, both capital and operational, and with careful planning the goal of universal healthcare can be delivered under an expanded taxation model or eventually under a system of social health insurance. Whatever changes are introduced to health coverage in Ireland, the process by which change is brought in must include:**

- **Informed public debate**

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<sup>481</sup> World Health Organization, Integrated Health Services – What and Why? – Technical Brief No. 1. WHO Geneva. 2008 Downloaded from [http://www.who.int/healthsystems/technical\\_brief\\_final.pdf](http://www.who.int/healthsystems/technical_brief_final.pdf)

<sup>482</sup> *ibid*

- Consultation with all relevant stakeholders, including patients and doctors
- Detail of the proposed model including cost and funding sources
- Analysis of current and future manpower resources needed for implementation
- A realistic time table for implementation.

<http://www.imo.ie/>

## Irish Medical and Surgical Trade Association (IMSTA)

IMSTA is the representative body for medical technology manufacturers, distributors and service providers in Ireland.

The medtech industry is one of Ireland's greatest success stories with as many as 18 of the world's top 25 medtech companies developing next generation devices here. The sector employs over 27,000 highly skilled people and exports over €8.5 billion worth of health products annually. IMSTA believes the Irish health service can build on the intensive investment in medtech to deliver a better, sustainable healthcare system accessible by all the people of Ireland.

It is our shared view at IMSTA that numerous challenges for industry and healthcare providers lie ahead and will ultimately constrain the effectiveness of the healthcare system to achieve optimum outcomes for the patients it serves. These include:

- *Silo budgets preventing a more holistic approach being taken*
- *Lack of clinical engagement in procurement*
- *Commoditisation of health products*
- *Failure to evaluate medical technologies from the patient's perspective*
- *Lack of real world data on outcomes*

In addition, procurement currently remains a transactional process, with a focus on driving down the purchase price of individual items rather than capturing the capability of a medical technology to improve the value (outcomes set against cost) and quality (defined as clinical efficacy, patient experience and safety) of the overall healthcare intervention. Continuing on this path is a missed opportunity and one that has negative consequences for Irish patients and taxpayers alike.

We propose five key recommendations for further discussion with the Oireachtas Committee on the Future of Healthcare. These include:

1. **Government should adopt a 'value-based' procurement strategy** to harness innovation to deliver better patient and public outcomes through new medical technologies and treatments <sup>1</sup>.
2. **The setting up of a single Health Technology Assessment agency** to align expertise and methods for the life science sector as a whole, to develop a value-based healthcare approach to the assessment of procedures, therapies and medical technologies.
3. That **1-2% of the health service non-pay procurement budget be provided annually**, primarily to SMEs, to fund the development of specific solutions for unmet health needs.
4. The Committee consider **the potential benefits of the Academic Health Science Network (AHSN) model** and use this to inform the development of equivalent structures in Ireland.
5. The **Committee invite IMSTA and other such stakeholders to develop the above proposals** for detailed consideration by the Committee.

We are strong proponents of the decision to consider a longer term view for health care and health policy in Ireland. IMSTA wishes to make a positive contribution to the debate, discussions and decisions that lie ahead. We look forward to discussing the content of this document in further detail in the near future.

## Introduction to the Medtech Sector

IMSTA is the representative body for medical technology manufacturers, distributors and service providers in Ireland. We represent a sector that provides health products, services and information in the fields of prevention, diagnosis, chronic management, acute intervention, remote monitoring, rehabilitation and palliation.

Medical technology or 'Medtech' is a subset of Health Technology, defined by the World Health Organisation <sup>2</sup> as the "application of organized knowledge and skills in the form of devices, medicines, vaccines, procedures and systems developed to solve a health problem and improve quality of lives."

Medtech offers the opportunity to revolutionise healthcare in the same way that other parts of our lives have benefited from the internet, smartphones and social media. It offers huge potential to improve the quality of healthcare delivered through earlier diagnosis, less invasive treatment options and reductions in hospital stays and rehabilitation times.

Medtech can facilitate the management and treatment of patients at the lowest level of complexity, leading to more self-care and self-management, more local diagnosis, treatment and management. Take as an example the case of Donal Burke a schoolboy suffering with Type-1 Diabetes (Appendix 2). When the HSE supplied him with an Insulin Pump his life was totally changed, as was the life of his family, and the burden on the health service was greatly reduced. This simple-to-use technology gave the boy back his life at minimal cost.

The Medtech industry is one of Ireland's greatest success stories with as many as 18 of the world's top 25 medtech companies developing next generation devices here. The sector employs over 27,000 highly skilled people and exports over €8.5 billion worth of health products annually. IMSTA believes the Irish health service can build on the intensive investment in medtech to deliver a better, sustainable healthcare system accessible by all the people of Ireland.

Medtech companies can also help the health system through productive partnerships and / or collaborations where the financial burden and risk is shared. Many other countries / healthcare systems utilise approaches such as Managed Equipment Service (MES) sourcing strategies, capital funding agreements, operational expertise, risk-sharing for outcomes, health economic analysis, and international benchmarking to deliver added value.

The benefits of medical technology are immense and their value to the health service should be considered in terms of outcomes rather than simply the front-end purchase price.

### Patient / Health Benefits

- Medtech **can save peoples' lives**. This happens in emergency situations, i.e. heart failure or an inflamed appendix where surgery is needed
- Medtech also **saves lives by diagnosing** a health problem accurately and at an early stage or by preventing a disease through modern testing methods
- Patients can recover faster than ever through medtech: less invasive surgeries, more efficient technology and integrated processes **allow for significantly reduced hospital stay times**
- Technologies aimed at prevention **allow early and accurate diagnosis** and can thus deter diseases and ailments

- Medtech provides easy-to-use, personalised technologies and e-solutions, **allowing a high level of self-management**, especially for people living with chronic conditions

### Issues with the Status Quo

*Like many health and well-being systems throughout Europe, the existing acute sector-led arrangements in Ireland were not designed to address the challenges of a growing, older population with long term conditions.*

A more holistic approach is required. Not only should the principal of local, least complex and least expensive care be at the core of the strategy – a primary care led service – but acute services should be rationalised to support a ‘population health’ approach with specialist services on an integrated basis.

Rationalisation of acute services will be necessary to support a primary care led integrated health and well-being system. It will be necessary to release investment to develop:

- *Primary care and community services – to meet 90-95 per cent of health and personal care needs*<sup>3</sup>
- *Secondary care based national clinical programmes – with the least complex care most local*
- *Specialist treatment and research centres*

Primary care should have dedicated resourcing for access to technologies, including diagnostics (imaging, laboratory tests, etc.). Access to such technologies will:

- *Enhance the quality (safety, efficacy and patient experience) of services*
- *Support increased ‘out of hours’ primary and community care services*
- *Facilitate less reliance on hospital based emergency services and a greater proportion of people’s care needs closer to home.*

Research by the Irish College of General Practitioners/Irish Cancer Society<sup>4</sup> identified the need to improve access for GPs to diagnostics, with current structural problems causing unequal delayed access and barriers to healthcare provision for all socio-economic groups in Ireland, especially patients who utilise the public healthcare system. The report makes recommendations, inter alia, for greater access to diagnostics and improved information sharing and workforce planning. These actions – prompted by the technology - would impact substantially on the landscape of cancer services in Ireland.

There are also significant, currently unrealised, opportunities to apply novel technologies to improve outcomes and reduce unwarranted variations in clinical and cost effectiveness within the acute sector. Best practice hospital care is becoming increasingly more specialised and the application of national clinical programmes to ensure hospital groups provide the necessary standardised models of care on a national and regional basis should have regard for the use of medical technologies.

There are a number of challenges for industry and healthcare providers if the benefits of novel medical technologies are to be realised.

- *Silo budgets preventing a more holistic approach being taken*
- *Lack of clinical engagement in procurement*
- *Commoditisation of health products*

- *Failure to evaluate medical technologies from the patient's perspective*
- *Lack of real world data on outcomes*

Procurement currently remains a transactional process, with a focus on driving down the purchase price of individual items rather than capturing the capability of a medical technology to improve the value (outcomes set against cost) and quality (defined as clinical efficacy, patient experience and safety) of the overall healthcare intervention.

Greater savings are to be made through the innovative and transformational changes to services that novel technologies can enable rather than the reductions in price achieved in the current environment – especially given that technology usually accounts for a very small percentage of the overall patient pathway costs.

For example, the decision to procure wound pads centrally does not take into consideration the number of times wound pads will need to be changed by a community nurse. What is the cost to the HSE to send a community nurse to visit a patient in their home compared to the price of a wound pad, let alone the interruption to the patient's daily life (work, caring, study, etc.)? See 'A More Holistic Approach' in Appendix 3.

International research findings conclude that a singular focus on procurement price can result in a failure to reduce total healthcare costs<sup>5</sup>.

Consider the comments of a successful indigenous SME on the marked impact current health system inefficiencies has on their ability to deliver their health products and services in the way that we do to other customers;

***“The HSE method of procurement greatly restricts the ability of clinicians to gain access to these cutting edge technologies. Clearly this has an impact on the clinicians who would use them and the companies who would provide them, but more importantly has an impact on the patients who would benefit from receiving them.***

***We have much to be proud of in our medical device industry but, at present, the body responsible for acquiring the products they yield, is sorely lacking in its ability to ensure our population benefit from the outputs generated.***

***Our experience with the HSE . . . should provide an insight into the complex and often challenging aspects faced by commercial entities attempting to deliver goods and services into this organisation. Despite an earnest desire and clear capacity of companies such as us to deliver high quality health products and services in an efficient and mutually beneficial way, the HSE, in its current position, does not possess the ethos to meet such offers in a meaningful or impactful way”.***

A culture in the health service and in government generally needs to be developed that sees industry as a strategic partner rather than a transactional supplier of goods and services.

At present, in the absence of such a strategic partnership, there is no requirement on industry to demonstrate that products can realise population health benefits and address resource allocation challenges, within the context of a relevant patient/disease time period, as opposed to the current annual budget cycle. This is further compromised by a focus on price and 'easy' data such as percentage spend against GDP or bed-stays rather than more difficult but more useful 'real world' outcome measures.

## The Opportunity that Exists

*The true value of any health and well-being intervention or system are the outcomes achieved for any individual or population, set against the cost*<sup>6</sup>.

Many European countries have sought to measure healthcare value over the past decade but have focused on 'processes' rather than outcomes. This is reflected in the various initiatives to improve the efficiency of payment systems, although of late there is a trend for governments and health policymakers to introduce performance goals for providers as part of the process of reforming reimbursement systems.

A move from 'block payments' to 'episode-based' payments to one or more providers represents a more co-ordinated approach to treatment by rewarding a single pathway of care and making better use of more expensive services, such as hospitals<sup>7</sup>. Advocates of such payment systems say that they are especially efficient for the treatment of chronic conditions. The Netherlands introduced such a system in 2010 for the care of diabetes, chronic obstructive pulmonary disease (COPD) and for vascular risk management. German insurers have been able to negotiate integrated contracts with multiple health providers since 2000<sup>8</sup>.

The introduction of Activity-Based Funding (ABF) in the hospital sector in Ireland sees providers funded in line with the activity that they undertake. The absence of an effective activity-based system has meant an absence of transparency around costs and has undermined adoption of new innovations which could improve access to earlier diagnosis<sup>9</sup>. The ABF approach is a fairer and more transparent system of resource allocation that will establish a clear link between money and activity because hospitals will be funded based on the quantity and quality of services they deliver to patients.

However, ABF will have to be utilised system-wide instead of solely in the acute hospital environment if integrated care through the health service is to be measurable.

Community Healthcare Organisations (CHOs) and the Hospital Groups will have to be geographically re-aligned and a new governance structure developed to manage greater coordination of health care providers in order to provide care for a geographic group of patients. An Accountable Care Organisation (ACO) offers a good example of this in practice and is an organisation characterised by a payment and care delivery model that seeks to tie provider reimbursements to quality metrics and reductions in the total cost of care for an assigned population of patients.

The challenge to both the medical technology industry and government is that medical technologies, whether:

- *high volume/low cost technologies or low volume/high cost*
- *technologies that are single use disposable or implantable, or*
- *assistive technologies including capital equipment which support the facilitation of a procedure or patient pathway*

are appropriately costed to ensure that no one hospital or provider is disadvantaged – such as using inferior technologies to 'balance the books'.

However, a key precursor to the costing of medical technologies (whether for ABF or as part of a procurement process) is the assessment of whether the medical technologies are of value to the health care system. This can be achieved in many ways, most notably in terms of clinical efficacy and cost effectiveness.

**A health technology assessment (HTA) is a complex appraisal which should assess considerations of safety, efficacy (or better, ‘real-world’ effectiveness), innovation and ideally incremental cost-effectiveness, as well as social, ethical and legal factors. Whilst the assessment of medical technologies is within the remit of the Health Information and Quality Authority (HIQA), the National Centre for Pharmacoeconomics (NCPE) has traditionally had responsibility for carrying out HTAs - exclusively for pharmaceuticals and not medical technologies. It is worth reminding that one of HIQA’s functions is to carry out HTAs to inform safe and effective health policies that are patient focussed and achieve best value.**

IMSTA contends that the health system in Ireland is inadequately resourced to undertake a methodical approach to the selection of innovative medical technologies or to provide an independent, timely and transparent assessment process. As a consequence, medical technologies are considered in cost terms alone. This leads to stifled adoptions and/or irrational price-lead procurement and undermines the contribution of medical technology to the development of ABF and a value-based approach to the improvement of the health and well-being of the nation <sup>10</sup>.

The failure to appreciate the value – and processes to ensure the practical application of a value-based approach to procurement and reimbursement - of a medical technology, could for example lead to unwarranted variation across the public and private sectors (or between Ireland and other jurisdictions in the UK and mainland Europe) in the provision of:

- *Molecular tests to patients thereby denying clinicians detailed knowledge of a patient’s cancer and therefore the best treatment options for them. (Early diagnosis often means a cancer is more likely to be treated successfully, intervention will be less complicated, and chances of survival may be higher, however, the ability to pay, cited by 88.5% of GPs surveyed, either ‘always’ or ‘usually’ affects access to referral services – ICGP/Irish Cancer Society 2016).*
- *Self-monitoring technology for conditions such as diabetes or for patients taking warfarin – reducing or negating the need to use hospital out-patient services. See Case Study in Appendix 4.*

One of the challenges for Governments and the medtech industry is gathering ‘real world’ data, especially with regard to outcomes, to inform development, as well as investment and procurement decisions. Whilst Ireland is already one of the most successful global medtech hubs – as mentioned above – it can continue to grow and consolidate. The opportunity exists to boost innovation and increase employment potential within the SME sector, as well support the production of ‘real world’ data.

Complementing the capacity and resources within the acute sector, Government should seek to utilise and develop the Small Business Innovation Research (SBIR) mechanism, a tried and tested government programme (widely used in UK and Europe, more recently in Ireland). It is intended primarily to help SMEs conduct research and development (R&D) but is not restricted to SMEs only.

Drawing upon a small, ring-fenced element of the health service non-pay procurement budget to find solutions for identified healthcare problems - the funding would be provided, primarily to SMEs, to fund the development of specific solutions for unmet health needs. In return, the Government would receive access to the innovative solutions developed. In addition to healthcare system savings and improvements in patient care, the multiplier effect would prompt other economic benefits, such as job creation <sup>11</sup>.

As part of this approach, Government should seek to develop strong, sustainable, cross-boundary networks between industry, healthcare providers, academia and others, to support the development and spread of high-impact, designated innovative technologies to address the specified healthcare problems. Consideration should be given to the adoption of a model similar to the Academic Health Science Networks (AHSNs) in England.

## IMSTA RECOMMENDS

1. **Government should adopt a ‘value-based’ procurement strategy** to harness innovation to deliver better patient and public outcomes through new medical technologies and treatments (IMSTA 2015).
2. **The setting up of a single Health Technology Assessment agency** to align expertise and methods for the life science sector as whole, to develop a value-based healthcare approach to the assessment of procedures, therapies and medical technologies.
3. That **1-2% of the health service non-pay procurement budget be provided annually**, primarily to SMEs, to fund the development of specific solutions for unmet health needs.
4. The Committee consider the **potential benefits of the Academic Health Science Network (AHSN) model** and use this to inform the development of equivalent structures in Ireland.
5. The Committee **invite IMSTA and other such stakeholders to develop the above proposals** for detailed consideration by the Committee.

## Concluding Remarks

***IMSTA believes that the five recommendations outlined in the previous section are fundamental to the reform and future successful enhancement and delivery of public healthcare services in Ireland.***

To repeat, we are strong proponents of the decision to consider a longer term view for health care and health policy in Ireland. The recommendations proposed at this point by IMSTA should be considered in the context of an overall reform programme. IMSTA wishes to make a positive contribution to the debate, discussions and decisions that lie ahead.

The medtech sector in Ireland has grown considerably in recent years. It is now estimated that 27,000 people are employed across 400 companies in this state alone<sup>12</sup>. In addition, directly exporting to over 100 countries worldwide, Ireland’s medtech sector is now the highest employer in Europe per capita.

A continuous focus on innovation is key to all sectors, healthcare and medtech are no different in this regard. For IMSTA and all member organisations it remains a critical ingredient to the future success of the sector as a whole. It is our view that fostering an

environment where innovation can flourish is central to achieving better patient outcomes and a sustainable healthcare system.

The medtech sector in general has considerable value to offer to the global health economy. We at IMSTA want to engage with you to ensure that Ireland optimises the opportunities that lie ahead, and that ultimately this supports patients in all healthcare settings across Ireland.

*We welcome the opportunity to engage further and directly with you on this journey to a better and more sustainable healthcare system.*

## **Appendix 1: About IMSTA**

IMSTA is the representative body for the Medical Technology supply industry in Ireland.

IMSTA provides a forum for the development and advocacy of policies that support innovation in medical technology to address patients' healthcare needs and is a member of GMTA, the Global Medical Technology Alliance, whose members are national or regional medical technology associations which represent innovative companies that currently develop and manufacture 85 percent of the world's medical devices, diagnostics and equipment.

IMSTA member companies in Ireland include the full spectrum of medical technology supply and service companies from SMEs to MNCs, many of whom have R&D and/or manufacturing facilities in Ireland.

IMSTA member companies provide highly trained clinical professionals, biomedical / clinical engineers and medical scientists to support the medical technology in use in the Irish health service. They provide training for clinicians, nurses, biomedical and clinical engineering and other health care professionals in the application and the use of innovative medical technologies.

**“Members of IMSTA provide safe, effective and innovative medical technologies that save and enhance lives, benefiting people and society”.**

### **Previous publications include:**

**2015** Health Policy Paper – proposing SBIR mechanism

**2015** NEW APPROACHES for procuring Effective Healthcare Solutions

**2014** ‘Should Ireland have a framework for evaluating new medical technologies?’  
(Discussion paper)

**2012** A Review of Current Procurement Practices in Ireland (with DCU and Enterprise Ireland)

**2011** Investing in Medical Technology: Good for patients and good for the economy

**2009** Working together to improve patient outcomes: A partnership approach to Medical Device Procurement

## Appendix 2: Case Study A

### *Freedom at last, thanks to medical technology*

The first speaker at the IMSTA annual conference was a seventeen year old Dubliner, **Donal Burke**.

A Leaving Certificate student at Castleknock Community College, he is a keen sportsman and musician. He plays hurling and Gaelic football as well as the guitar. However this tall, confident and good looking lad has had to live with a disease that affects thousands of Irish people every year. Since Donal Burke was three years of age, he has managed Diabetes, type 1. However this has not been without inconvenience and difficulties.

“All my life I have had to make sure that sugar levels were properly controlled. That meant that I had to eat three meals at the same times, every day, even if I was away on holidays and the time zone was different.

“I also had to make sure that I had access to my insulin injections. So when I was going to school, heading off on holidays or even going out to play football with my mates, I had to be careful. I usually ended up with a case for my clothes and another one with the syringes and medication,” he explained.

Five years ago Donal swapped the needles and injection for a special diabetes pump, which monitors his condition and allows him to pump the correct dosage of insulin when required.

His mother, Jacinta, was reluctant to move to the pump, but Donal and the local nurse convinced her to let him try it. “It was not that I did not like the pump, but Donal had been great managing his diabetes and had been taking his injections. I was afraid of change rather than fearful of a pump. But they convinced me to let him try the pump. And to be honest, after a month or so, if anyone tried to take it off him, I’d have kicked up murder,” Jacinta explained.

“The pump allows Donal to lead a normal life. He is now 17 years of age and six foot one. So I can’t really baby him anymore! However the fact that he has grown so tall so fast has brought its own problems. The amount of insulin required varies so we have to be extra careful”.

Night time is the worst as this is when the insulin levels are at their lowest. Maturity has resulted in Donal’s condition fluctuating. Indeed he has had two or three diabetic comas before he got the pump.

Eighteen months ago, the medical team who look after Donal identified a new pump with advanced facilities to help him take better control of the condition. This new pump, not only alerts you if your insulin levels are low, it also administers the correct amount for you. Donal was the first patient in Ireland to get this new device and it effectively gives him the peace of mind and great quality of life.

He explained that for the first time he now can live a normal live and both he and his parents have the confidence to let him do so. “It’s the first time since I was three that my mother does not know my blood levels and while that suits me, she finds it hard to let go. But I can now play GAA and go on holidays knowing that I am not restricted to eating at the same time every day, or leaving my friends to check my bloods and inject myself,” he explained.

### **Appendix 3: Case Study B**

#### ***A more holistic approach***

In 2012, the **Stockholm County Council (SCC)**, which runs most of the city's hospitals, offered an innovative tender for wound care products.

Instead of looking solely at product price, the invited bids included three hypothetical patient cases and asked bidders to calculate the total cost of treatment for each.

As part of the tendering process, suppliers needed to determine the total cost of the wound care element using a calculation model that the SCC provided: the calculation included the unit cost of the wound care dressings, the number of dressing changes, staff costs for time spent changing dressings (hourly rates for nursing were provided), as well as transportation costs to and from patients' homes. The tender also considered the expected level and frequency of complications caused – or avoided – by using the suppliers' wound care dressings. It is notable that the winning bid came from the bidder with the highest-priced products: the company was able to show a lower total cost of care over time and could document its claims with clinical evidence.

Best practice: Requiring that bidders calculate the total cost of care – including costs related to complications – for a variety of patients helped SCC move beyond purchase price to consider costs on a more holistic level.

### **Appendix 4: Case Study C**

#### ***Self-management in the home***

##### ***An example of the use of technology and education to transform care for patients is the warfarin monitoring service in Durham and Darlington, England.***

An estimated 1 million people in the UK take warfarin; the medication is the most commonly prescribed anticoagulant, slowing the rate at which blood clots. In so doing, it reduces the risk of potentially seriously conditions such as deep vein thrombosis, pulmonary embolism, heart attack and stroke. However, its use involves careful monitoring, which has traditionally involved seeing a healthcare professional for a blood test to measure how quickly the blood is clotting. The test will indicate whether the warfarin dose needs adjusting or not.

These tests usually require attending a clinic, at least monthly and sometimes as frequently as weekly. There is significant disruption to a person's life; the challenge of securing time away from work or other responsibilities etc. Too often the impact on the warfarin patient means losing money and time – and overall quality of life with it. Patients cared for by County Durham and Darlington Foundation Trust now have the option to use a digital self-testing service.

They are trained to take a finger prick blood sample, put it onto a test strip, and then place the test strip in a monitor with which they are provided. The monitor gives a reading of the person's international normalised ratio (INR), a measure of how quickly blood clots, which he or she can then share with clinic staff via an automated phone call.

Software automatically shares the figure with clinical staff, who check it, and the patient receives an automated call back letting them know whether they need to adjust the dosage.

No need to attend a clinic. The patient can choose the time of day at which they submit their reading and at which they receive the call back with their dose.

It has also helped improve the patients' outcomes. Before the project began, these people were only in therapeutic range around 60 per cent of the time. By the end of the trial, time in therapeutic range had increased to around 75 per cent<sup>13</sup>.

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<http://imsta.ie/>

## **Irish Nurses & Midwives Organisation**

The Irish Nurses and Midwives Organisation (INMO) warmly welcomes the decision, of the Oireachtas, to initiate this debate on the future of healthcare in Ireland. We believe, as the pursuit of safe quality care and patient focused practice is the hallmark of this Organisation, that the establishment of this committee offers the potential for consensus for a single-tiered, universally accessible, public health service where access is determined solely by need and not by ability to pay.

### ***Fundamentals for a single-tiered Health Service***

Recognising the current two-tiered structure, with its perverse incentives, we believe that a timeframe, of at least 15 years, will be required to develop a uniform, single tiered public health service. This process of transformation will require political and societal consensus, ensuring consistent public health policy, supported by adequate funding.

### ***Current Realities***

The economic downturn of the last eight years has negatively impacted on the ability of frontline staff, in particular nurses and midwives, to deliver the highest quality care based on international best practice. This negative impact has arisen from a misguided political perception that investment in healthcare services is a waste. Whilst we acknowledge that funding has increased, in the last two years, with total expenditure now €14.3 billion this remains 20% less than in 2007 despite greater service demands.

### ***Changes to Models of Care***

As the priority must be integrated care this transition will involve significant changes to our acute, primary and social care service models. In particular it must be recognised that the required shift, away from acute to primary care, will involve a period where both pathways are maintained as no existing service can be ended until an alternative, quality assured and accessible service is available to the local community.

The transition must involve a detailed review of our acute bed and operational capacity within our **acute services**. This review must deliver additional beds to address severe overcrowding in a number of hospitals. We must also ensure acute hospitals are fully operational on a 7/7 basis with team working, fully utilising the skills of all staff, a fundamental requirement.

We are also calling for radical reform of, and expansion to, our **primary care services**. This will involve all health professionals, providing primary care services in teams, being directly employed. Existing contracts, for both GPs and Consultants, can be retained, but not renewed, while all GPs/Consultants must be afforded the opportunity to move from existing contracts to a direct public contract. In addition to this our primary care services, if they are to provide access on an extended seven-day basis, will require significant numbers of additional health professionals,

particularly in the public health/community nursing areas, and this must be planned for as part of an overall workforce plan.

In recent years, in the absence of any public debate, the provision of **long term care** has been privatised and de-professionalised in the absence of adequate, sustained, investment in our public long term care facilities. In a single-tiered system this policy must be reversed and the State must be in a position of providing long term care, when it is required, to all our citizens with world class physical infrastructure. The current practice of investing only to improve existing buildings, to meet HIQA standards, actually results in a decrease in public capacity for older care.

The provision of **disability services** will also require significant reconfiguration and radical reform during this transition period. The current reliance upon external agencies, some of them within the public service while others are in the private sector, to provide these services has, in the past, served this country well. However, the reality is this type of provision can lead to inequality of access and, in more recent times, a loss of public confidence with regard to the proper utilisation of all monies granted or donated. We must shift towards a directly provided model and again this can be achieved over a medium timeframe. This must be accompanied by legislation which guarantees access to all services, as a human right, for the disabled person.

While most **mental health services** are currently directly provided, by the State within the public health system, they have been, for many years, subject to huge underfunding, loss of staff and inconsistent in their availability in different regions of the country. The transitional process must see increased investment which must not only touch upon capital infrastructure but, critically, on educating and retaining sufficient numbers of health professionals to provide a comprehensive, community based service over the seven-day cycle.

### ***Health Workforce***

A cornerstone of this transformation must be the development of a health workforce plan which clearly identifies the human resources for health required to staff this expanded, comprehensive, public service. We cannot rely upon overseas recruitment (apart from the ethical dilemmas it creates) to staff our health service. We must, as a first goal, seek to educate and retain people in this country. This will require the new health service, which will be the largest employer in the State, to be a world class employer offering excellent pay and other terms and conditions of employment. In return for this the service can expect dedicated, committed and quality assured care from all staff.

### ***Funding***

Politically the process of change to delivering a single-tiered world class public health service will require fundamental reform of the current funding model. This element must be underpinned by a willingness to commit the required adequate amount of funding at a minimum of 10% of GDP with 12% to 14% over the transitional period. This, in turn, will address current and future workforce needs,

ensure investment in necessary capital infrastructure and, thereafter, maintain health spending at the required level to ensure a world class service for all. In that regard funding, through a progressive taxation system, is the most equitable. This will require cross party political consensus which, to date, has been absent with regard to shaping our nation's health services.

### **Conclusion**

Against this background the journey, beginning with the work of this Oireachtas Committee, must see a transformation, as to how we deliver healthcare and how the political system views the public health service as a social good benefiting - the individual, communities and the economy. Complacency must be guarded against with public health policy being the subject of regular reviews spread over the transformational timeframe. We must address, in a timely and meaningful manner, all obstacles thus preventing dilution of a commitment to a single-tiered system, essential for social cohesion, the health and wellbeing of the population, and, ultimately, a growing economy.

### **FUNDAMENTALS FOR A SINGLE-TIERED HEALTH SERVICE**

The Irish Nurses and Midwives Organisation (INMO) warmly welcomes the establishment, by the Oireachtas, of this special Committee to consider the future of healthcare in Ireland based on the central tenant of equity, fairness and quality.

The INMO believes this must be the first step in a radical, comprehensive, transformational and sustained process of change leading to a seamless universal single-tiered health service with access based solely on health need rather than ability to pay is a fundamental social good. This service must provide all essential health services required at all stages of the life cycle.

The achievement of this objective will require short, medium and long term actions, spread over 15 years plus, but will deliver significant improvements for individuals, families and the economy.

Shaping, forming and sustaining, this single-tiered, universally accessible, public health service (including ownership and delivery), will require political consensus stretching far beyond the normal electoral cycle. It will require this, and future, governments, and oppositions, to accept that the transformational change required cannot be interfered with for political reasons. This will be important particularly during the transitional period when additional investment, both current and capital, will be required and when existing incentives, targeted at private healthcare, will have to be phased out.

All government policies must be shaped to promote the maintenance of good health for the whole population. This must include taxation policies which encourage healthy lifestyles while heavily taxing all products which lead to illness and obesity i.e. alcohol, cigarettes, sugar drinks and snack foods.

Annual expenditure, on a single-tiered service, must, at a minimum, be maintained at 10% of GDP (12% to 14% during the transitional period). Separate funding, over a

five to seven year period, is necessary for capital investment to improve existing health infrastructure and develop new community based health facilities.

Over the last 12 years, many policy and organisational reform programmes have been attempted. These have not delivered qualitative and quantitative improvements but have fragmented services and diminished integrated care. The transition, to a single-tiered system, must see simplified, transparent and lean, organisational structures with funding and accountability devolved to frontline managers who can respond to changing need, demographics and demand.

Ireland's future, single-tiered, health service, must also provide a dynamic, proactive and rewarding career for all its staff. In reality this new service will be the largest employer in the State and must be an employer of choice with excellent HR practices. It must also be recognised that, in this global economy, health professionals are mobile and, in particular, Irish health professionals, are recognised and highly regarded across the world. The working environment, career and reward structures, must be competitive and must ensure that we attract, and retain, the best and brightest health professionals and support staff in the interests of quality care and best possible patient/client outcomes.

### **Recommendations:**

***It is recommended that this Committee propose that as public policy, endorsed and supported by all political parties, this country move to a single-tiered, universally accessible, directly funded public health service where access to care is solely determined by need and not ability to pay.***

***It is recommended that it be accepted that this transformational change will take a minimum of 15 years and will require sustained political consensus with regard to the levels of capital and current funding required.***

***It is recommended that this public policy be the subject of regular reviews, spread over 15 years, to address all issues that arise thus preventing any dilution of a commitment to a single tiered system, essential for social cohesion, the health and wellbeing of the population and, ultimately, a growing economy.***

### **CURRENT REALITIES**

Over the last eight years, the Irish health service has been subject to radical contraction, in an unmanaged and unplanned way, which has left it unable to meet the demands being placed upon it.

In the same period, particularly between 2009 and 2014, funding for the health service was reduced, in real terms, by over €4 billion resulting in the premature contraction/curtailment of services without viable alternatives. This has negatively impacted upon the ability of frontline staff to deliver the highest quality of care underpinned by internationally proven best, evidenced based, practice and has had a negative effect on the health of the population through delayed access to services.

This has all taken place, not just because of a financial emergency or deep recession, but also because successive governments have never accepted that a quality assured health service is a social good essential for a dynamic economy. They have all too readily accepted the argument that the Irish health service is wasteful and a black hole in terms of taxpayer's money. This is an unfair, and incorrect, assessment as, despite all of the pressures upon it, standards of care, once accessed, are very good because of the commitment and professionalism of staff.

This contraction, in terms of budgets and staffing, has, at a minimum, resulted in the following:

- a loss of 2,000 public beds (acute and long term);
- the privatisation, in large part, of all services for older people in this country;
- severe contraction, in an unmanaged way, of mental health services, with large gaps, in service provision, across the country;
- silent, but very harmful, cuts in disability services; and
- very severe contraction, despite many public utterances by successive Ministers, in community based health services particularly in such areas as public health and community nursing, home care/home help, and community based services provided by allied health professionals.

It is acknowledged that, in the last two years, some increase in budget allocation has taken place. However, we would bring to the Committee's attention that, even after additional funding for the health service, this year the total expenditure is €14.3 billion when, in 2007, it was almost €17 billion.

The past seven years has also seen an unmanaged contraction, in terms of staff, and the following must, again, be noted:

- a loss of over 5,000 nursing/midwifery posts, amounting to a reduction of 13.5% of total employment;
- a loss of 3,500 general support and care staff;
- an increase in the number of medical personnel by over 1,500;
- a small increase (800) in the number of allied health professionals; and
- a reduction, of 1,200, in the number of clerical/administrative/managerial staff.

This unmanaged contraction, which was without purpose or direction other than budget saving, has left the service grossly understaffed, particularly in the frontline,

where patients/clients receive care. This represents an immediate crisis for our health service. In addition, this contraction has resulted in the forced emigration of thousands of young health professionals. A major challenge will be to attract back these health professionals while we educate additional numbers of health professionals and ensure they remain upon qualification.

To provide a comprehensive 7/7, quality assured, service will require the replacement of these lost staff together with additional staff recognising the shift to extended day service availability.

## **CHANGES TO MODELS OF CARE**

### ***Integrating Care***

The key objective, within this reform programme, must be to develop, deliver and maintain highly integrated care pathways for every user of the service. This requires, as stated previously, a simplified organisational structure which clearly indicates responsibility for service delivery. This can only be done by devolving responsibility, for the provision of **all** care, to the frontline.

Acute hospitals must operate, on a 7/7, basis with ever present lines of communication to Primary and Social Care services. The service user must be assured they will have access to the appropriate health professional, over this seven day cycle, with both the quality, and quantity, of healthcare available remaining consistently high. We must abandon the increasing tendency to silo service models and offer the patient/client a fully integrated quality assured service.

### ***Acute Services***

A core requirement will be a significant expansion in our acute bed numbers in a number of hospitals across the country.

- The current OECD figures confirm that Ireland, at 2.8 beds per 1,000 of the population, has a major under supply of acute beds (averaging at 4.8 beds per 1,000 of the population) and this must be addressed.
- These additional beds must be the required mix of day and seven day beds to reflect the changing nature of service delivery and the increasing shift to procedures done on a day basis.

It will also be necessary to greatly expand access to diagnostic and treatment services, over the seven-day cycle, in all major acute hospitals which will require investment in both staff and equipment.

Any transformational programme must involve, as a central requirement, that all new consultant staff work under a **public only** contract providing services, on an extended day basis, over the seven-day cycle.

- This will require significant additional numbers of Consultants, particularly in the core specialisms of Medicine, Surgery, Paediatrics, Obstetrics and Emergency Medicine.
- It will also facilitate a reduction in the system's reliance upon, and number of, doctors in training, (Non-Consultant Hospital Doctors - NCHDs).
- It must also recognise a transitional period during which existing contract holders, at Consultant level, will continue, if they wish, on their existing contracts or, alternatively, migrate to the new **public only** contract.

Staffing levels, in all acute services, must be evidence based, and maintained under the direction/control of the frontline clinical manager. This work has commenced, in the nursing/midwifery area, and should be extended across the service as part of the change programme. This will ensure consistency of staffing and patient safety.

### ***Maternity Services***

As part of this major reform we must also fully implement the recently published Maternity Strategy with its emphasis upon choice and quality of care for the pregnant woman.

This must include, and will require planning for, the nationwide availability of community based, accessible, midwifery led services. These should be linked to the greatly expanded primary care services referred to below.

A cornerstone of this very welcome strategy is the need to greatly increase the number of midwives, working in the public system, to ensure that the ratio of midwife to births stands at 1 to 29.5 which is recognised as being an optimal staffing level for quality assured care.

### ***Primary Care***

The cornerstone of any single-tiered universally accessible health service will be the development of a primary care health service which works, at a minimum, on a seven over seven basis, with access being available on a 24/7 basis in major urban areas.

All staff, providing primary/community care services, should be directly employed on a public only contract. They must work on a team basis with the individual having the right to directly access the relevant health professional. Health professionals should also be in a position to cross refer, any patient, to another health professional in a different discipline, as required, to ensure the patients' needs are met. It is also imperative, in the interests of patient safety, that frontline health professionals have a reporting relationship to their senior colleagues.

This critical part of the transformation process will require a radical alteration to the current contract relating to General Practitioners (GPs). All future contracts should

involve direct employment, extended day rostering and full integration into the primary care team with all other health professionals.

- Existing contract arrangements must be allowed to continue. All new contracts must reflect the reality of a single-tiered service with universal access delivered by directly employed staff.
- Where existing contracts are altered all staff in that practice should, together with that GP or group of GPs, be subsumed into the public health service.
- In a situation where the GP, (or group of GPs), do not wish to alter their existing contract other practice staff should still, in the interests of integrating care, be offered the opportunity to transfer to the public health sector.

Primary care centres must be built, complete with significant diagnostic and treatment services available within them, and it is recognised this will require sustained capital investment.

All primary care centres must provide at a minimum:

- direct access to the full range of allied health professionals;
- a full range of basic diagnostic and treatment services; and
- health promotion/screening services to promote the maintenance of good health and not just treat ill health.

The transformation programme should, ultimately, see the balance of funding move away from hospital (secondary) care to primary care services. This is not to suggest cost reductions but to allow the provision of a wider range of services, at a lower cost, per intervention. The shift to primary care should also assist in the promotion of healthier lifestyles, aided by targeted taxation measures, to reduce the incidence of ill health in the community over time.

Arguably the greatest challenge facing any future health service is the combination of demographic change, management of chronic diseases, and the growing incidences of obesity and the health challenges which arise. These can only be managed, treated and minimised by the existence of a primary care service which is not only accessible but reaches out to the population.

### ***Care of Older Persons***

To deliver a single-tiered universal health system the State must reverse its existing policy, of silently privatising care of the older person services, and commit to public provision of all services, for the older person, into the future. This must include a costed planned capital building programme for new facilities.

In addition nursing practice has progressed and expanded to include nurse prescribing and administration of medications under protocol. This development must be to the forefront of developing more efficient, patient centred, care in the community (home/care centres). This would replace the current practice of the elderly citizen being transferred to the acute hospital to access the most basic levels of intervention because this service is currently not available, or catered for, in our existing care of the elderly facilities/services. '*The system*' must catch up to the development in nursing practice and move immediately to develop extensive nursing led services in care of the elderly facilities.

This will require the phased elimination of current subventions to private nursing homes. It must also see significant capital investment, in new long term care facilities, recognising the aging population, increasing life expectancy and the resulting increased morbidity which will require long term care in the coming decades.

Seeking profit/financial gain has no place in a single-tiered public health service. The State must accept responsibility for the delivery of high quality care, whether it be in the home, day/community based facilities or long term care facilities, for our senior citizens as part of this transformation of our health care system.

### ***Disability Services***

The key objective, with regard to Disability services, is to ensure the individual always has access to appropriate qualified professionals who seek to ensure the person reaches their full potential while fully integrating into his/her community. Additionally, the human rights of persons with disabilities must be enshrined in legislation to ensure equity of access and parity of esteem with their fellow citizens.

In considering this aspect of our health care service it must be recognised that the provision of disability services has, over many decades, been devolved, by the State, to various voluntary organisations and not for profit community based groups. It should be recognised that, for the most part, the services have been of the highest quality and the State owes a great debt of gratitude to these providers.

However it has to be also recognised that the delivery of disability services, through these disparate groups, has led to gaps in service provision and variations of standards which cannot be ignored. Equally, particularly in recent years, there have been difficulties, with regard to funding and other financial matters, which cannot be ignored and have damaged public confidence.

Against this background, and in order to again ensure equality of access and the highest, consistent, standards of service, the transition, to a single-tiered service, must involve the State, through direct provision, in providing disability services. This model should address the holistic health issues, throughout the life cycle, bearing in mind the need for the State to provide services as the role of families and carers may diminish with increasing life expectancy. The Registered Nurse in Intellectual Disability (RNID) is the only holistically trained professional capable of supporting these services into the future.

A particular challenge, over the next 15/20 years, in the area of disability, will be balancing the ongoing shift from institutional care to community based living facilities. This requires greater levels of infrastructural investment, where it is appropriate, while also involving the provision of intensive supports, in residential facilities where necessary, to optimise the lives, opportunities, potential and well-being of the person with a disability.

### ***Mental Health***

It is self-evident that the State has failed to provide a comprehensive range of services, regardless of means or location, to our fellow citizens encountering mental health difficulties over many years. There are examples of world class services in this country. However, we must also acknowledge examples, over many years, of neglect, failure and, at times, segregation, of those with a mental health illness which cannot continue.

The transition, to a single-tiered health service, must see very significant investment, linked to the primary care centres referred to earlier. This will allow the individual access services, on a 24/7 basis, fully utilising the full range of specialist professionals who should be located in both the primary care centres and emergency departments of large hospitals in urban areas.

Most mental health services are already delivered through the existing public health service. However, this has been subject to severe cutbacks, in recent years, and confusion over the provision of new services and staff. The transformation programme must see this service receiving the attention it warrants so that it can be accessed, at all times, by those who need support.

### **Recommendations:**

***It is recommended the reform/transitional programme deliver a fully integrated service, within a flat management structure, with responsibility, with autonomy, devolved to clinical frontline managers who can access all services for the patient/client.***

***It is recommended that, as part of this transition, the recently published Maternity Strategy, is implemented as a matter of priority thus providing choice to the pregnant woman.***

***It is recommended that the new service involves all health professionals fully utilising their skills and competencies. This must entail direct access for all patients/clients, to any health professional, and the ability for health professionals to cross refer depending upon the needs of the patient/client.***

***It is recommended that the existing service model, providing disability services, be dismantled, over this 15 year period, and replaced with directly delivered services with a key focus upon fully utilising health professionals and providing, under legislation, guaranteed access to appropriate services.***

***It is recommended that an expanded range of mental health services are provided, on a seven-day basis through primary care centres fully utilising the skills of all health professionals.***

## **EALTH WORKFORCE**

An immediate challenge, facing any transformation programme, will be the development of a health workforce plan which identifies the human resources for health necessary to provide this expanded service. This plan should recognise the public good, in terms of overall health and wellbeing, arising from a properly staffed service and include timelines for full implementation.

It is a reality that, currently, our staffing levels, skills mix, roles and function are based on historical factors. They are not related to the demands currently on the system, patient/client acuity and dependency and the turnover of staff, particularly professional staff, within our health service.

In that context a cornerstone, of any programme, must be an assessment of future need, based upon the form and type of service to be delivered and how we will, recognising the worldwide shortage of health professionals (in particular nurses and midwives), educate and retain sufficient numbers of our own to meet service requirements. Recognising the global labour market we cannot rely upon unethical overseas recruitment to staff our services into the future.

This will require significant work, informed by available international evidence and best practice, of intra professional working including a review of roles and functions. This must seek to ensure the full utilisation of skills, with manageable workloads recognising the acuity/dependency of patient/clients. Ongoing employer supported education and professional development is a must for a modern developing health service. This ensures the commitment to innovation and development of new methods of care delivery which, in turn, retains staff as they have a greater input into best practice and development of services.

In the formulation of this multi-faceted plan, and in the context of our single-tiered service being a dynamic world class employer, we must also target health professionals who have left this country in recent years. The reality is that, particularly in nursing/midwifery, we have an aging workforce with increasing numbers of retirements taking place over the next 10 years. This must be recognised, in this workforce plan, as we maximise the number of undergraduate places, in all disciplines, as well as targeting overseas recruitment to attract back those who have left in recent years. All of these professionals will be necessary to establish, and maintain, optimum staffing levels which, in turn, are proven to enhance outcomes for patients/clients.

The key, to this workforce plan, is that the Irish public health service will become an employer of choice, with excellent terms and conditions of employment. This will attract, and retain, the numbers of dynamic, committed, health staff necessary to deliver a world class health service.

### **Recommendations:**

***It is recommended that the new health service, as the largest employer in the State, must be, recognising the worldwide demand for Irish health professionals, an employer of choice offering excellent pay and other terms and conditions.***

***It is recommended that the move to a single-tiered service, providing a full range of services on a seven-day basis, must include a comprehensive workforce plan which will ensure the following:***

- ***Ireland educates, and retains, the required number of health professionals to staff the expanded public health service;***
- ***staffing levels, within the service, are determined by an evidenced based approach, informed by international best practice, which will involve assessment of patient acuity and dependency and acceptance of the professional judgement of the health professionals involved; and***
- ***that all direct care in the reformed health service is provided by the most appropriate person in the most appropriate place closest to the patient's/client's own home where possible.***

***It is recommended that all new contracts, for Consultants and General Practitioners, specify public only employment with existing contract holders being offered the choice of moving to the new contract or remaining on their existing contract which would not be renewed when it expires or the individual retires.***

### **FUNDING**

In 2013 OECD figures state the government allocated 7.2%, of Ireland's GDP, to public health spending. These figures confirm public expenditure, on health in Ireland, has decreased since 2009 and now represents 67.4% of total health expenditure in this country. The figures also confirm the degree of contraction in health expenditure over the period 2009 - 2014, was unparalleled when compared to any other OECD country.

This level of public expenditure is significantly below the OECD average, of approximately 9.2%, and further exacerbates the years of underfunding, of our public health service, covering the last 25 years.

In parallel with this direct, publicly allocated, level of funding, the same OECD figures confirm that individuals, either through private insurance or direct out of pocket expenditure, account for 32.6% of the total level of expenditure, in 2013, in this country. Indeed, in tandem with the reduction in public expenditure, on health, since 2009, private expenditure, whether from private insurance or direct cost to the individual, has increased.

It should also be noted that while this data reflects that out of pocket individual spending, on health insurance, remained relatively constant, in the years 2005 - 2007, this spending has risen, in proportion and volume, compared with private insurance expenditure in the years 2008 - 2013 and has remained consistently above the 2005 - 2007 levels. In other words those who could afford to, increased their out of pocket expenditure, on health, which begs the question what negative consequences arose for those who could not afford any additional expense.

When taken together this overall level of expenditure on health, either through government expenditure, private health insurance or direct out of pocket payments, confirm that our total expenditure, at this time, is approximate to 10% of GDP. However the manner of this expenditure, which clearly reinforces the two-tiered structure, only serves to guarantee faster access to diagnostics and treatment for those who can either afford private insurance or direct out of pocket costs. This is inherently unfair and inequitable.

Recently NERI have produced a forecast of Irish healthcare expenditure from 2014 - 2015 in view of the demographic changes expected to occur and their implication for, and pressure on, health spending. As the study evidences, Ireland will likely face a confluence of factors that will significantly impact health costs including an increasingly aging population, a decrease in fertility, migration and changes in life-span and morbidity. Indeed:

- *While Ireland currently has one of the youngest populations in the EU, the population over the age of 65 is projected to nearly treble over the next three decades from about 606,000 in 2015 to between 1.7 and 1.8 million individuals in 2046. This implies increased expenditures due to the higher costs associated with these cohorts as well as changes in the overall allocation of resources within the public system. (Kelly 2014).*

Having reviewed the current practice in Ireland for the financing and provision of healthcare services, as well as forecasts for cost implications of inaction and modelling of proposed reform measures, we propose the following:

- as stated we propose the abolition of the current two-tiered system of healthcare provision in favour of universal access to services, free at point of delivery, with access based on need;
- establish a single-tiered health service funded from general taxation - acknowledging that various models of general or specific taxation may be deployed to achieve this objective;
- determine a quantum of funding that is necessary and sufficient to meet the healthcare demands of the Irish population into the future, and to do so based on a cross party, cross sectoral, process which embraces the concepts of equity of access, based on need, and develops a changed service which truly meets the needs of the population;

- create a health service which adequately meets the healthcare needs of the nation;
- emphasise sustainability, cost management and equity in the funding and provision of healthcare; and
- adopt best practices and models of care which produce the best health outcomes.

The move to this funding model must also include:

- the phased abolition of all tax reliefs pertaining to private health insurance;
- the ending of any contracting for services to provide direct care; and
- the phased ending of subventions to private nursing homes.

It is recognised this reform will take an extended period due to a range of factors including contracts/bed stock/development of new facilities. This approach to funding, both during the period of transition and thereafter, must secure and maintain the support of both the political system and the taxpayer.

The shift to funding, through general taxation, and the phased abolition of tax reliefs and subventions, for healthcare, must be undertaken in a very open and transparent manner if it is to enjoy cross community support. This must see public perception change from health insurance gives you fast/better access to one where it is understood a progressive taxation system, within which everyone pays their fair share, leads to the provision of a world class accessible health service **for all**.

### **Recommendations:**

***It is recommended that this public health service is funded through a progressive general taxation system which will seek to ensure that every citizen's contribution is based upon their ability to pay.***

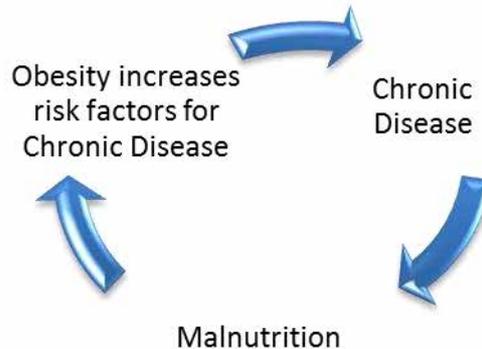
***It is recommended that, once established, the public health service be funded to a minimum of 10% of GDP recognising that, during the transitional stage, the funding levels necessary will be 12% to 14% of GDP.***

***In tandem with this move to a single-tiered service, funded through general taxation, it is recommended that all tax reliefs, for health insurance policies and direct subventions, to private nursing homes, be phased out and ultimately eliminated. It is recommended that all public policy be geared to encourage healthy living and active lifestyles. This should include, as a first step, increased taxation on sugary drinks and snack food which encourage obesity.***

<https://www.inmo.ie/>

## Irish Nutrition and Dietetic Institute

Poor nutritional health and lifestyle contributes to a vicious circle of overall ill health and increases the risk of chronic disease. For example, overweight and obesity, a condition which is highly prevalent in Ireland, increases the risk of chronic disease such as cardiovascular disease, and some cancers. Together, malnutrition, obesity and chronic disease, which are on the increase in Ireland, currently costs the state over a billion euro each year.



To reduce health inequalities and future proof the health system, we must include nutrition as an integral part of health planning and policy.

Dietitians are the *only* group of health professionals who are recognised by the state (CORU) to have the qualifications necessary to provide nutrition education, intervention and counselling to enable adults to prevent these chronic diseases across the lifespan from pre-pregnancy to old age and end of life.

Against a backdrop of the public being bombarded through media and social media with misinformation about diet and health from unregulated sources, the numbers of Dietitians in the health service fall dramatically short of where they should be in order for Healthy Ireland (HI) to deliver on their goals for the health of the nation, or indeed for the provision of an adequate service in the public health sector.

The Irish Nutrition and Dietetic Institute (INDI) is the professional body representing qualified and registered dietitians in Ireland and we make the following recommendations for action:

- To meet the objectives of Healthy Ireland, to sustain the health of the nation, prevent and manage disease in the population, and reduce inequities in service provision, it is recommended that workforce planning initiatives address the urgent requirement for dietetic services across the Population from pre conception to end of life.
- The establishment of a Health and Social Care Professionals Office in the HSE and a corresponding office in the Department of Health to ensure parity of esteem with Medical and Nursing colleagues

### **INTRODUCTION**

We all aspire to live a long and healthy life with our families whilst making a contribution to our communities. For the majority of us that aspiration is realised. Generally speaking, health can be maintained by a combination of good nutrition, regular exercise and social interaction.

The purpose of this submission is to highlight the importance of good nutrition, its role in health, as well as disease prevention and treatment, and to explore solutions that can be provided across the life course to improve the health and wellbeing of Irish people using the expertise of registered Dietitians. It will also reference some numbers in the context of requirements for workforce planning into the future and make some suggestions in terms of stakeholder consultation, resource allocation, and organisational structure to ensure that nutrition care is integrated into health service strategy and planning.

The committee identified priority areas and has developed associated work streams. The ones that we will be discussing encompass Integrated Care, Chronic Disease Management and the Dietitian's role in the delivery of a safe, high quality, equitable health service.

### **THE IMPORTANCE OF GOOD NUTRITION**

Poor nutritional status leads to poor health outcomes. Institute of Public Health data <http://www.publichealth.ie/healthinequalities/foodpoverty> indicates that people living on lower incomes tend to have less healthy diets. Obesity, is more prevalent in areas of economic disadvantage which can be attributed to lack of access to transport, finance and information leading to health inequalities that begin at birth and remain across the life course. There has been much discussion around the obesogenic environment in which we live, which can further widen the gap between those who can live a healthy life and those who don't.

With obesity and disease related malnutrition costing over a billion euro *each* in Ireland each year it is natural that nutrition occupies the minds of the public and those who plan policy and deliver health care. The rates of obesity are rising, as is the incidence of malnutrition in the community. Both of these conditions have consequences for the health of the nation and the costs to the health service. If we are serious about reducing health inequalities and future proofing the health system, we must include nutrition as an integral part of health planning and policy.



### **OBESITY**

In Ireland, 1 in 4 children, 2 in 3 adults and 4 in 5 people over the age of 50 are overweight or obese. Overweight people have a BMI of greater than 25kg/m<sup>2</sup> and obese people have a BMI of over 30 kg/m<sup>2</sup>.

Growing up in Ireland, 2011 tells us that children who experience rapid weight gain in the early years are more likely to become overweight or obese. 80% of children who are obese at age 10-14 will be obese adults.

The prevalence of obesity among Irish adults (18-64 years) has increased significantly between 1990 and 2011, from 8% to 26% in men and 13% to 21% in women, with the greatest increase observed in men aged 51-64 years.

This does not improve as we age, with the TILDA study indicating that among those over 50, 43% are overweight and a further 36% are obese according to their body mass index. TILDA found that older people who are obese visit their GP more frequently, take more medications, and a higher proportion report poly-pharmacy (concurrent use of five or more medications) than non-obese individuals.

It is estimated that the daily cost of obesity is over €3 million in the Republic of Ireland, with the total spend in 2009 estimated to be €1.13 billion, accounting for almost 3% of the total healthcare spend. International data suggests that a person who is obese will incur 25% greater health care expenditure per year compared with a person with a healthy body mass index (BMI). In a time when the population is ageing, people with obesity will be living longer with co-morbidities so this figure is set to rise.

### **Consequences of Obesity**

Obese and overweight people are also more likely to suffer from chronic diseases. (See Table 1)

**Table 1: Relative Risk of Health Problems Associated with Obesity**

<b>Risk Level</b>	<b>Clinical Condition</b>
<b><i>Slightly increased (relative risk 1-2)</i></b>	<ul style="list-style-type: none"> <li>• Cancer (breast in postmenopausal women, endometrial, colon)</li> <li>• Low back pain.</li> <li>• Reproductive hormone abnormalities. Polycystic ovary syndrome, Impaired fertility.</li> <li>• Foetal defects arising from maternal obesity.</li> <li>• Increased anaesthetic risk</li> </ul>
<b><i>Moderately increased (relative risk 2-3)</i></b>	<ul style="list-style-type: none"> <li>• Coronary heart disease</li> <li>• Osteoarthritis (knees)</li> <li>• Hyperuricaemia and gout</li> <li>• Asthma.</li> </ul>
<b><i>Greatly increased (relative risk &gt; 3)</i></b>	<ul style="list-style-type: none"> <li>• Type 2 Diabetes and insulin resistance</li> <li>• Hypertension; Dyslipidemia and Stroke</li> <li>• Gall bladder disease</li> <li>• Breathlessness, Sleep apnoea.</li> </ul>
<b><i>WHO Report: Obesity: Preventing and Managing the Global Epidemic</i></b>	<a href="http://www.who.int/nutrition/publications/obesity/WHO_TRS_894/en">http://www.who.int/nutrition/publications/obesity/WHO_TRS_894/en</a>

There is an abundance of confused, often inaccurate advice about nutrition and health available to the public. The Healthy Ireland (HI) Framework sets out to achieve an increase by 5% and 6% in the number of adults and children respectively with a healthy weight. Evidence-based messages on nutrition and health are essential to achieve these HI targets, and Dietitians are the health professionals who are equipped to help deliver these goals by empowering people to make the necessary lifestyle changes to prevent obesity and chronic disease. The Department of Health is also about to launch a National Policy on Obesity and

revised Healthy Eating Dietary Guidelines (HEDGs). INDI has contributed to both HI and HEDG's.

### **Prevention and Treatment of Obesity**

In 2015 the Royal College of Physicians of Ireland Policy Group on obesity published 'An expert report on how to clinically manage and treat obesity in Ireland.'. Over half of the policy recommendations pertaining to the management and treatment of children who are overweight or obese directly include a unique role for a Dietitian. Similarly, five out of six recommendations from the World Health Organization report on 'Ending Childhood Obesity' in 2016 include a role for a Dietitian. <http://www.who.int/end-childhood-obesity/en>

All of the interventions below are delivered as part of a multi- disciplinary team and are provided in hospital and community settings.

**Table 2: The Dietitians Role in Obesity Prevention across the Life- Course**

Life Stage	Dietitians Role
<b>Infants</b>	Supporting new mother to initiate and sustain breastfeeding, a key risk area is during the transition from hospital to home. Public Health Nurses are not expert in nutrition and there is a role for Dietitians to play in the education of their PHN colleagues and mothers.
<b>Pre- School</b>	Dietitians contribute to HSE preschool guidelines. See <a href="http://www.thehealthwell.info/obesity-intervention/healthy-incentive-pre-schools-hip-project">http://www.thehealthwell.info/obesity-intervention/healthy-incentive-pre-schools-hip-project</a>
<b>School Going</b>	Design and implementation of healthy eating programmes for schools in partnership with health promotion officers.
<b>Maternal and Infant Health</b>	Maternal obesity has been found to be the most significant factor leading to obesity in children (HSE & RCPI 2013). Almost half of all pregnant women in Ireland are overweight leading to an increased risk of Gestational Diabetes.  Dietitians work with mothers, pre-natally, during pregnancy, post-natally and intra partum to manage weight and risk factors. They also care for babies who experience faltering growth to ensure they optimise their nutritional status and reach their developmental milestones.
<b>Older People</b>	Creating guidelines and resources that support families and carers. Advising residential care facilities and developing healthy eating programmes and cooking supports in the community

### **Nutrition and Chronic Disease**

Maintaining a healthy weight can help to modify the risk factors outlined above for Chronic Diseases and, as with obesity, Dietitians can support prevention, treatment and secondary

prevention of Chronic Diseases, leading to better outcomes and reduced burden of disease for patients and their families and more efficient use of resources for the health system.

**Table3: The Dietitians Role in Chronic Disease**

<b>Disease</b>	<b>Dietitians Role</b>
<b>Diabetes</b>	<p>There are almost 200,000 people living with diabetes in Ireland. This includes an estimated 160,000 with the most common form, Type 2 diabetes. Diet is integral to the management and control of diabetes.</p> <p>Dietitians have a role to play in the prevention of Type 2 Diabetes through the development of targeted diet and lifestyle interventions. They can also support other health care professions through education on nutrition to make every contact count.</p> <p>Once a patient is diagnosed with Type 2 Diabetes, Dietitians support the management of these patients through structured education programmes, behaviour change techniques and facilitating supported discharge from hospital for complex patients so that care can be delivered close to home.</p>
<b>Cancer</b>	<p>Maintaining healthy weight has been shown to be effective in modifying the risk of developing some cancers. If a patient is diagnosed with cancer Dietitians care for them from diagnosis to palliation. They are an integral part of the multidisciplinary team in medical oncology, surgical oncology and radiation oncology. Dietitians see patients as inpatients, in oncology day care settings and manage complex patients requiring home nutrition support (enteral and parenteral) in partnership with the patient's consultant.</p>
<b>Renal Disease</b>	<p>10% of the population has renal disease., with 1% on dialysis, and this cohort is growing. Diet is integral to the management and control of renal disease. Dietitians advise on the increasingly restricted diets that are required as the renal disease progresses. Dietitians influence the medical management, as they assess the nutritional adequacy; fluid and nutritional needs; micronutrient requirement and the management of bone metabolism.</p>
<b>Cardiovascular Disease</b>	<p>Dietitians play a key role in the primary and secondary prevention and management of hyper and hypo tension and recovery post stroke. They provide dietary advice on cholesterol and healthy eating post-surgery or cardiac event and advise on weight loss.</p>
<b>Other Conditions</b>	<b>Dietitians Role</b>
<b>Cystic Fibrosis</b>	<p>Evidence has shown that improving and maintaining good nourishment in cystic fibrosis (CF) results in better functioning lungs. Where drops in weight are noticed a special nutritional plan is developed. The CF patient can work together with their Dietitian to improve their eating patterns or medication use.</p>
	Feeding difficulties have been found to affect 60-90% of children

<p><b><i>Disabilities – Children and Adults with Cerebral Palsy, Autism Spectrum Disorder (ASD), Down Syndrome</i></b></p>	<p>with Cerebral Palsy . Many children with Autism Spectrum Disorder exhibit selective eating and therefore have self-limiting diets which are unbalanced and problematic. Equally, children with conditions such as Down’s Syndrome, Spina Bifida and Muscular Dystrophy experience a range of nutritional difficulties including undernutrition, eating, drinking and swallowing (EDS) disorders, constipation, vitamin &amp; mineral deficiencies, bone problems, overweight/obesity, among others. A significant number of those presenting with EDS difficulties go on to require tube feeding. All of these require specialist dietetic intervention.</p>
<p><b><i>Mental Health</i></b></p>	<p>Dietetic interventions, provided as part of a multi-disciplinary team to individuals with mental health conditions and their care providers, can lead to reduced nutrition-related side effects of psychiatric medications, better self-management of concurrent and comorbid conditions, and improved function overall. Dietitians help with disordered eating and provide weight management and lifestyle groups to help address poor nutritional health in someone who has mental health issues.</p>
<p><b><i>Dementia</i></b></p>	<p>The most scientifically supported lifestyle factors for Alzheimer’s disease are also known risk factors for cardiovascular disease and diabetes. Dietitians provide nutrition education and counselling to enable adults to prevent these chronic diseases which may help protect the brain from damage and reduce risk/severity of dementia. When dementia is present a key challenge in managing patients is the prevention and treatment of malnutrition and assessment and management of feeding difficulties. A lack of intervention can result in disease progression and ongoing cognitive decline, increased rate of infections, functional decline, frailty and falls, increased hospitalisation as well as reduced survival &amp; increased mortality. Dietitians work within hospital and community teams to provide a whole system solution to the management of malnutrition in patients with dementia to optimise outcomes for patients who have the capacity to live healthy lives and improve quality of life for palliative patients and ensure that end of life care is supported and compassionate.</p>

**Malnutrition**

There are 147,000 malnourished people in Ireland and the healthcare cost associated with adult malnourished patients in Ireland is estimated at €1.4 billion.

Malnutrition is frequently undetected and untreated, due to lack of awareness or education about how to recognize and treat it effectively. Those most at risk include patients with cancer, gastrointestinal disease, dementia, stroke/neuromuscular disease, COPD, renal disease or any disease associated with serious injury.

According to the Irish Society for Clinical Nutrition and Metabolism (IrSPEN), malnourished patients cost three times more than non-malnourished hospital patients per year. Around

32 % adult patients in nursing homes are malnourished, as are 25 % of adults in receipt of home care packages.

The consequences of malnutrition include increased dependency and disability; poor wound healing, pressure sores, poorer quality of life and increase risk of mortality.

Malnutrition impacts on healthcare costs including an increased number of GP visits and number of prescriptions, increased need for admission to hospital, longer length of stay, lower rate of return to independent living, and greater likelihood of requiring home health care. The economic implications of adult malnutrition have been estimated by Rice & Normand 2012 based on a model developed by BAPEN UK. This analysis found each malnourished patient has an associated cost of €5,357 euros to the HSE.

**Table 4: The Dietitians role in the treatment of Malnutrition**

Setting	Dietitians Role
<b>Hospital setting</b>	Dietitians develop plans for training their nursing colleagues to use malnutrition screening tools . This facilitates early identification and referral to the Dietitian for intervention and planning of nutrition support to the patient. There is potential for expansion.
<b>Community</b>	Community Dietitian can train GPs, Community Nurses and other health professionals in primary care to screen for malnutrition. INDI is currently exploring ways of teaching community workers to identify the early signs of Malnutrition in the community so that appropriate intervention can occur earlier.
<b>Residential Care</b>	The Health Information and Quality Authority (HIQA) has introduced specific criteria and requirements for nutritional standards to be implemented in all nursing homes, including private, public and voluntarily run homes. Staff need to be able to access Dietitians to support the nutritional care of patients at risk of malnutrition; support compliance on specialised diets such as puree diets and diabetes and ensure healthy eating is promoted.

### **WHO WE ARE**

Founded in 1958, the Irish Nutrition & Dietetic Institute (INDI) is the Professional Body representing the interests of over 700 qualified and registered Dietitians in Ireland. Regulated by the Health and Social Care Regulator (CORU), Dietitians are clinicians who operate across clinical and scientific areas encompassing the spectrum of public and private healthcare provision.

### **What is a Dietitian?**

A Dietitian is a health professional who has a Bachelor's degree specialising in foods and nutrition, as well as a period of clinical placement in a hospital and a community setting. It takes at least four years of full-time study at a university to qualify as a Dietitian, furthermore 20% of the profession in Ireland hold Masters or Doctoral degrees. Dietitians apply the science of nutrition to promote health, treat and prevent malnutrition and provide therapeutic dietary guidelines for patients, clients and the public in health and illness. There are only two routes to qualifying as a Dietitian in Ireland, one is through the 4-year Trinity College Dublin (TCD)-DIT BSc in Clinical Nutrition and Dietetics and the other is a

postgraduate MSc in University College Dublin (UCD), also in Clinical Nutrition and Dietetics. Dietitians are the only group of people with qualifications recognised by CORU (the State Regulator for health and social care professionals) to advise and manage nutrition-related conditions on an individual basis. The title Dietitian is protected and it is not possible to qualify as a Dietitian in Ireland or England and meet the state regulation requirement through a part-time course.

### **What do We do?**

Dietitians are trained to scientifically critique research papers and make evidence based recommendations. The NHS (<http://www.nhs.uk/explore-by-career/allied-health-professions/careers-in-the-allied-health-professions/Dietitian>) describes one of the major skills of a Dietitian as translating scientific and medical decisions related to food and health into simple language to inform the public. Dietitians are interested in science, people and food and are trained to be able to communicate with people from all areas of the community. The Dietitian is trained to translate complex scientific principles into simple, positive and motivating language, for the benefit of all service users. A relatively large proportion of Dietitians engage in high quality published medical and scientific research which is well regarded in these fields both nationally and internationally.

### **Hospital**

In hospitals Dietitians assess and treat people who require nutrition advice and support associated with their medical condition and health status. The Dietitian manages the nutritional care of patients who require nutritional support such as fortified meals, oral nutritional supplements, enteral or parenteral feeding.

They also provide patients with therapeutic diets, which are used to optimise the well-being of patients with specific medical conditions. They work across the hospital environment and can have patients from every surgical and medical specialty. In Ireland we have Dietitians working in cardiology, cystic fibrosis, diabetes, gastroenterology, GI surgery, transplantation, spinal injuries, intensive care, neonatal intensive care, maternity services and infant feeding, oncology, renals, paediatrics, care of the elderly, inherited metabolic disorders, rehabilitation, and end of life care. Dietitians also train, support and advise other health professionals, and students in the hospital.

### **Community**

Community Dietitians work in the Primary Care setting with Primary Care Teams and deliver nutrition training for health care professionals as well as providing individual patients with therapeutic dietary advice. Many Community Dietitians are involved in the delivery of education for people with Type 2 Diabetes in the community. Community Dietitians also work closely with health promotion services around the country, working alongside health promotion colleagues in a range of settings, such as schools, preschools, and local communities.

They see and treat patients across the life course. Their activities encompass, weight management, care of patients with disabilities (both intellectual and physical), care of patients with mental health issues (including dementia) and public health nutrition.

### **WORKforce PLANNING, stakeholder consultation and organisational structure**

According to the HSE census of 2014 there are 440 Dietitians employed in the public sector in Ireland. The majority are located in the acute hospital setting where they provide specialist therapies. To give an example of current staffing levels, figures from the National Cancer Registry indicate that there are 50,000 people either in the acute or post-acute

phase of cancer treatment in Ireland at any given time. With only 36 dietitian posts working across the country with cancer patients, this equates to a caseload of 1:1388. Those attending private hospitals for chemotherapy are more likely to access a dietetic service. There are approximately 120 Dietitians working in the community. To provide some context, there are currently approximately 750 Speech and Language Therapists and 1,127 Occupational Therapists in primary care. There are 4.7 million people in Ireland. In the community setting there is an average of 1 Whole Time Equivalent Dietitian per 50,000 of population. To achieve the objectives of the strategies listed below the ratio will need to change to 1 per 15,000 which will mean that 80 Dietitians will need to be employed each year over the next 5 years. This will bring the total number of Dietitians employed to 670.

<b>Strategy</b>	<b>Agency</b>
<b>Community funded schemes (Nutrition)</b>	HSE
<b>Development of clinical pathways of care for the management of disease related malnutrition</b>	HSE
<b>Diabetes cycle of care</b>	HSE
<b>Healthy eating and active living programme</b>	HSE
<b>Healthy Ireland in the Health Services- National implementation plan</b>	Cross Agency
<b>Healthy Ireland – Nutrition Goals</b>	Cross Departmental
<b>National Cancer Strategy</b>	Department of Health
<b>National model of care for Stroke</b>	HSE
<b>National model of care for Paediatrics</b>	HSE
<b>National model of care for Universal child health</b>	HSE
<b>National Obesity policy</b>	Department of Health
<b>National standards on nutrition and hydration</b>	HIQA/ HSE
<b>National Women &amp; Infants' Health Framework</b>	Department of Health
<b>Nurture Programme</b>	HSE

At present only 40 Dietitians graduate each year in Ireland, this will not be enough to meet the nutritional health needs of the Irish population.

There is a chief Medical Officer in the Department of Health and a corresponding position within the HSE. There is a Chief Nursing Officer and an equivalent in the HSE. There are 70,000 Health and Social Care Professionals in Ireland and there is no dedicated position for them at all.

**RECOMMENDATIONS FOR ACTION**

- To meet the objectives of Healthy Ireland, to sustain the health of the nation, prevent and manage disease in the population, and reduce inequities in service provision, it is recommended that workforce planning initiatives address the urgent requirement for dietetic services across the country.
- INDI would like to see the establishment of a Health and Social Care Professionals Office in the HSE and a corresponding office in the Department of Health to ensure parity of esteem with Medical and Nursing colleagues

<https://www.indi.ie/>

## Irish Patients Association

The IPA is on public record, stating that the weakness in the current government (majority) can be its greatest strength, in so far as all parties can demonstrate that they can work together for the benefit of all present and future patients. The lack of this unification in the past has facilitated fragmentation of focus.

Since our inception we have witnessed many studies, strategies and attempts at reform of our Health care systems. Many of these that have failed for various reasons – in fact the only industry that has thrived, has been the reform industry within the public health care system.

Waiting lists illuminate the reality that for decades OUR health care-system which is managed and planned by people has failed Irish Society. Waiting lists; for timely access to outpatient appointments, elective surgeries, access to hospital beds, tests, specialist consultants, GP's, community services etc ultimately cost lives and cause injury to patients.

As a signatory to the European Charter of Patients' Rights we commissioned DCU to review this charter – The report written by Professors, Donal O Mathuna, Prof A Scott, Adam McCawley, et-al.

We call for Irish Patients equity of access to health care by put on a constitutional basis as outlined in the DCU study on the European Patients Charter of Rights and Responsibilities. (Appendix 5 snapshot)

<http://www.drugsandalcohol.ie/6115/1/3201-3335.pdf> copy attached

The European Court of Justices ruling and subsequent EU directive on cross border care are significant developments for citizens within the EU by upholding a right to receive health care in another member state. We are initiating a public awareness campaign on this. "Patients' Rights have no Borders" see attached (hard copies can be sent to you for the committee. (appendix4)

The language of the violation of patients' rights is far stronger in driving accountability.

The Irish Patients Association pan European initiative "Pact for Patients Safety" highlights key material and procedural committeemen's we seek from Public Health care systems.

Finally in a spirit of true partnership we ask the committee to make public any of these suggestions which are not compatible with its goals.

A key challenge for the committee is to restore trust among patient's communities and society that you will deliver what you say you will do - your greatest challenge is convince current private patients who currently can avail of timely private access would buy in and vote for a universal access where they would join waiting lists that represent 25% of an entire population of Medical and GP visit care patients.

## Submission Key Reform Suggestions:

- Establish a truly independent council of Bio-Ethics – (We will publish a critique of existing resource in late Sept 2016.) to informed society eg What does Equity of Access mean.
- Build the system around the needs of patients in all areas of contact – multi annual budgets.
- Deliver patient Centered care as per values International Alliance of Patient Organisations
- Protect Patient Safety everywhere legislate if necessary see procedural and material needs Pact for Patient Safety ( see appendix 3)
- Legislate to enshrine equity of access to health care – The ECJ ruling on timely access to elective treatments has led to the Cross Border directive (see waiting lists appendix 2)
- Legislate to enshrine open disclosure to patients when things go wrong – (We have currently started a EU wide survey of legalisation in member states est completion Oct 2016)
- Legislate to hold public service managers accountable for their performance. Mismanagement in one department deprives another of scarce resources. No different to Doctors Nurses Pharmacist's etc. Challenge vested interests legislate for accountability if necessary.
- Protect transparency for planned reforms include communities involved – de politise no sweetheart deals for political advantage.
- Previous reforms have great reports and action plans but appalling management of change skills.
- Freeze all personnel in their current positions until the system identifies its needs.
- If the prize is a downsized network invest and retire surplus capacity
- Build in performance benchmark.
- Be honest money following the patient means that! If one hospital underperforms they will lose staff and resource's as other areas become more competitive
- Protect independent patient advocacy
- The committee commission a work value analysis of new regions, hse , doh.
- Revisit the continuation of the Corporate entity of the HSE downsize the DOH – The entire country is equal to a medium size city.
- Invest in IT.
- Identify disincentives for new graduate doctors and nurses who go abroad after significant public investment in their education.
- Plan the reimbursement process for new innovative medicines and medical device technologies.
- Promote Life time immunisations
- Invest in Nutrition and Hydration in communities and hospitals
- Invest in greater protections from antibiotic resistant infection in hospitals and community
- Include screening at birth for emerging health problems such as Sickle Cell disease
- No one solution is the answer - ie Acute or Community , develop a unified system of patient and citizen Centered care with horizontal and vertical integration within health and the wider public service. Eg should local government have budgets for home improvements for patients awaiting discharge- engage early with affected populations.

**Above all be honest in what can and cannot be achieved, be truthful with staff, communities and the media. End spin it too, does not advance improved access to care**

## **Appendix 1**

### Current Activities Overview

Our engagements; the HSE's Emergency Department Task Force committee, The Consultants Appointment Advisory Committee, Type 2 Consultants Contract Committee, HSE Implementation Steering committee on HIQA findings into Portlaoise Tragedies. We have and are also involved with regulators MCI, PSI, CORU, PHECC – in the past we were also represented in the ill-fated implementation group on The Health Strategy Quality and Fairness, the Primary care Strategy – Finally participated in the Performance Verification Groups that was the base for significant wage increases in the noughties. National Non Clinical Ethics research committee. National Committee on Antimicrobial Infections.

We initiated public awareness campaigns; of Health Care acquired infection, Safe Medicines, dangers of counterfeit medicines, we are founding signatory of the European Charter of Patients' rights soon to be an official EU anniversary, we commissioned academic research on the Irish Legal Implications of this charter, the importance of life time immunisations and so on.

In September 2016 we will launch the Irish contribution to a pan European campaign "Patients' Rights have no Borders, The re-establishment of an independent council of Bio Ethics, critique almost complete and in October publish a survey of EU states statutory position regarding open disclosure to patients or family's when something goes wrong with the patients care.

Finally after our financial demise in 2013, In 2015 we launched our Pact for Patients safety for patients/ citizens by their representatives, which has 23 founding's signatories

## Appendix 2

### A note on Public Waiting Lists

Public waiting lists are the hard evidence of our two tier health system.

DCU study for the IPA on patient's rights and responsibilities as per the European Charter of patient's rights (which SMCM ) is founding signatory state that the rights on Equity of access is a **social and economic right** and is driven by what society is willing to pay through taxes. This is why accountability is so important, inefficient use of financial and other resources impact on patients who need access to these scarce resources.

### **Waiting Lists**

**For a** long time the public have looked at the inpatient elective waiting lists, the IPA has been messaging the seriousness of those waiting for their first consultant "*led*" ( not necessarily consultant ) appointment. We have argued for many years that the % of these patients (citizens) of all holders of medial or GP cards is in the region of 20% +/- If these patients were private patients it simply does not happen.

Thankfully media is now looking at the total number of patients ie outpatient / and elective or inpatient.

The Outpatient list has been open to massaging Nov/Dec 2013 where 60 k were taken off the list only to bleed back in the following months despite media comment at the time about the messaging.

What happened was Minister gave funding for private consultations, however they returned to public hospitals the private consultation was ignored and they re-joined the list – the unverified cost of this was in the region of €6M + (wasted for those who needed further care) – who was accountable here?

If you research waiting list actions you will see verification processes, delegation to Special Delivery Unit, NTPF etc. to monitor/ administer lists that every hospital should have the inhouse competency to manage.

The only shared waiting lists between public and private patients is usually for access to innovative new drugs, this delay is associated with the state agreeing on reimbursement costs for the drugs, there have been a number of public campaigns by some groups for this access that is not appropriate to secure their access, the system must be proactive by being aware of the development pipeline.

### Appendix 3

#### PACT FOR PATIENT SAFETY

The Pact for Patient Safety is an initiative driven by the Irish Patients' Association to facilitate health authorities and policymakers, healthcare professionals and healthcare providers, to make concrete commitments towards better protecting patients from unnecessary harm (see full Pact [here](#)). The Pact outlines 10 key commitments to be driven **by patients, and for patients**, at global, EU and national level. These commitments include:

##### **Procedural Commitments:**

1. Involve patients
2. Publish data
3. Provide access
4. Incentivise safety
5. Raise awareness

**Material Commitments:** Clear and legally binding guidelines at national and regional level on:

6. Patient informed consent for all treatments
7. Risks to patients including those associated with medicines, clinical, management, and equity
8. Evidence-based use of medicines and medical technologies
9. Use of approved treatments and technologies according to the medical need of the patients

## 10. Sufficient healthcare staffing to support patient safety

### **Founding signatories to the Pact include:**

1. European Men's Health Forum (EMHF)
2. European Liver Patients' Association (ELPA)
3. European Patients' Forum
4. European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)
5. National Concern for Healthcare Infections (UK)
6. Scotland Patients' Association (Scotland)
7. The Patients Association (UK)
8. Czech Association of Patients (Czech Republic)
9. Council of Representatives of Patients' organizations of Lithuania (Lithuania)
10. Foundation for Patient Safety (Poland)
11. Spanish Heart Patients Association (Spain)
12. French Diabetes Association (France)
13. DiabetesDE (Germany)
14. Diabetes Ireland (Ireland)
15. Focus Ireland (Ireland)
16. Irish Cancer Society (Ireland)
17. Asthma Society of Ireland (Ireland)
18. Europa Donna Ireland (Ireland)
19. National Service Users Council (Ireland)
20. Irish Patients' Association (Ireland)
21. Italian Liver Patients' Association (Italy)
22. Italian Diabetes Association (Italy)

## **Appendix 4**

### **May 3rd 2016 - Patients' rights have no borders...as well as risks!**

Patients would access cross-border healthcare services when adequate healthcare treatments are not available in their home country, when the relative services are managed better elsewhere or when the nearest available healthcare treatment is in another Member State, as happen in the case of many border areas.

Currently, cross-border healthcare accounts for approximately 1% of the overall EU public health spending – around €10 billion per year.

According to the Special Eurobarometer 425 on “Patients' rights in cross-border healthcare in the European Union” published in May 2015, only 5% of people living in the EU have received medical treatments in another European country in the last year. The report shows that in the majority of cases patients had not planned to benefit from cross-border medical treatment. Indeed, among these, only 2% of them received treatment in a foreign country because they had actually planned to do so, while 3% of patients needed to be treated unexpectedly when already abroad.

The World Health Organization report on “Cross-Border Healthcare in Europe” also underlines that the volume of patient mobility within the European Union is relatively low because individuals are unwilling to travel to other countries for healthcare. But in the areas where patient mobility is high, issues related to the impact of cross-border healthcare services on patients, health professionals and health systems are more relevant.

The report on the state of play of the Cross-border Healthcare Directive (CBHC), published by the European Commission in September 2015, clearly shows that the European citizens' awareness about their right to seek healthcare in another EU country remains low and only the 10% of European citizens are aware of the National Contact Points (NCPs).

Indeed, less than 20% of them feel that they are informed about their cross-border healthcare rights and just the 2% take advantage of these rights and go abroad when more qualified and specialized healthcare centres are available.

These aspects have increased the consciousness that a better coordination of healthcare policies across the EU is needed and the impact of the Directive 2011/24/EU will depend largely on the knowledge that patients have of their rights under the law, also in relation to the cross-border healthcare access and repayments.

Moreover, an appropriate implementation of the Directive will also help the remaining 98% of people that decide to stay, or cannot move from their country for personal reasons, to get a better quality and high standards of healthcare services at local level. So, the correct implementation of the Directive 2011/24/EU will give advantages to all patients and will enhance cooperation between Member States.

Furthermore, is important to underline that a proper communication towards citizens and patients concerning the opportunities provided by the Directive on cross-border healthcare has to include a careful analysis on the related potential risks and possible uncomfortable situations that foreign patients could face as misunderstandings, fraud, deceptions, etc.

The meeting was a debate among civic and patient associations from different Member States, experts in the field of civil rights, Institutional representatives, National Contact Points and several stakeholders at EU level.

It was held on **3 May 2016** at the European Parliament in Brussels and was hosted by [MEP David Borrelli](#), Co-Chair of the EFDD Group and Co-Founder of the Interest Group.

**STEPHEN A MC MAHON , ADVOCATE**

[HTTP://IRISHPATIENTS.IE/](http://IRISHPATIENTS.IE/)

## Appendix 5

# EUROPEAN PATIENTS' CHARTER FOR IRELAND



Irish Patients' Association

PRESENTED AT THE ROYAL COLLEGE OF SURGEONS IN IRELAND APRIL 18TH 2005

BY THE IRISH PATIENTS ASSOCIATION AND DUBLIN CITY UNIVERSITY  
(SCHOOLS OF NURSING AND LAW AND GOVERNMENT)

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1. RIGHT TO PREVENTIVE MEASURES	8. RIGHT TO THE OBSERVANCE OF QUALITY STANDARDS
2. RIGHT OF ACCESS	9. RIGHT TO SAFETY
3. RIGHT TO INFORMATION	10. RIGHT TO INNOVATION
4. RIGHT TO CONSENT	11. RIGHT TO AVOID UNNECESSARY SUFFERING AND PAIN
5. RIGHT TO FREE CHOICE	12. RIGHT TO PERSONALIZED TREATMENT
6. RIGHT TO PRIVACY AND CONFIDENTIALITY	13. RIGHT TO COMPLAIN
7. RIGHT TO RESPECT OF PATIENTS' TIME	14. RIGHT TO COMPENSATION



## **Irish Pharmaceutical Healthcare Association**

Investing in health should be seen as value, at preventive, maintenance, curative and palliative levels. Medicines have played, and will continue to play, a central role in healthcare gains in recent decades, leading to the cure of disease and the alleviation of previously long-term debilitating conditions. With over 7,000 medicines in development, the exciting new wave of medical innovation will play a key role in delivering better health outcomes for patients and healthcare systems. The pharmaceutical industry is a key partner in healthcare, identifying unmet medical needs and investing long term in research and clinical trial programmes.

The pharmaceutical industry has pioneered many initiatives that facilitate early discharge from hospital and delivery of community and home based care that otherwise would necessitate hospital admission and care, e.g. the delivery of home care therapy. As part of a support for allocating resources to the lowest level of complexity necessary, and to support a greater role for primary care, public health literacy and the appropriate use of self-management of care for minor illnesses should be further encouraged.

Innovation in healthcare is essential. The ability to adopt to the innovation that will arise over the next ten years will be vital for Ireland. Irish patients deserve the same access to the new drugs that will come to the market as patients elsewhere in Europe.

Patients would benefit from a funding model that focuses on outcomes that improve, and often prolong patients' lives. Ireland should move towards a funding system that focuses on outcomes for patients. Activity based funding should be viewed as just the first step of this journey. The challenges of anticipating and evaluating pharmaceutical innovation, of cost, pricing and service adoption, require an array of experts from both industry and Government (regulators, clinicians, management) working on technical issues and shared data towards the over-arching goal of providing medicines that improve patient outcomes.

An appropriate set of policy principles guiding value-based payment should be agreed, meeting the objectives of sustainable financing, timely access to new medicines for patients and the appropriate incentivisation of innovation.

The technical requirements to enable payment for value/outcomes should be addressed, including the implementation of patient identifiers and the investment in IT infrastructure, registries and real-world evidence reporting systems. This will generate insight into opportunities for performance and outcomes improvement along the patient pathways that we serve.

## **Recommendations**

Patients in Ireland deserve the same access to new medicines as patients elsewhere in Europe. The Oireachtas Committee should state an explicit policy goal for the health service that the uptake of medicines innovation will be a core capability and that the systems, evaluations and information necessary to evaluate innovation and use it cost-effectively shall be developed and resourced appropriately.

The uptake of innovation for patients' best outcomes will best be achieved by partnership between the State and industry. This means collaborative, stable working relationships between the State and industry, with Pricing and Supply Agreements and other arrangements tuned to meeting the key policy objectives.

To ensure value for money, treatment should take place at the lowest appropriate level of complexity. Self-management of healthcare, including the appropriate use of non-prescription medicines, contributes to the strategy of allocating resources to the lowest level of complexity possible. Investment in public health literacy and the promotion of appropriate self-management will enable a more efficient use of resources.

Ireland should take the necessary measures to grow the number and range of clinical trials in Ireland, as a benefit to patients and in order to increase our scientific and life sciences industry capacity and reputation.

More flexible, value and outcomes-based models of funding healthcare, where designed appropriately, offer a way forward to achieving the best value for investment in health and would benefit patients. Activity based funding is a valuable first step on this journey.

Outcomes-based payment models should be designed on the basis of clear principles and evidence so as to align the value created for payor, patients and provider, encourage innovation by clinicians and support particular therapies.

The Oireachtas Committee should support specific reporting measures and investment in IT infrastructure that will enable the design and implementation of effective outcome and value-based funding of healthcare.

## **Part One: Strategic issues**

The key challenges for a ten year plan for the health service in Ireland is to achieve the best possible health and well-being of the population, with value and effectiveness for the resources devoted to this goal. An important goal is to achieve confidence that investment in health – at a personal, community and State level – works for all. This is not simply to achieve technical efficiency, but a widespread understanding, underpinned by evidence, that well-targeted, sustained investment in health delivers clear net economic and social benefits

for all. Investing in health should be seen as value, at preventive, maintenance, curative and palliative levels. Without a shift to a perspective of investment and value, and putting in place the capacity to assess and decide priorities on that basis, the dominant narrative around health is likely to remain about cost, inefficiency and unmet need.

### *Health gains due to medicines*

Innovative medicines have been responsible for paradigm shifts in healthcare. Since the 1980s, in developed countries, we have seen death rates from HIV fall by over 80% due to advances in medicines<sup>483</sup>. Since the 1990s deaths from cancer have fallen by 20%<sup>484</sup>. Recent pharmaceutical innovation means 95% of people living with Hepatitis C can be cured through a 12 week course of medicines<sup>485</sup>. The effective use of preventive care, vaccines and medications can slow disease progression, avoid illness and reduce costs.

Medicines play a role in helping people to live longer; a recent OECD study has shown that there was an increase in life-expectancy of 4 years in Ireland in the period from 2000-2011. A separate study on 30 OECD countries has showed that up to 73% of the improvement in life expectancy was attributable to medicines.

### *Innovation pipeline*

With over 7,000 medicines in development<sup>486</sup>, the exciting new wave of medical innovation will play a key role in delivering better health outcomes for patients and healthcare systems.

The evolution of medical science, and particularly our understanding of the genetic causes of disease, is opening up a promising new era of pharmaceutical innovation addressing many unmet needs. As they have in the past, pharmaceuticals will continue to play a major role in transforming the standard of care, moving towards more personalized and targeted drug technologies and enabling improvements in patient, health and social outcomes.

The pace of change, the direction science is taking and the cost may seem to pose very daunting challenges for health services globally, and for Ireland in particular, given some of our deficiencies, for example, in relation to health information technology infrastructure.

A strategic issue posed for a ten year view of Irish health services is how Ireland can and should aim to be an early adopter of healthcare innovation, particularly in medicinal therapies.

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<sup>483</sup> EFPIA, The Pharmaceutical Industry in Figures 2015

<sup>484</sup> PhRMA, Biopharmaceutical in Perspective, Spring 2015

<sup>485</sup> PhRMA, (2014), 25 Years of Progress against Hepatitis C and PhRMA (2015), 2015 profile

It is useful to set an explicit policy objective that Ireland will make innovative medicines available in our health services, so that patients in Ireland have the same access to new medicines as patients elsewhere in Europe.

The Government's Strategy for Research and Development, Science and Technology, *Innovation 2020*, states that innovation is critical to our social development:

*'Innovation is vital to address the sustainability of Ireland's health system, and to address health challenges, including the development of more effective treatments and strategies for disease prevention through behavioural and lifestyle change'<sup>487</sup>*

*'The highest performing healthcare systems have research embedded in service delivery and produce innovation and outcomes that are of benefit to patients, enterprise, the nation's health and the tax payer as funder.'<sup>488</sup>*

The value of innovation in healthcare is to deliver better outcomes for patients. This is the context in which our Association advocates a strategic commitment to the uptake of medicines innovation in our health services.

**Recommendation 1:** Patients in Ireland deserve the same access to new medicines as patients elsewhere in Europe. The Oireachtas Committee should state an explicit policy goal for the health service that the uptake of medicines innovation will be a core capability and that the systems, evaluations and information necessary to evaluate innovation and use it cost-effectively shall be developed and resourced appropriately.

The second issue is how to achieve this objective, embedding the uptake of pharmaceutical innovation in the health services. The pharmaceutical industry recognises that there is a key challenge about cost and affordability, which is linked to pricing and the incentivisation of, and reward for, innovation. In addition, the health services are challenged to understand and evaluate appropriately the nature of the innovation being made available and in the pipeline.

The challenges of anticipating and evaluating pharmaceutical innovation, of cost, pricing and service adoption, require an array of experts from both industry and Government (regulators, clinicians, management) working on technical issues and shared data towards the overarching goal of providing medicines that improve patient outcomes.

The issues involved are not confined to Ireland of course; key considerations about value, access to innovation for patients and paying for outcomes are relevant at European and international levels. Therefore, the IPHA believes Ireland needs to consider how to develop

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<sup>487</sup> Innovation 2020, p.20

<sup>488</sup> Ibid., p.48

collaboratively the capacity to adopt new models of reimbursement for medicines which are linked more closely to the value of innovation.

The role of clinicians is central in the adoption of innovative therapies. In respect of new medicines, we believe that Clinician Review Groups, as used in some therapy areas like oncology, play an important role in assessing the value of new medicines.

While different roles and mandates must be respected, a close degree of partnership and collaborative working in a stable policy framework makes the best policy results possible. Pricing and supply agreements between IPHA and the State are one aspect of this. Over a ten year period, the content and range of such agreements and working relationships should strengthen and adapt to meet the needs of the healthcare vision adopted in the State.

**Recommendation 2:** the uptake of innovation for patients' best outcomes will best be achieved by agreement and collaborative, stable working relationships between the State and industry, with Pricing and Supply Agreements and other arrangements tuned to meeting the key policy objectives.

Medicines have an important role to play in all aspects of healthcare, from self-management of minor ailments to primary care, complex tertiary care, through to palliative care. IPHA supports the strategic direction of allocating healthcare resources to enable treatment at the lowest level of complexity possible that is, fostering a greater emphasis on self-management and primary care. The case is well-made elsewhere that this will enable a more efficient and sustainable use of resources in health services. Self-management of healthcare, both to achieve healthy living and better health status, has an important role to play. Within that, the appropriate use of medicines to deal with minor illnesses contributes to better outcomes and efficient use of resources. Enabling this will be improved levels of health literacy in the population.

In addition, IPHA also advocates – and its member companies actively support – programmes which enable patients to receive assistance in their homes in their adherence to medicines. The value of these programmes in terms of patient welfare and avoidance of hospitalisation costs should be further recognised and promoted.

**Recommendation 3:** self-management of healthcare, including the appropriate use of non-prescription medicines, contributes to the strategy of allocating resources to the lowest level of complexity possible. Investment in public health literacy and the promotion of appropriate self-management will enable a more efficient use of resources.

Clinical trials are essential to medicines development. A higher number and range of clinical trials in Ireland will bring further benefits of innovation to patients in Ireland.

Ireland has invested significantly in life sciences education in recent decades. We are growing our workforce's capacity to provide world class clinical research. The State should promote participation in clinical trials both as a way of bringing innovation to patients and of increasing Ireland's scientific knowledge. Pharmaceutical companies that are members of IPHA conduct Phase II, III and IV clinical trials in Ireland, to evaluate the safety and the effectiveness of the medicine.

IPHA encourages policymakers to benchmark Ireland's clinical research environment against best in class in Europe, e.g. the record of Denmark.

Clinical research in Ireland can be further supported by

- an administrative environment that facilitates clinical research within hospitals, including appointment of a designated research hospital signatory for clinical trials;
- an agreed process for reviewing sign-off requests;
- dedicated research time for staff and ring fenced research funding;
- the establishment of a national Research Ethics Board for multi-institutional studies, as has been done in other jurisdictions
- consistent adherence to legislation, guidance and timelines by Research Ethics Committees.

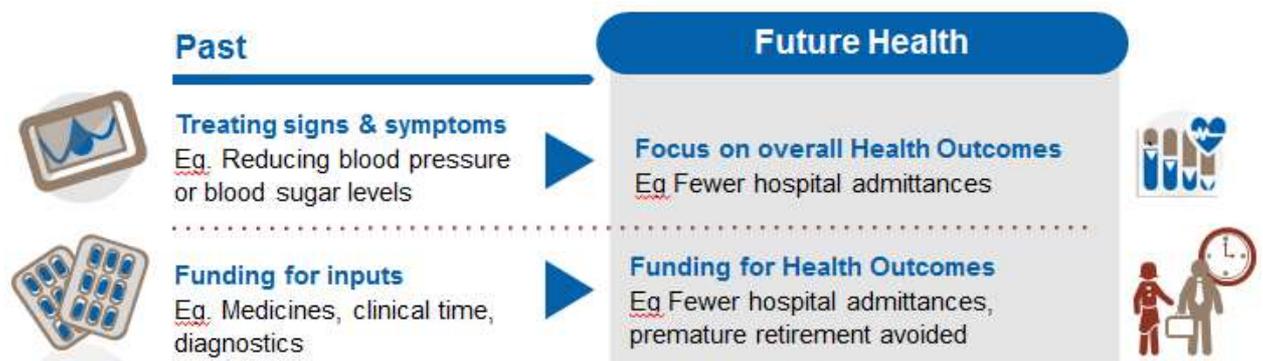
**Recommendation 4:** Ireland should take the necessary measures to grow the number and range of clinical trials in Ireland, as a benefit to patients and in order to increase our scientific and life sciences industry capacity and reputation.

## **Part Two: Funding issues – outcomes and value**

Given the innovation pipeline and what is known about the cost of research and bringing advanced new medicines to patients, Government and industry stakeholders need to work together to identify new ways of sustainable and flexible pricing mechanisms that recognise the value of innovative medicines.

Current pricing policies may not be fit for purpose for the new wave of technology in the future. The sustainability of our health system will not be solved simply by buying things more cheaply. The emphasis should change to aligning expenditure more to value, that is, to the actual outcomes achieved for patients and to providing the right incentives to transform how we deliver care.

The health services in Ireland and patients would benefit from a model that focuses more on health outcomes. Focusing on health outcomes is attractive for patients, the Exchequer and health services as, the State would pay providers for 'positive patient outcomes' (e.g. emergency visits avoided), rather than paying for an input like a medicine. Payment would be made for 'what works', thereby improving the cost-effectiveness of the public service provision.



Health outcomes based models offer a way forward, because they set the right incentives, offering a reward for those interventions that deliver most value. Rewards would be tied to specific results or outcomes achieved (e.g. exacerbations/relapses avoided), not merely the amount of treatments (e.g. individual medicines) supplied or used.

### Best practices

A 2016 OECD health policy report “Pricing – Paying for outcomes”, looks at the ways that various OECD countries are paying for outcomes. It concluded,

*‘investment in payment innovations generate good bang for the buck. Fundamentally, they are helping to align payers and providers. And more broadly health systems, towards what they aim for – that is, best outcomes for patients given resources invested.’<sup>489</sup>*

The OECD report makes reference to the issue that paying for “positive patient outcomes” is difficult to measure and implement and health services worldwide are attempting projects that could be replicable across chronic disease areas.

There are technical barriers which need to be overcome and implementation will require the support of all healthcare stakeholders. The key technical barrier that needs to be overcome is the implementation of the individual patient identifier number as this means that patients’ health outcomes can be measured.

The funding for outcomes concept is becoming part of healthcare policy development in Ireland, as evidenced in the HSE’s Activity-Based Funding Programme Implementation Plan 2015 – 2017. It is critical of course to link activity to outcomes.

Some pharmaceutical companies are already taking accountability for the performance of their medicines in terms of health outcomes. The key to effective and sustainable

<sup>489</sup> [http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/better-ways-to-pay-for-health-care\\_9789264258211-en#page1](http://www.keepeek.com/Digital-Asset-Management/oecd/social-issues-migration-health/better-ways-to-pay-for-health-care_9789264258211-en#page1)

implementation of these concepts is to have well-designed parameters agreed between the supplier and payor.

Concepts include reimbursement tied to the response level of patients prescribed a particular medicine or linked to certain levels of hospitalisation avoidance. Some similar arrangements are beginning to be put in place in Ireland by bilateral agreement between the supplier and the HSE. Some companies have been willing to ask for payment only for positive patient health outcomes. There are examples where the company will provide initial doses free of charge to identify responders or where the company will reimburse hospitals for any non-responders within a defined period of commencing treatment; as a result, the healthcare system only pays for patients with positive health outcomes.

The value of a medicine can include the level of support and service that is provided to the patient. Some IPHA member companies, for instance, add a nurse-led patient support program, self-management programs, smart phone patient recorded outcomes in real time and adherence programs, as a service alongside the prescription. These additional services are designed to improve patient outcomes and, although sometimes cannot be studied in combination with clinical outcomes, should be part of the value proposition for the medicine and so be considered as part of a flexible funding model. This will incentivise companies to provide programmes that improves the patient's usage of medicine and in the case of chronic disease, enables them to become a more empowered self- manager of their condition.

In the long-term, tying incentives and payments to health outcomes is not just appropriate for medicines but for healthcare systems as a whole. Funding outcomes offers a coherent support to meeting economic and affordability challenges. When used appropriately, it offers the promise of a transparent way of pricing and rewarding health interventions, and will allow patients, payors and clinicians to be assured of value.

**Recommendation 5:** more flexible, value and outcomes-based models of funding offer a way forward not just for medicines expenditure but for broader areas of the health services

Outcomes based funding models for medicines – and other interventions - need to be founded on a number of common principles agreed between stakeholders, including:

- Timely and equitable access for patients who will benefit from new therapies
- Distribution of the economic value created by continued incentives for innovation, recognising the important role of intellectual property rights
- Evidence-based and accompanied by solid real-world data collection
- Appropriate levels of transparency in the design of outcomes-based models to ensure that the interests of all parties are protected
- Outcomes measures to be well defined
- Value based, recognising that a 'cost plus' payment or 'lowest price procurement based' approach is inappropriate for valuing new technologies and creating an environment that will encourage on-going innovation

- Aligned incentives to ensure that outcomes flow through the system, and that it is not just medicines where payment for outcomes is applied
- Optionality and flexibility: in some cases these models will not be appropriate because simpler pricing schemes may be more adapted

**Recommendation 6:** outcomes-based payment models should be designed on the basis of clear principles that align the value created for payor, patients and provider, encourage innovation and are flexible for particular therapies.

For Ireland to avail of promising collaborations in health outcomes in the short-term and medium term, it is recommended that the Oireachtas Committee would give its support for several inter-related specific measures:

- Implementation of the patient identifier number as soon as possible, as this means that patients' health outcomes can be measured. Electronic patient records will also be essential to collect Real World Evidence (RWE) of performance
- The collection and use of Patient Recorded Outcomes Measures (PROMS) and Patient Recorded Experience Measures (PREMS) so that the patient experience and observations are incorporated.
- Investment in the appropriate infrastructure and policy change to ensure that health outcomes are appropriately measured and tracked – this will not only be an enabler for new pricing and contracting models but will also generate insight into opportunities for performance and outcomes improvement along the patient pathways that we serve. Outcomes-based pricing will require better capture of outcomes data, through registries and interoperable and harmonised electronic patient records, and the ability to analyse and link different data sets, including clinical, patient reported and administrative measures within an environment that respects data privacy. Rapid development in e-health and cognitive use of big data will support the needs for capturing outcomes data.
- Ensuring that efficiencies from the better use of medicines are translated into improved and more efficient patient care.

**Recommendation 7:** the Oireachtas Committee should support specific reporting measures and IT infrastructure that will enable the design and implementation of effective outcome and value-based funding of medicines.

### **Part Three: Other issues for consultation**

Several issues raised by the Oireachtas Committee are strictly outside IPHA's role, e.g. the design of public entitlements, the financing of healthcare, purchaser/provider roles and the role of healthcare professionals in relation to policy change in these areas.

Suffice it to say that it is our working assumption that public policy in Ireland is, and shall be, aimed at providing timely access to medicines to the population as a whole based on medical need. We believe that any barriers, financial or otherwise, to that goal should be

identified and removed. This would include any potential geographic inequities in access to medicines arising from different arrangements with regard to medicines in hospitals across the State.

We believe that our recommendations relating to payment for outcomes and value can be implemented within different health financing models (i.e. the method whereby the resources for health are raised from the population). Indeed, divergent financing models exist across Europe, while each health system has an active interest in achieving improved efficiency in the allocation of resources to best patient outcomes.

IPHA member companies have considerable interaction with healthcare professionals in continuing education, clinical research and patient services projects. Our experience is that healthcare professionals are strong advocates for innovation and the best outcomes for their patients.

<http://www.ipha.ie/en/homepage.aspx>

## **Irish Pharmacy Union**

The **Irish Pharmacy Union** (IPU), with 2,200 members working in over 1,700 pharmacies which employ almost 22,000 people, is the representative and professional body for community pharmacists. Our mission is to promote the professional and economic interests of our members. Members of the IPU are committed to delivering a quality, accessible, personal and professional service that puts the patient first and has as its primary goal the optimisation of the health and well-being of society. Community Pharmacists are located in every town, village and community in the country. Research shows that consumers and patients visit their pharmacies far more frequently than any other part of the healthcare system, with 85 million visits to pharmacies each year making pharmacists the most accessible healthcare providers.

This submission outlines how the development of pharmacy services is essential for the optimisation of healthcare services in Ireland and sets out the key role that community pharmacists, working collaboratively with the other professions, can play in the development of the health service, particularly primary care, in Ireland as has been done elsewhere.

In an environment of demographic pressures, a growing and aging population and limited resources, the healthcare system is under unprecedented pressure, with increasing demand for health care resulting in hospitals being overstretched and GPs struggling with their existing workloads, which will, according to themselves, continue to increase with the ongoing expansion of universal healthcare. Pharmacists do not seek to replace GPs nor to usurp their role. On the contrary, by working collaboratively to the top of their scope, pharmacists can support GPs in providing patient care and treatment, allowing valuable GP time and resources to be applied to patients who need them most.

Experience internationally highlights the role that pharmacists, when enabled and resourced to practise at the top of their scope, can play in taking pressure off other parts of the healthcare system, including GPs and hospitals, and improving patient health. The introduction in the UK, for example, of pharmacy-based services including a Minor Ailment Scheme, Medicine Use Reviews and New Medicine Services have been shown to significantly contribute to easing the pressure on other parts of the healthcare system and have made a substantial contribution to improving the accessibility of healthcare services. Expanding pharmacists' role in patient care in Canada, where they have responsibility for monitoring patients' conditions, ordering and acting on lab tests where necessary and adjusting medication regimes, has been shown to achieve tighter control of conditions such as hypertension, a key risk factor for cardiac health.

### **Policy Options:**

The IPU submits that the policy options available include expanding the role of the community pharmacist and introducing properly resourced pharmacy-based services, which have been shown to operate very effectively in other countries. The submission sets out a menu of additional services that can be provided by pharmacists to the public to support and assist in the provision of universal healthcare.

### **Provision of Primary Care Services:**

There is an extensive network of approximately 1,800 pharmacies already established across the country, each with its own private consultation room. This provides an opportunity to expand access to primary healthcare without significant additional capital expenditure. Instead, by expanding the services that pharmacists provide, many of the healthcare needs of patients can be addressed in the existing facilities and infrastructure already in place in pharmacies across the country.

### **Pharmacy Contract:**

One of the crucial building blocks in developing and reorienting the model of care towards primary and community care is developing a new pharmacy contract fit for the 21<sup>st</sup> century. It is now 20 years since the HSE last negotiated a contract with community pharmacists. The HSE needs to commit to engaging with pharmacy contractors as a matter of priority.

### **Key Recommendations**

1. Immediate commencement of negotiations on a new pharmacy contract to accurately reflect the legal and regulatory framework that pharmacies operate in today. The contract should form the basis for developing and enhancing primary care services.
2. The immediate roll out of a national pharmacy Minor Ailment Scheme.
3. The establishment of New Medicine Service and Medicine Use Reviews.
4. The immediate exemption of vulnerable patients from the medical card prescription levy and review the prescription levy for all others with a view to phasing it out entirely over a multi-year period.
5. Immediate action to tackle medicine shortages.
6. An immediate change to legislation to allow equity of access to emergency hormonal contraception for women who hold a medical card.

### **Pharmacy Contract**

The current pharmacy contract agreed in 1996 was seen at the time as a modernising contract and positioned pharmacy well for many years. The Contract predates the Pharmacy Act by more than a decade and does not accurately reflect the legal or regulatory framework within which pharmacies operate today. Since 1996 a number of schemes and new services have been introduced in a piecemeal manner, and many disparate and, at times, confusing changes or restrictions in the terms and conditions and rules applicable to the schemes have been made. There is also no provision in relation to funding or updating IT infrastructure to create efficiencies and cost savings within the system. A new pharmacy contract is now urgently needed.

There is recognition that pharmacists can deliver far more services than are currently delivered and it is obvious that the public and the health service stand to benefit from enhanced pharmacy services. In 2015 the Department of Health opened negotiations with the IMO on a new contract for GPs. It is now beyond time that negotiations should commence with the IPU. A new contract should set out the basis upon which new services, as outlined in this submission, could be delivered.

## **Policy Options: Expanding the role of the Pharmacist**

### **1. Minor Ailment Scheme**

The Minor Ailment Scheme is an internationally-recognised extended pharmacy service, which demonstrates how pharmacists can improve public health access, shape future services and broaden pharmacy roles to deliver quality patient care and improve health outcomes.

The primary aim of a Minor Ailment service is to enable medical card patients to receive treatment of common illnesses free of charge direct from their local community pharmacy in a timely manner and without the need for a visit to the GP.

In a figure cited by the Pharmaceutical Society of Ireland (PSI) in 'Pharmacy Ireland 2020'<sup>490</sup>, it is estimated that ten minor ailments: back pain, indigestion, dermatitis, nasal congestion, constipation, migraine, acne, cough, sprains and strains, and headache, were responsible for 75% of the cost of minor ailment consultations and 85% of the cost of prescriptions for minor ailments.

Minor Ailments Schemes have been rolled out across the UK and in Canada. The most recent and comprehensive of these studies is the '*Community Pharmacy Management of Minor Illness: MINA Study*'<sup>491</sup>, which was published in January 2014 and was led by the University of Aberdeen.

- The researchers found that over the course of the study, approximately 13.2% of all A&E consultations and 13.2% of GP consultations for common ailments could have been managed in community pharmacies, which are similar statistics to those found in earlier studies;
- The study found that outcomes were equally good regardless of whether patients were treated at a pharmacy, A&E or GP practice;
- The cost of treating a minor ailment in an A&E setting was almost five times greater than that of treating it in a pharmacy setting;
- The cost of treating a minor ailment in a General Practice setting was almost three times greater than that of treating it in a pharmacy setting;

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<sup>490</sup> [http://www.thepsi.ie/Libraries/Publications/Interim\\_Report\\_of\\_the\\_Pharmacy\\_Ireland\\_2020\\_Working\\_Group.sflb.ashx](http://www.thepsi.ie/Libraries/Publications/Interim_Report_of_the_Pharmacy_Ireland_2020_Working_Group.sflb.ashx)

<sup>491</sup> <http://www.pharmacyresearchuk.org/our-research/our-projects/the-minor-ailment-study-mina/>

- Of the patients interviewed, convenience was deemed to be the main deciding factor in determining where a patient would seek care for a minor ailment and distance was in the top three in determining where the patient would go for treatment;
- The rate of re-consultation to a GP or other health professional following a consultation with a pharmacist regarding a minor ailment was low, varying between 2.4% and 23.4%.

Following the publication of a Health Research Board review of pharmacy-based Minor Ailment Schemes in other jurisdictions<sup>492</sup>, the IPU liaised with the HSE on the design and implementation of a pilot Minor Ailment Scheme which commenced on July 1<sup>st</sup> and is to run for three months.

The ailments eligible for treatment under the pilot scheme are dry eye, dry skin, scabies, threadworm and vaginal thrush. The pilot scheme involves 19 pharmacies located in just four towns: Edenderry, Kells, Macroom and Roscommon.

We now wish to ensure that the scheme becomes a national service and would therefore like to see the Department of Health and HSE immediately roll out a national Pharmacy Minor Ailment Scheme following completion of the three-month pilot scheme.

### **Medicines Use Review Service**

The Joint Committee on Health and Children's Report on the *Adverse Side Effects of Pharmaceuticals* recommended that the role for the pharmacist in community health should be expanded and provision made for regular medication reviews for all patients<sup>493</sup>. Medicines Use Reviews are most appropriate for assessing compliance and improving medicines-taking through concordance. Data from Scotland, which has very similar population demographics to Ireland, shows that targeted in-depth Medicine Use Reviews conducted by pharmacists with patients taking multiple medicines for chronic conditions reduced hospital readmission rates by a third.

Empowering pharmacists to optimise medicine use – ensuring that the patient is prescribed the right medicines for their condition, at the right dose, and is taking them correctly and that medication-related issues are identified and eliminated – is proven to improve health outcomes and enhance people's quality of life, as well as reducing the need for costly hospital care.

### **New Medicines Service**

The objective of the New Medicines Service (NMS) is to help people who are newly prescribed a medicine for certain long term conditions to manage their condition and to improve their medication adherence through providing clinical support at the outset of taking new medication. Non-adherence can result in patients' conditions deteriorating, further complications arising and can lead to premature mortality. The most current and

<sup>492</sup> [http://www.hrb.ie/index.php?id=906&tx\\_hrbpublications\\_pi1%5BshowUid%5D=708](http://www.hrb.ie/index.php?id=906&tx_hrbpublications_pi1%5BshowUid%5D=708)

<sup>493</sup> <http://www.oireachtas.ie/documents/committees29thdail/committeereports2007/side-effects.pdf>

comprehensive study of the NMS in the UK was carried out for the NHS by the University of Nottingham '*Understanding and Appraising the New Medicines Service in the NHS in England (029/0124)*' and provides evidence that adherence rates increase significantly in patients that avail of the service and that there were both clinical and economic benefits from the service<sup>494</sup>.

#### **4. Extended Vaccination Service**

The pharmacy profession welcomed the decision by the then Minister for Health to introduce legislation in 2011 to facilitate pharmacists in participating in the seasonal influenza vaccination programme. In Ireland the successful introduction of the pharmacy-based flu vaccination service has proved pharmacists have the ability to deliver professional healthcare services. Evidence for the benefit of improved convenience and accessibility which pharmacists provide is seen in the numbers of patients deciding to get their flu vaccinations in a pharmacy setting. During the 2014/2015 flu season, which saw 51,560 flu vaccinations carried out in pharmacies, 23% of the patients vaccinated in a pharmacy had never been vaccinated before and 83% of these patients were in an 'At-Risk' Category<sup>495</sup>.

Making the flu vaccine available in pharmacies has significantly improved access and promoted uptake of this vital public health intervention. We are pleased that the previous Minister for Health legislated for pharmacists to provide vaccination for shingles and pneumococcal disease also. We look forward to the HSE putting reimbursement arrangements in place so as to allow patients to access the pneumococcal vaccinations from their pharmacist, as is the case for flu vaccination.

Pharmacists in other countries routinely offer a wider vaccination service. In most states of the USA, in addition to influenza, pharmacists can offer vaccination against pneumococcal disease, meningococcal disease, tetanus and hepatitis A and B, as well as travel vaccines. We would like to see our pharmacy vaccination services extended similarly to include a far wider range of vaccines.

#### **5. Health Promotion Service**

With 85 million people visiting community pharmacies every year in Ireland, pharmacists are in an ideal position to communicate health promotion messages. Community pharmacists have delivered a number of such campaigns in recent years, in conjunction with patient groups and the HSE, and are now seeking a more structured health promotion role with the support of the HSE. This year, as part of RTÉ's *Operation Transformation* campaign, 'Million Pound Challenge', almost 1,000 pharmacies signed up to carry out weekly weigh-ins and provide weight management advice to patients. Pharmacists have an integral role to play in the campaign as frontline healthcare professionals in communities across the country. Last year's one-day collaboration with pharmacists, 'Know your Numbers', was described by *Operation Transformation* as 'one of the most important days in *Operation Transformation* history'.

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<sup>494</sup> <https://ipu.ie/wp-content/uploads/2015/06/Appendix-A-of-IPU-Submission-Nottingham-University-Report-on-the-New-Medicines-Service.pdf>

<sup>495</sup> [http://www.thepsi.ie/Libraries/Pharmacy\\_Practice/PSI\\_2014\\_15\\_Report\\_on\\_Seasonal\\_Influenza\\_Vaccination\\_Service.sflb.ashx](http://www.thepsi.ie/Libraries/Pharmacy_Practice/PSI_2014_15_Report_on_Seasonal_Influenza_Vaccination_Service.sflb.ashx)

## **6. Health Check Service**

Early detection of chronic illnesses, coupled with early intervention and treatment, was a cornerstone of the previous Government's *Healthy Ireland* strategy<sup>496</sup>. Pharmacy-based health checks would have significant advantages in terms of reach, accessibility and cost-effectiveness. Health checks could prove effective in identifying those at risk of developing a chronic disease such as diabetes mellitus, cardiovascular disease, osteoporosis and chronic obstructive pulmonary disease.

## **7. Chronic Disease Management Service**

In Canada, pharmacists' scope of practice has been extended to include Chronic Disease Management: monitoring patients with chronic illnesses, ordering lab tests where appropriate, and renewing and adjusting their prescriptions to ensure tighter control of their symptoms and delivering better treatment outcomes. The clinical benefits of pharmacy involvement in chronic disease management are compelling, with a large evidence base detailing that pharmacists have the most frequent contact with patients with chronic diseases, due to their accessibility.

Despite a severe shortage of primary care doctors in Canada, extending pharmacist services in this way has resulted in better access to healthcare and a substantial reduction in morbidity and mortality rates from illnesses such as heart disease and diabetes. Canadian pharmacists are also authorised to prescribe medications in emergency situations, when it isn't possible to get a doctor's prescription. Given our existing deficits in access to primary care in Ireland, a similar approach would provide equivalent benefits.

## **8. Anticoagulation Service**

In Ireland, most patients attend a hospital warfarin clinic to have their INR tested, typically having to wait for several hours before their results are confirmed. Indeed, in some parts of the country, there is no such clinic. Community pharmacists, as experts in medicine, have an ideal skillset to manage patients on warfarin successfully and are well placed to provide such a service. Examples exist of pharmacies successfully providing anticoagulation services in Ireland. With appropriate supports from the HSE, this service could be rolled out to more pharmacies with the attendant cost savings for the HSE, which currently provides the service in the hospital setting at great cost, and benefits for patients, who would no longer have to travel to a hospital and who see their Time in Therapeutic Range (a key measure of the quality of warfarin treatment) improved. Again, this service could be expanded into more pharmacies in areas of identified need without the HSE incurring upfront capital or infrastructural costs.

## **9. Monitored Dosage System Service**

It has been estimated that up to 50% of patients do not take their medication properly, resulting in sub-optimal health outcomes and increased cost to the healthcare system. Monitored Dosage Systems (MDS) are devices or packaging systems in which doses of one or more solid oral medications can be organised according to day and time of

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<sup>496</sup> <http://health.gov.ie/healthy-ireland/>

administration, making it far easier for patients to comply properly with complicated medicine regimes and enabling carers to monitor patients' use of medicines. MDS improve patients' confidence in medication taking and, by improving adherence, reduce medicines waste and prevent previously non-compliant patients from requiring admission to high cost healthcare facilities. In addition, provision of monitored unit dose systems to patients in the residential care setting has been shown in a number of European studies to reduce nursing costs. Many pharmacies provide this very valuable service to their patients, although it is not, as yet, formally recognised for reimbursement by the HSE.

## **10. DUMP Scheme**

Unused and un-needed medicines are a significant source of risk in people's homes, as a means for suicide and deliberate self-harm, accidental poisoning in children or environmental pollution. A Disposal of Unused Medication Properly (DUMP) scheme encourages patients to return their unused medicines to their local community pharmacy for safe disposal. Such schemes have operated in certain regions in the past but, to be truly effective, need to be established nationwide on a sustainable basis.

## **11. Reclassification of Medicines**

Pharmacists want to see greater access for consumers to self-care opportunities by increasing the number of medicines available without prescription with the advice and support of a pharmacist, in line with other countries such as the UK and New Zealand. This will enable people to access treatments for minor and self-limiting ailments, allowing doctors to focus on more complicated illnesses. Pharmacists would utilise their clinical knowledge to help patients choose the appropriate medication to deal with minor ailments. Medicines that could be reclassified include sumatriptan for migraine, newer anti-allergy medicines like fexofenadine and a wider range of analgesics, which are already available without prescription in the UK and elsewhere.

## **12. Emergency Hormonal Contraception (EHC)**

An amendment to legislation, proposed by the IPU, is planned to allow medical card holders avail of an Emergency Contraception Service. Private patients already have access to emergency contraception from a pharmacist without prescription. The IPU proposal seeks to grant equity of access to medical card patients, which is of importance given the time sensitivity of emergency contraception. The IPU proposal is in line with the recommendations of the HSE's Irish Contraception and Crisis Pregnancy (ICCP) Study 2010<sup>497</sup>. The IPU calls on the Oireachtas to pass the necessary legislation early in the next Dáil term.

## **13. Prescription Levy**

Medical card holders, who once received prescribed medicines free of charge, are now required to pay a levy of €2.50 per item, a cost which has increased fivefold since it was first introduced in June 2010 at 50c per item. Many patients, particularly those on fixed incomes, just cannot afford to pay the levy. Instead, they gamble with their health every day, either by reducing their medication or by stopping it entirely. The ultimate outcome is

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<sup>497</sup> [https://www.ucd.ie/t4cms/ICCP-2010\\_REPORT.pdf](https://www.ucd.ie/t4cms/ICCP-2010_REPORT.pdf)

sicker patients, with more complex medical needs, needing advanced care in an already extremely overburdened health system. The imposition of the levy is creating more future demand for a health service that is already struggling to cope.

The impact of the levy can be seen from the findings of a public survey conducted by Behaviour & Attitudes Survey on behalf of the IPU, undertaken in March of 2015. In the survey, 28% of medical card holders said that they 'think twice' about taking their prescribed medicines because of the cost of the levy and 1 in 7 confirmed that they have not filled a prescription because of the levy. In addition, a study funded by the Health Research Board (HRB), and co-authored by researchers in University College Cork and Trinity College Dublin, has revealed that prescription charges on the medical card scheme led to reductions of up to 10% in the use of medicines by Irish patients, with some types of medicines being affected more than others<sup>498</sup>.

Putting economic barriers in the way of patients taking their medicine does not make sense. People living with heart disease, or at risk of the disease, should be focusing on getting better and keeping well, not worrying about how they are going to pay for their next vital prescription. Poor adherence to treatments, especially in the case of chronic illness and long-term patients, will mean more hospital stays, more pressure on our already struggling health service and more cost to the Exchequer in the treatment of these patients in the long run. Patients need to be supported not penalised.

The IPU is calling for a two-step approach. Firstly, we are calling on the Oireachtas to immediately exempt the following vulnerable patients from the prescription levy:

- Patients in residential care settings;
- Patients with intellectual disabilities;
- Patients receiving treatment under the Methadone Treatment Scheme in respect of other medication that they may require;
- Homeless patients including those in homeless shelters; and
- Palliative care patients and other patients who have their medicines changed on a daily/weekly basis.

Secondly, we are calling on the Oireachtas to review the Medical Card Prescription levy, with a view to phasing it out entirely by steadily reducing the amount over a multi-year period.

#### **14. Medicine Shortages:**

Medicine shortages are an ongoing, increasing and very complex problem that is putting patients' health at risk. On a daily basis there are multiple shortages of medicines in the supply chain and, in many cases, a nationwide lack of critical prescription medicines.

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<sup>498</sup> <https://ipu.ie/home/article/irish-pharmacy-union-publishes-major-study-on-access-to-the-healthcare-system/>

Results from a survey of IPU members undertaken in July of this year highlighted the scale of the problem, with 99% of pharmacists indicating that they had experienced medicine shortages in the previous 3 months. Nearly a third (30%) had encountered shortages of 20 or more medicines, and almost half (46%) of pharmacists believe that their patients' health outcomes had been "adversely affected by medicine shortages"<sup>499</sup>.

Patients can sometimes wait for weeks to get a new supply of a common drug. Not only is this putting their health at risk but it is causing undue stress, fear and anxiety for them. Instead of directing their efforts and professional expertise towards the needs of patients, pharmacists are spending anything from 5 to 30 hours plus a week resolving medicines shortages and firefighting on behalf of their patients.

Falling medicine prices have exacerbated the problem, as more medicines are either being exported out of the country to other jurisdictions where medicine prices are higher, or are simply not being supplied. While it is entirely appropriate that the HSE should seek to maximise the value for its spend on medicines, it needs also to be aware of the impact of pricing policies on continuity and security of supply.

This is an extremely serious situation that needs to be urgently tackled. We propose that a dedicated working group be established made up of representatives from the Department of Health, the HSE, the Health Products Regulatory Authority and the IPU to identify and monitor medicine shortages and take immediate appropriate action on a drug-by drug basis when shortages arise.

## Conclusion

Community pharmacies are an essential accessible healthcare resource in every community. Pharmacies provide employment to 22,000 staff nationwide and pharmacists are often the only healthcare profession accessible to people in their own communities. At a time when many villages and small towns around the country no longer have a bank, a Garda station, a post office or, in some cases, a GP service, local pharmacies remain a cornerstone of that community. The future of the healthcare system rests in the advancement of pharmacists' roles and the extension of services and the future of pharmacy rests on the ability to offer additional services to local patients in a local setting within the community, in collaboration with other healthcare professionals.

There is clear evidence to show that pharmacy-based services in other jurisdictions have led to considerable improvements in patients' health outcomes and consequent savings to healthcare budgets.

In Ireland, pharmacists have the requisite expertise, skillset and accessibility to introduce these additional services, which can assist in delivering on the Government's programme of improving the health and wellbeing of people living in Ireland. Pharmacy-based services can improve patient health outcomes and, simultaneously, free up key resources in other areas of the healthcare sector.

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<sup>499</sup> <http://ipu.ie/wp-content/uploads/2015/08/IPU-Medicine-Shortages-Survey-2016-Results-and-Comments-3.pdf>

The ability of pharmacists in Ireland to deliver additional key services is beyond doubt. The introduction of the flu vaccination service and reclassification of Emergency Hormonal Contraception have shown that pharmacy can deliver, in a cost-efficient manner, services that patients want and avail of.

The focus of the healthcare system must be towards the creation of a patient-focused health service delivered at the lowest level of complexity and as close to people's homes as possible. Pharmacists play a vital role in ensuring patient safety and wellbeing and are available and willing to engage on a change agenda which involves expanding the role of the pharmacist for the betterment of the healthcare system.

**Derek Reilly, Contract Manager, IPU**

<https://ipu.ie/home/>

## Irish Platform for Patient Organisations

It is clear to IPPOSI members that the whole-system challenges that exist in the Irish health and social care system require fresh, long-range thinking combined with long-term, cross-party political commitment. There is also a clear need to establish a universal single tier service where patients are treated on the basis of health need rather than on ability to pay. The Committee therefore has the unique opportunity to establish a long-term vision on how the health and social care system can work best for those that need it most.

Members of this Committee are to define a clear 10-year strategy based on a concrete vision of what needs to be achieved by 2026. This vision needs to be based on an agreed outcome which will give IPPOSI members a target for where this journey is leading us and what citizen and patient benefits will arise. Setting targets presents both financial and political challenges but this cross-party Committee is well placed to hold tough on such targets.

Through an internal consultation process, members of IPPOSI have identified a number of key areas which, if properly supported, will enable a paradigm shift in the long-term planning for the future of healthcare in Ireland. These include:

1. Person-centered, coordinated care
2. Integrated sharing of Health and Patient Data
3. Rare Diseases and Chronic Diseases
4. Primacy of clinical research
5. Access to Health Innovation
6. National framework for scaling up of healthcare innovations
7. Primary care and front-line staff

At the end of this submission, IPPOSI offers views on the health service funding model which would be best suited to Ireland, as well as eight specific recommendations to Government or other actors which the Committee should consider in its report.

### **Person-centered, coordinated care**

The policy narrative around the future direction and ambition of the Health and Social Care system needs to fully embrace the concept of people as partners in their own health and wellbeing and to firmly place *person-centered, coordinated care*<sup>500</sup> very firmly at the heart of future strategies and engagement. Policies should be based on the principles of patient empowerment, shared decision making, self-management support, care planning and goal setting as well as listening and patient narratives.

Understanding “what matters to you” instead of “what’s the matter with you” represents a fundamental shift in approach to healthcare. The importance of person-centered approaches and empowerment strategies (see example below) should be recognised and

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<sup>500</sup> Redding D, (2013) "The narrative for person-centred coordinated care", Journal of Integrated Care, Vol. 21 Iss: 6, pp.315 – 325 <http://www.emeraldinsight.com/doi/abs/10.1108/JICA-06-2013-0018>

adequately resourced across health and social care in Ireland and should be a key driver of the development of national strategies in this area.

*An example of a person-centered approach is the OpenNotes initiative ([www.opennotes.org](http://www.opennotes.org)) in the United States of America, the evidence from which suggests that opening up GP visit notes to patients may make care more efficient, improve communication, and may help patients become more actively involved with their health and health care. Over 10 million patients across the USA now have access to their GP visit notes through this programme.*

The committee should promote the principles of self management of patients in addition to the care they receive from direct services, towards achieving improvements in health, activity levels, quality of life and mood that is cost effective, sustainable, and applicable to patients across the hospital and community settings (see example below). Investment in clinically effective, chronic disease self-management interventions needs to be prioritised.<sup>501</sup>

*An example of a cross-setting self-management programme is the Better Health, Better Living programme in Beaumont Hospital, Dublin. This six-week programme is based on the model developed by Stanford University, California. To date over 100 patients have been through the programme, learning valuable skills and techniques to assist them in becoming better self-managers of their illness.*

### **Integrated care based on sharing of patient and health data**

The reorganisation of care delivery in Ireland requires the adoption of patient-centric integrated care<sup>502</sup>. By putting patients' care pathways at the centre of the system reform, integrated care systems can deliver improved and tailored health outcomes while creating efficiencies in settings where they are delivered.

Improved electronic information sharing between health and social care providers and their 'third sector' partners<sup>503</sup> is paramount to ensure that the patient receives the right level of care based on a centralised health record. Therefore investment is needed to drive the paradigm shift, moving from a transactional (e.g. eReferral) approach to healthcare to a secure document / record-based system (e.g. Electronic Health Record) built on the foundation of a fully implemented unique patient identifier. Interoperability of existing and future systems will be paramount as well as citizens and professionals having appropriate access (based on patient consent) to the record no matter where they are in the health and social care system.

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<sup>501</sup> HIQA Health technology assessment of chronic disease self-management support interventions:

<https://www.hiqa.ie/publications/health-technology-assessment-chronic-disease-self-management-support-interventions>

<sup>502</sup> "The organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money" (World Health Organization)

<sup>503</sup> non-governmental and non-profit-making organizations or associations, including charities, voluntary and community groups, cooperatives, etc.

Ireland also needs networked patient registries in place to offer value-based healthcare and to improve significantly the ability to share anonymized patient data both within Ireland and across borders. The capability of monitoring the “right patient, right treatment, right time” can be achieved through setting up a centre of excellence that would support the development of networks of high quality, standards-based, disease-specific registries<sup>504</sup>.

### Rare Diseases and Chronic Diseases

A fundamental aspect of the development and implementation of person-centered, coordinated care in Ireland is that by focusing on those in society who are most vulnerable (e.g. older and younger populations), we will get it right for the rest of the population. This especially applies to those with rare or chronic diseases, who are particularly disadvantaged by the lack of certain services (e.g. clinical genetics and timely access to diagnostics) and treatments in Ireland. IPPOSI recommends that the requirements and needs of rare disease patients<sup>505</sup> be specifically highlighted as part of the long-term, ten year strategy. IPPOSI also recommends that the strategy focus on solutions for chronic diseases as due to an aging population, chronic diseases account for over 70% of disease burden worldwide<sup>506</sup>.

### Primacy of Clinical Research

Clinical research needs to be at the core of the Irish health services, embedded within every team and every department, with clinicians supported through adequate research training and incentivised to undertake that work. In addition, clinical trials need to be established as a routine aspect of healthcare in Ireland. Trials allow access to innovative therapies but also the rigour involved in running a trial raises the quality of care across the board. IPPOSI members believe that through enhanced, ring-fenced funding, the positive health and related economic impacts of clinical trials (as were recently published by Cancer Trials Ireland<sup>507</sup> will be replicated in other clinical areas.

This committee should move to boost clinical research in Ireland through:

- investing in protected time for clinicians who wish to be involved
- a guaranteed career structure for research nurses, data managers & others contributing to healthcare research, integrated within Irish health services
- investment in research networks and associated infrastructures to allow access to trials for patients near to where they live.
- the appointment of a research tsar by the HSE, with a ring-fenced budget, and a clear vision and strategy, would be an important first step in demonstrating cross-party commitment to best practice in clinical treatment, to best innovation in science, and to best outcomes for patients.<sup>508 509</sup>

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<sup>504</sup> <http://www.ipposi.ie/images/Towards%20a%20National%20Strategy%20for%20Patients%20Registries%20Report.pdf>

<sup>505</sup> <http://www.health.gov.ie/blog/publications/national-rare-disease-plan-for-ireland-2014-2018>

<sup>506</sup> [http://health.gov.ie/wp-content/uploads/2014/03/tackling\\_chronic\\_disease.pdf](http://health.gov.ie/wp-content/uploads/2014/03/tackling_chronic_disease.pdf)

<sup>507</sup> <http://www.cancertrials.ie/images/uploads/2016%2005%2018%20DKM%20Economic%20Impact%20of%20Cancer%20Research%20Final%20Report.pdf>

<sup>508</sup> [http://www.ipposi.ie/images/CRI\\_Report\\_May\\_13th\\_2008\\_low\\_res\\_1.pdf](http://www.ipposi.ie/images/CRI_Report_May_13th_2008_low_res_1.pdf)

## Access to Health Innovation

The availability of new health innovations (such as new medicines, technologies, devices, processes) is a vital component of a good health service. In recent years challenges have emerged in access to new and often expensive treatments. IPPOSI members believe it is unacceptable for Irish patients to be denied access to health innovations while patients elsewhere in Europe have access.

Transparency and communication are key themes for patients and their organisations within the processes relevant to the approval, assessment and reimbursement of health innovations. The decision-making process to reimburse therefore needs clarity on who the decision maker is and what the criteria for that decision includes. In order to increase transparency and trust in the process, the decision needs to be independent of politics and should directly involve the perspectives of patient representatives.

IPPOSI also recommends that more consideration be made of innovative Early Access Programmes for new medicines and technologies so that Irish patients can be among the first in Europe to have access to new innovations. Early Access Programmes exist in Ireland<sup>510</sup> and within other European countries<sup>511</sup> and these should be learned from. This will ensure that once given the green light by the European Medicines Agency, patients can benefit without delay.

## National framework for scaling up of healthcare innovations

Members of IPPOSI believe that innovation is alive and well in the Irish health system, albeit in a fragmented manner - many innovations are only operational in limited deployments with isolated pilots unable to access the necessary scale-up supports and incentives to make a real difference. Indeed, many updates to the provision of healthcare services often have their origin in patient communities, academia and industry. The success, or failure of these ground-breaking innovations can be determined by the capacity and willingness of the health system to adopt it at a particular time.

A proposed solution is a national framework where public, private and patient thinking on solutions for sustainable healthcare can be harnessed<sup>512</sup>. The Irish Health Innovation Hub<sup>513</sup> is the beginning of this process. However, a longer-term approach is required to include a mechanism by which innovative ideas can be recognized, quickly adopted, scaled up and implemented as well as a formal system to monitor and evaluate innovative ideas.

## Investment in primary care and front-line staff

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<sup>509</sup> <http://www.mrcg.ie/go/news/news/launch-of-the-mrcg-manifesto-for-medical-research>

<sup>510</sup> <http://health.gov.ie/wp-content/uploads/2015/07/Final-Public-Health-Plan-for-the-Pharmaceutical-Treatment-of-Hep-C-Final-Copy-Circulated-July-2015.pdf>

<sup>511</sup> [http://www.abpi.org.uk/our-work/library/industry/Documents/early\\_access\\_to\\_medicines\\_scheme.pdf](http://www.abpi.org.uk/our-work/library/industry/Documents/early_access_to_medicines_scheme.pdf)

<sup>512</sup> [http://www.eu-ems.com/summary.asp?event\\_id=254&page\\_id=2247](http://www.eu-ems.com/summary.asp?event_id=254&page_id=2247)

<sup>513</sup> <http://hih.ie/about-hihi>

IPPOSI encourages the development of a national infrastructure of primary care teams to relieve pressure on acute hospitals. Increasing primary care expenditure will be required to include the appointment of more GPs, practice nurses and public health nursing, alongside allied healthcare professionals, more management of chronic disease in the community, including more care at home.

In addition, to combat the urgent issue of professional burnout across primary, secondary and tertiary systems, the welfare of front-line workers should be paramount. Commitment to work culture improvements (e.g. initiatives such as ‘hellomynameis’) can contribute to a more positive healthcare environment where patient experience is improved and front-line staff feel better appreciated and valued.

## Funding Model

The determination of the funding model for a universal, single-tier health service should be guided by the definition and goals of universality. Indeed IPPOSI members question whether the definition of ‘universality’ will extend to both public and private healthcare provision? Patients access services through different schemes and routes so we question how the committee plan to approach the existing public vs private service divide?

IPPOSI believes there is a need to support the integration and interconnection between the health and social care systems. The lack of designated funding for social care forces many families to place a loved one in residential care prematurely, when home help, day-care or respite could have kept them at home. Consequently, vital social care services are increasingly available only to those with the highest needs and lowest incomes, rather than as a universal service supporting the whole population. If increased resources are to be made available, a strategic approach based on increased support for community care should avoid the current ‘see saw effect’ between the primary, secondary and tertiary care settings.

In addition, funding models that are outcomes-based (i.e. activity-based) will only be implementable based on data that is integrated. This can then be used to drive performance-related data collection which will lead the paradigm shift from a service-centered system to a more person-centered one.

The choice of funding model should also be guided by independent evidence developed by organisations such as the Economic and Social Research institute (ESRI). The ultimate decision should be made based upon three criteria<sup>514</sup>:

1. Technical merit and likely performance;
2. Feasibility for implementation in relation to the changes required; and
3. The likelihood of support from key stakeholders

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<sup>514</sup> Thomas S & Darker C. (2013) What is the right model of universal health insurance for Ireland?. In: Tom O'Connor (eds). *Integrated Care for Ireland in an International context: Challenges for Policy, Institutions & Specific Service User Needs*. 19 Rutland Street, Cork, Ireland: Oak Tree Press.

A 'Benefits statement' could also be provided in order to clarify the patient-level and system-level benefits that will arise from Universal Health Care in terms of access, cost, quality and other metric improvements.

## **IPPOSI Recommendations**

We propose eight solutions which could be affected through the committee's approach to developing a ten-year plan for the Irish health and social care system. These would help to create a system which treats everyone equally, taking account of specific needs, integrates care and is underpinned by a universal, publicly-funded system.

1. Place person-centered, coordinated care very firmly at the heart of future strategies and engagement
2. Move from the current transactional-based approach to healthcare, to an outcomes-based funding model, defined in partnership with patients, to promote sustainability and increase access.
3. IPPOSI encourages a firm commitment to improving the lives of people with rare diseases or chronic diseases.
4. The significant contribution of research and innovation to provide healthcare solutions needs greater recognition and support.
5. The necessity of making anonymised patient data available for care improvement and research purposes is paramount.
6. Increase support for the development of a national infrastructure of primary care teams
7. Directly support the welfare of front-line staff to empower and enable them to shape the future transformation of the system.
8. Increase the capacity and willingness of the health system to adopt and scale-up clinically-effective health innovations.

<http://www.ipposi.ie/>

## Irish Rheumatology Health Professionals Society

Rheumatic and Musculoskeletal disorders (RMDs) are a group of more than 200 different conditions that affect 1 in 4 people of all ages, equivalent to 1.2 million Irish citizens ([www.eular.org](http://www.eular.org)). It is estimated that 2% of the EU GDP is spent on direct medical care of RMDs. RMDs are the leading cause of disability in Ireland. RMDs cause the single greatest socioeconomic cost of any disease group due to lost productivity from long-term work absence and due to the payment of disability benefits.

There will be a dramatic increase in the prevalence of RMDs in the next decade due to an increasing and ageing population. RMDs impede the ability of people to remain economically and socially active when becoming older. The social and economic impact of RMDs will be accentuated by the necessity to maintain the larger, ageing Irish population in work to a later age.

Many RMDs, such as rheumatoid arthritis, have seen major advances in specialist treatment in the past decade, effective in preventing joint damage and patient disability. The need to develop Rheumatology services for the provision of better care for patients with RMDs in Ireland is recognised by the Health Service Executive (HSE). In 2010, a National Clinical Programme for Rheumatology (NCPR) was established with the overarching aim of: ***"Adopting a chronic disease model of care so as to facilitate a right person, right place, first time approach to patients with RMDs."***

In 2016 the NCPR produced a model of care for Rheumatic and Musculoskeletal Diseases in Ireland (<http://www.hse.ie/eng/about/Who/clinical/natclinprog/rheumatologyprogramme/modelofcare.html>). The model of care notes that Ireland has one of the lowest ratios of rheumatologists to population in the EU and when implemented will bring service provision for RMDs in line with evidence-based practice and international standards of care.

The model of care envisages expansion of rheumatology services in a hub-and-spoke model of tertiary centres operating within 6 rheumatology networks coterminous with the new hospital groups and integrated with Community Healthcare Organisations (CHOs). This will provide co-ordinated care and uniform standards of service delivery for patient across the networks supported by the development of clear referral protocols, pathways and therapeutic standards. The cost of implementing this model can be realised through the prevention of RMD disability and its high direct and indirect costs and by implementing efficiencies in current utilisation of specialist services such as high technology drug expenditure.

## **Recommendations and Key Priorities for 10 Year Plan:**

8. Rheumatic and Musculoskeletal disorders (RMDs) to be formally acknowledged as one of the largest direct healthcare costs in Ireland today.
9. Rheumatic and Musculoskeletal disorders (RMDs) to be formally acknowledged as the single largest indirect cost due to disability in Ireland.
10. Implementation of the National Clinical Programme Rheumatology Model of Care as the basis of a 10 year healthcare plan for integrated medical care (eg non-surgical) of RMDs.
  - xii. Establish one consultant rheumatologist per 79,000 population (WHO)
  - xiii. Establish a multidisciplinary team to work with each consultant in delivering care of RMDs
  - xiv. Provide appropriate facilities for each Rheumatology MDT to deliver care of RMDs
  - xv. Rheumatology centres to work as networks across each hospital group to optimise clinical services, education and research.
  - xvi. Establish a Treat to Target model for disease management in RMDs that will result in maximal disease outcomes and maximal economic benefits
  - xvii. Sustain and develop self-management programmes for RMDs in collaboration with patient organisations such as Arthritis Ireland
  - xviii. Further develop the specialist physiotherapist triage scheme for RMDs
  - xix. Further develop RMD management in primary care with appropriate access to diagnostic and therapeutic modalities for GPs
  - xx. Implement recommendations of Fit to Work coalition to effect reductions in work disability
  - xxi. Implement a National Fracture Liaison Programme to prevent fractures from Osteoporosis
  - xxii. Establish RMD units in each network to provide inpatient care for RMDs
11. Acknowledge that investment in and development of RMD treatment will reduce disability and that this will reduce indirect costs from disability.
12. Acknowledge that due to the chronic nature of RMDs cost effective strategies aimed at reducing disability in large populations can only be realised through long term planning and investment such as envisaged in the 10 year Irish healthcare plan.
13. Acknowledge that the short term nature of Irish Healthcare funding to date is one of the reasons why RMD services in Ireland are so underdeveloped.
14. Recommend integrated primary, secondary and community health care of RMDs to be led through the HSE Rheumatology Model of Care.

## What are Rheumatic and Musculoskeletal disorders?

Rheumatic and Musculoskeletal disorders (RMDs) are a group of more than 200 different conditions which may result in damage to the muscles, bones and joints of the body. The European Union League against Rheumatism estimates that RMDs affect 1 in 4 Europeans of all ages, equivalent to 127 million Europeans and 1.2 million Irish citizens (www.eular.org). Table 1 lists the most common and important RMDs.

**Table 1: Common Rheumatic and Musculoskeletal disorders (RMDs)**

<b>Osteoarthritis (OA) and Regional MSK pain</b>	500,000 people affected in Ireland. 1 in 4 adults in the UK are affected by longstanding Musculoskeletal problems that limit everyday activity and 30% of all GP consultations are about MSK complaints (Department of Health (UK), 2006).
<b>Rheumatoid Arthritis (RA)</b>	At least 40,000 people in Ireland have RA. 70% of people with RA cannot work outside of home due to RA, costing the state €1.6 billion (Bevan et al., 2009a). Early intervention can prevent joint damage and disability in patients with RA.
<b>Spondyloarthropathy (SpA)</b>	Over 44,000 people in Ireland are affected (Bevan et al., 2009a) by this inflammatory disease predominantly affecting the spine including ankylosing spondylitis & psoriatic arthritis. Early intervention prevents disability in patients with SpA.
<b>Osteoporosis</b>	1 in 5 men and 1 in 2 women > 50yrs will develop a fracture due to osteoporosis. Hip fracture is fatal for 20% of patients with permanent disability for 50% (Stafford et al., 2004). Fractures can be prevented by treating osteoporosis.
<b>Systemic Rheumatic Disease: Connective Tissue Disease and Vasculitis</b>	2,000 people in Ireland affected. Multisystem diseases with high morbidity and mortality. Specialist multidisciplinary care improves outcomes and quality of life.
<b>Juvenile Idiopathic Arthritis (JIA)</b>	1,200 children in Ireland affected (Arthritis Ireland, 2016) - early specialist care within months of diagnosis prevents permanent joint damage, growth retardation and disability.
<b>Fibromyalgia and Soft Tissue Rheumatism</b>	2% of women, aged 20-55. One of the most common reasons for patients to visit a GP is widespread MSK pain attributed to abnormal pain processing (Department of Health, 2006)
<b>Gout</b>	Gout is the commonest inflammatory arthritis and prevalence is increasing – in line with obesity - with 1 in 40 of the UK population now affected (Kuo et al, 2014)

Arthritis is the leading cause of disability in people aged 55 years and over and hence is the greatest cause of health service usage (Vos et al., 2015). Over 1 in 5 Irish people

have some form of arthritis (Arthritis Ireland, 2015a) and the condition accounts for over 30% of all general practitioner (GP) visits (Bevan et al., 2009a). A recent report from the Central Statistics Office (2008) confirmed that chronic back pain is the second commonest condition among adults, after hypertension. The Institute of Public Health MSK briefing document in September 2012 found that 169,000 adults (5.1% of the population) had rheumatoid arthritis in the previous 12 months, which had been clinically diagnosed.

### **The Economic impact of RMDs**

RMDs give rise to major health resource utilisation – the direct costs of RMDs are estimated to account for 2% of the European GDP making it one of the top 4 disease groups in terms of healthcare costs ([www.eular.org](http://www.eular.org)). Effective health resource utilisation for RMDs is achieved by providing a population health approach providing preventative, self-management and primary care services for most patients with RMDs and specialist services for more complex and serious diseases which comprise 15-20% of RMDs. RMDs cause the single greatest socioeconomic cost of any single disease group due to lost productivity from long-term work absence and due to the payment of disability benefits. They represent 39% of all occupational diseases and are the main cause of early retirement, impeding the ability of people to remain economically and socially active when becoming older.

### **Population Growth and Ageing in Ireland 2016-2016**

As the demographic profile in Ireland changes, with increased life expectancy and rising numbers of the population moving into the middle and older age groups, it is expected that the prevalence of RMDs will increase dramatically in the next decade. RMDs impede the ability of people to remain economically and socially active when becoming older. An effective strategy to treat RMDs will be critical to maintain patients in social independence thus reducing nursing home care demands in the future as well as maintaining patients in work to a later age.

### **The New Therapeutic Strategy for RMDs**

New medical therapies are radically changing the approach to RMD management and are significantly affecting clinical outcome, preventing **disability and maintaining patients'** social and economic independence. For example the introduction of improved therapeutic strategies and biological medications for rheumatoid arthritis and spondyloarthritis, means that lasting disease remission is the new therapeutic goal (Emery et al., 2008) for up to 100,000 Irish patients. Preservation of work status, maintenance of quality of life and prevention of joint damage and disability result from successful treatment. Previously up to 70% of RA patients were unable to work outside of the home.

Not all RMDs require intensive specialist services and a population health approach is the most appropriate model for service delivery. Figure 1, which applies to all chronic conditions, shows the segmentation of complexity (levels 1-3) as it relates to RMDs. It is important to appreciate that these three levels are not distinct cohorts of patients; people in each level can improve or deteriorate and move between levels.

Figure 1: Population Health approach as it relates to Musculoskeletal health (Taylor, 2007, HSE, 2008b, Minnock et al., 2012)



**Level 1:** Individuals who have RMDs that are well controlled by the patients themselves. It is assisted by self-management participation and as required primary care support (approximately 70-80% of patients).

**Level 2:** Individuals with more complex illness. They may have one or more chronic illness of varying severity, but are not at risk of hospitalisation if they are well managed in the community (approximately 15-20% of patients). These patients can be monitored by self-management participation and identified via achievement or non-achievement of specific treatment goals.

**Level 3:** Individuals with complex conditions, often with complications. They require specialist care, intensive intervention and are at high risk of hospitalisation (Approximately 5-7% of patients).

### **National Clinical Programme for Rheumatology Model of Care**

*"To develop a chronic disease model of care to facilitate a right person, right place, first time approach to patients with rheumatic and MSK disorders."*

## **Achievements to date**

Rheumatology is the medical specialty dedicated to the treatment of RMDs. The NCPR was established in 2010 and comprised of representatives of all health professionals involved in Rheumatology care in Ireland. To date it has delivered:

- The appointment of seven additional Consultant Rheumatologist posts. This significantly increased the number of posts from 26.5 WTE to 33.5 WTE representing a 25% growth in Rheumatology Consultant numbers.
- The establishment of a Musculoskeletal Physiotherapy Initiative in collaboration with the National Clinical Programme for Trauma and Orthopaedic Surgery, with twenty-two Clinical Specialist Physiotherapists in place nationally. To date, this initiative has removed 71,714 patients from Rheumatology and Orthopaedic waiting lists. On foot of this success an additional six Clinical Specialist Physiotherapists were allocated through the 2016 service planning process.
- Endorsement by the National Director for CSPs of the Irish Rheumatology Nursing Forum Business Proposal for Advanced Nurse Practitioner and Clinical Nurse **Specialist Posts to implement 'Treat to Target' as standardised care for patients with inflammatory arthritis**. Further, the national director and the Chief Information Officer confirmed their co-sponsorship for the associated rheumatology electronic patient record pilot to capture essential treat to target outcome data.

## **National Clinical Programme Rheumatology Model of care**

Based on European Action Towards Better MSK Health (European Bone and Joint Health Strategies Project, 2004) and The MSK Service Framework (Department of Health (UK), 2006), a patient centred model of care for Rheumatology Services in Ireland was agreed by the NCPR, RCPI, the Rheumatology Clinical Advisory Group representing consultant rheumatologists throughout Ireland and Arthritis Ireland representing patients (<http://www.hse.ie/eng/about/Who/clinical/natclinprog/rheumatologyprogramme/modelofcare.html>)

## **Recommendations of the Model of Care**

### **Quality Solutions**

- Establish Rheumatology Clinical Networks (RhCNs) that are underpinned by robust clinical and corporate governance structures
- Develop/agree/implement national clinical guidelines, standards of practice, care pathways with all partners that move from prevention and self-care through to

hospital care and ensure that the use of primary and secondary care is **appropriate to patients' needs**

- Care pathways to include detailed and agreed clinical audit measures and all services must engage in clinical audit.
- To agree and implement disease specific and patient focused quality outcome measures
- To enhance and develop self-management and patient education programmes that are tailored to particular levels of complexity and risk e.g. those developed by Arthritis Ireland
- **To further develop "fracture-liaison" programmes so as to ensure that patients with osteoporosis are identified and treated in a timely manner**
- A national arthritis registry to be established
- To utilise the International Classification of Functioning, Disability and Health (ICF) as a framework to develop these measures. Activity and participation outcomes to be measured in tandem with outcomes that focus on body structure and function

### **Quality Solutions: Education and Research**

- To develop an accredited Continued Professional Development (CPD) programme in the assessment and treatment of MSK conditions for all disciplines. This programme to include e-learning modules
- To promote service-related and translational research programmes related to rheumatic diseases
- Develop and agree an integrated competency framework for each discipline working in rheumatology services across primary, secondary and tertiary services
- To review and develop, in partnership with the Higher Education Authority and Universities, MSK training programmes in the undergraduate courses in all the relevant disciplines

### **Access Solutions**

- Provide access to a Multidisciplinary Team (MDT) at community level which will enable individual and population-based self-management support, education, optimal clinical and social care in the most appropriate setting, education, avoidance of complications, improved outcomes and optimal quality of life

- Facilitate care across the chronic disease spectrum e.g. a falls clinic in primary care can be used to identify those at risk of osteoporosis and could also be used for health promotion in patients at risk
- Increase consultant rheumatology time by 40% within 1 year – this to be achieved by taking all rheumatology consultants off General Internal Medicine (GIM) call and by appointing new consultant rheumatologists.
- Develop and increase extended scope role in nursing, occupational therapy pharmacy and physiotherapy and to enhance multidisciplinary/interdisciplinary management
- Provide full MDT access to all dedicated rheumatology services, only one third of the recommended nurse specialists, occupational therapists and physiotherapists are in post nationally. An integrated workforce planning exercise needs to be completed on MDT staffing levels requirements in implementing the proposed model of care. Secondary care services to have an outreach component
- Developing educational programmes and liaising with community MDTs will facilitate optimal management of MSK conditions in the community and avoid “inappropriate” referrals
- To examine the possibility of integrated care protocols for patients on biologic therapies

### Value Solutions

- To develop and agree an evidence-based national guidelines for use of biologic therapies, including biosimilars, in a cost-effective manner in conjunction with the Medicines Management Programme
- To develop cost effective (eg:- community based, protocolised, etc.) infusion programmes which will provide economies of scale and substantial savings (vial sharing savings of €100,000/yr/100 patients treated or savings associated with use of biosimilars)
- To review usage of drugs within the General Medical Scheme, in particular those where efficacy is unproven
- To work with the OPD programme to ensure that all patients seen at OPDs are appropriately referred and have all the pre-assessment work-up completed prior to attending outpatient clinics in secondary care
- **To reduce the ‘did not attend’ (DNA) rate to 12% as per National OPD performance improvement programme**

- To liaise with Department of Social Welfare and to reduce MSK work-related disability costs (estimated €350m/year) by 10% in 2 years
- By introducing/rolling out an effective fracture-liaison programme including a falls risk assessment, to substantially increase the numbers of patients with fractures assessed to 90% within 1 year

<http://www.irhps.ie/>

### Key References (full list at [www.hse.ie](http://www.hse.ie))

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## Irish Rural Link

Issue	Recommendations
Access to Specialist Healthcare	<p>Irish Rural Link welcome Centre of Excellences for the delivery of specialist healthcare. However, the speed of access to specialist healthcare continues to be an issue, especially for people with no private health insurance, with people often waiting up to a year to see a specialist. Also the cost to people living in rural areas to access specialist care is higher as there are extra costs incurred such as travel costs, cost of caring and in some cases cost of accommodation.</p> <p>Irish Rural Link recommends</p> <ol style="list-style-type: none"> <li>1. Access to specialist healthcare must be based on need and not on person's ability to pay.</li> <li>2. Supports for people to assist in cost of travel, cost of accommodation etc must be introduced for people receiving specialist treatment.</li> </ol>
Cost of Medicine	<p>The cost of medicine in Ireland is still higher than most EU countries. People on low or limited income but who are not entitled to a medical card can often find it difficult to meet the cost of medicine, especially if they have to take regular medicine. The cost of medicine needs a thorough examination and alternatives explored.</p>
Ageing Population	<p>It is clear Ireland's ageing population is a growing area of concern for this Government and for future policy makers. An ageing population will put an increased strain on a country's health and caring services. Home based caring is the preferred option for family and for Government.</p> <p>Irish Rural Link recommend that Home-Care packages are adequately funded and resourced and that other services required, such as public transport, are available, especially in rural areas to ensure people can access medical and other healthcare appointments.</p>
Meals on Wheels	<p>Meals on Wheels is one service that facilitates older people to remain in their own home and reduce their length of stay in hospital. It can also link older people into other health services and reduce rural isolation, especially men living alone. However, it needs to be adequately funded and resourced to enable to continue to provide this vital service.</p> <p>Irish Rural Link recommend</p> <ol style="list-style-type: none"> <li>1. HSE funding for Meals on Wheels needs to be increased and multi-annual funding made available to allow organisations better plan and budget for the service.</li> </ol>

	<p>2. Stronger relationship between the HSE and Meals on Wheels organisations is needed and the valuable service meals on wheels provide in reducing the burden on the health system needs better recognition.</p>
Mental Health Services	<p>Mental Health needs to be at the forefront of the Future of Healthcare in Ireland. Rural isolation can have a very negative impact on a person's mental health, especially for men living alone. Mental health services in rural areas can be difficult to get to and to access due to lack of public transport and lengthy waiting times. The number of deaths in Ireland by suicide is almost three times more than the number of deaths on the nation's roads but yet there is very little mention of this number compared to road deaths.</p> <p>Irish Rural Link recommend</p> <ol style="list-style-type: none"> <li>1. More staff in mental health services need to be put in place to reduce waiting times.</li> <li>2. An awareness campaign be developed on Mental Health in Rural Ireland especially among men living alone.</li> </ol>
Community Development Officers	<p>Irish Rural Link recommend that each HSE region would have a dedicated Community Development Officer to help promote better health and wellbeing, ensure health inequalities are removed and access to healthcare is based on need.</p>
Health Needs Analysis and Rural Proofing	<p>Department of Health, HSE and other agencies must work closely with the Department and Minister of Regional Development and Rural Affairs to ensure all health policies and strategies are rural proofed and encompass all aspects of rural life.</p> <p>A social and health needs analysis and not just an economic analysis must be carried out prior to any proposed closure of health services in a rural area.</p>

## Overview

Irish Rural Link (IRL) is the national network of rural community groups, representing over 600 groups and thousands of individuals committed to socially, environmentally and economically sustainable rural communities.

People living in rural areas face many of the same difficulties in accessing healthcare, in particular for specialist services, and lack of available services but this can be exacerbated in rural areas by the lack of or limited availability of other necessary services, such as transport, so people can make medical appointments.

Rural isolation can have a severe impact on a person's mental health. Men living alone, especially older men are a very vulnerable group. The number of people who die by suicide each year in Ireland is higher than the number of people who die on the nation's roads, however, a lot of stigma still surrounds mental health and suicide and Ireland have not reached a stage yet, especially rural Ireland, where people will talk openly about problems they may be experiencing.

Implementation of measures for suicide prevention needs to happen as a matter of urgency and mental health services must be adequately funded and resourced.

### ***Access to Specialist Healthcare***

Irish Rural Link welcomes Centre of Excellences for the delivery of specialist healthcare. However, the speed of access to specialist healthcare continues to be an issue and leads to inequalities in terms of income. The two-tier system that occurs for specialist healthcare must be removed. Access must be based on a person's need and not on their ability to pay or if they have private health insurance. People with private health insurance can be fast-tracked to specialist care. With the cost of private health insurance increasing, many people, especially in rural areas can no longer afford to pay this.

People living in rural areas are faced with extra costs when accessing specialist healthcare. People will have to travel to access the specialist healthcare and in some cases may need to accommodation if receiving treatment. These costs are incurred by the patient. There is also the cost of caring, with another person having to travel with the patient. These extra costs that people incur must be considered in any future of healthcare discussion.

### ***Cost of Medicine***

The cost of medicine in Ireland is still higher than many EU countries. For people on low income or limited income who are just over the threshold for a medical card are impacted the most by the cost of medicine, especially for people who need to take medicine on a regularly. Although, generic medicines are available, there can be little difference in the price of these. The cost of medicine must be explored.

## ***Ageing Population***

It is clear Ireland's ageing population is a growing area of concern not only for this government but also for future policy makers. It is expected that in thirty years the number of people over the age of 65 will double. The ageing population will not only increase financial strain on the countries' finances but also on health and caring services themselves. These services need to be developed and improved upon to meet future demand for healthcare and meet the healthcare needs of an ageing population. For people living in rural areas other services need to be also be available, such as a robust public transport system, so they can access such healthcare services. Research indicates that home based caring is the preferred option for many families as well as Government as it is the most cost effective method. This Government has outlined in the *Programme for a Partnership Government*, they will improve supports and services for older people to live independently in their own home.

## ***Meals on Wheels Service***

Meals on Wheels is one service that already exists which facilitates older people to remain in their home and can reduce their stay in hospital. It is also a proven catalyst towards other community and state services for those-in-need. It is plugging the gaps in the system left by the health services. It links people into other services, such as the Public Health Nurse, befriending services and it can reduce rural isolation. For many, especially men living alone, the person delivering a meal may be the only person they might see in the day or week. However, it cannot continue to provide this service without adequate support and funding.

Meals on Wheels service is a critical component of the continuum of care services that enable older people to remain living in the community or to return to their own homes after hospitalisation. However, there are many challenges that are hindering Meals on Wheels delivering the vital service it provides and need to be addressed to ensure older people can remain in their own homes and live independently.

- ***Funding of Meals on Wheels***

Adequate funding is essential to the survival of Meals on Wheels and for it to become a sustainable service to older people. The level of funding Meals on Wheels Network receive is very limited and often inadequate to provide the service needed to meet the costs and demand for the service. Currently,

service providers receive funding from a range of sources, lacking their impact while also creating confusion over the application process. Many organisations simply do not have the capacity to apply for funding due to the complex application. A great deal of time and resources is also spent on fund-raising events limiting the effect on their core services.

The Health Service Executive (HSE), under Section 39; provide the largest financial subsidy to providers of Meals on Wheels. However, members feel that the funding available is insufficient to meet the modern costs associated with service provision such as rent, food produce/ingredients, wages and governance etc. For many the fragmented, limited and sometimes inadequate funding threatens the sustainability and quality of Meals on Wheels services.

- *Greater Role for the HSE*

There is an opportunity now for the HSE to play a greater role in the development in Meals on Wheels. It should not only act as a funding source for Meals on Wheels services but it should also act as a support mechanism for organisations. Support for Meals on Wheels organisations can vary from region to region for example some regions provides community development workers while other HSE regions provide little or no practical support. Network members view themselves as the voluntary arm of the HSE and whether the HSE see this as the case is another matter. Due to the fragmented nature of current Meals on Wheels services a constant concern remains over their long-term sustainability. Planning, management and financial support from the HSE is necessary to ensure that the future development of the Meals on Wheels service occurs in a more balanced, uniform and streamlined way, and is in a position to meet the likely growth in demand for the service.

### ***Mental Health Services***

Rural Isolation can have a negative impact on a person's mental health. Rural isolation is a particular issue among men, and especially older men, who are living alone and this group can be more susceptible to mental health problems. With the closure of services, such as Post Offices, rural schools, Garda Stations, local pubs over the past few years, many people, mainly older people who live alone, the issue of isolation has increased.

In 2015, there were 451 deaths by suicide in Ireland<sup>515</sup>, this is almost three times the number of road deaths recorded on the nation's roads in the same period (166 road deaths in 2015)<sup>516</sup>. However, there is very little mention of the actual number of people who die by suicide each year in Ireland. The stigma surrounding mental health and suicide is still very prevalent especially in rural areas and in particular among men. The stigma around asking for help or talking about their problems has not changed in rural areas.

The lack of consistent mental health services and lengthy waiting times to see a counsellor or other mental health professional through public health system can also be a deterrent for people to seek the help they need.

## **Recommendations**

Irish Rural Link ask the Oireachtas Committee on the Future of Healthcare to consider the following recommendations

### **1. Access to Specialist Healthcare**

As mentioned above IRL are supportive of Centres of Excellence and welcome that a higher level of care can be provided through these centres. However, access to specialist healthcare remains two-tiered. People who can pay or have private health insurance are fast-tracked to care, while people with who cannot afford to pay or do not have health insurance have to wait, sometimes up to a year, to see a specialist. IRL recommend that access to specialist care is based on need and not ability to pay. People with private health insurance cannot be given priority.

The extra costs people living in rural areas have to incur to access specialist healthcare, such as travel costs, accommodation costs, caring costs must be examined and supports made available to reduce the burden of these costs to patients.

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<sup>515</sup> CSO (2015) "Vital Statistics Yearly Summary" Births, Deaths and Marriages

<http://www.cso.ie/en/releasesandpublications/ep/p-vsyst/vitalstatisticsyearlysummary2015/>

<sup>516</sup> RSA (2015) <http://www.rsa.ie/RSA/Road-Safety/Our-Research/Deaths-injuries-on-Irish-roads/>

## **2. Cost of Medicine**

The cost of medicine must be reduced in line with that of other EU countries. People who are on low income but are over the threshold for a medical card are hit the most by the high cost of medicine. A review of the Drugs Payment Scheme must be undertaken and more allowances given to low income families who need to take medicine on a regular basis.

## **3. Home Based Caring**

Home care packages need to be adequately funded so home based caring can be developed and assist with older people remaining in their own homes. Other services that can assist people to remain in their own home or return to their home after a stay in hospital must also be adequately and a stronger link developed between all services. As mentioned above, the importance of public transport for older people and people with a disability in rural areas plays a crucial role in helping them remain in their own home and be able to access hospital, GP and other medical appointments. This cannot be overlooked in any Government policies on future health and cross departmental and agency work is essential on this.

## **4. Meals on Wheels**

HSE funding must be increased to fund Meals on Wheels services adequately and multi-annual funding to allow organisations better plan and budget for the service they provide in the short to medium term.

The lack of direction from policy makers leaves the services in a vulnerable state while also limiting their effect on the local community and the wider health service. IRL calls for the HSE to take sole responsibility for the delivery of Meals on Wheels services in Ireland through a guaranteed and standardised funding support through a Service Level Agreement.

## **5. Stronger Relationship between HSE and Meals on Wheels Organisations**

Improved co-operation between Meals on Wheels organisations and the HSE is now needed so that for some the burden on the health service can be reduced. The improved co-operation between the two organisations can lead to earlier discharge

from hospitals and referral of new recipients to Meals on Wheels organisations from the local hospital which can increase the number of recipients while reducing isolation. Although there are huge numbers of people availing of meals on wheels, there remains a stigma attached to the service while the number of recipients can also be improved through developing the referral system. The referral system can be expanded upon by reinforcing the relationship with Public Health Nurses and gaining acknowledgement of Meals on Wheels services at national level also eliminating the stigma.

IRL recommend that HSE and Meals on Wheels service providers should meet twice a year in order to facilitate greater interaction and understanding of each other. The regular interaction will also allow the state agencies to inform service providers about changes to regulations and policy, allowing them to be proactive. Service providers within the network are congest that governance structures including risk assessment and associated essential remedial action are set to be introduced to the sector, placing increased pressure on staff and volunteers. For smaller organisation especially, this governance structure presents fear as they feel they are under resourced and untrained to comply.

State agencies should assist Meals on Wheels organisations to comply with governance structures and relevant regulation through regular training and educational programmes both for staff, boards and volunteers who are vital to the sustainability of organisations. Training also needs to be provided on proper guidelines and food safety labelling.

## **6. Mental Health Services**

Mental Health needs to be at the forefront of the Future of Healthcare in Ireland. Investment into mental health services all across the country is imperative. The link between rural isolation and rural isolation among men living alone in particular, and mental health needs to be tackled with adequate funding made available for mental health and other services in rural areas such as transport, which is very often a lifeline to people in alleviating the problem of rural isolation. Measures developed to prevent suicide must be implemented as a matter of urgency and more awareness campaigns to remove stigma surrounding mental health, especially in rural areas must be put in place. IRL would recommend that the Committee consider an

awareness campaign be developed on Mental Health in Rural Ireland and one specifically on Rural isolation among men living alone and how it impacts on their mental health.

## **7. Community Development Officers**

IRL recommend that each HSE region would have a dedicated Community Development Officer. A community approach to healthcare can help to promote better health and wellbeing in a community and ensure that health inequalities are removed and access to healthcare is based on need<sup>517</sup>. Part of the Community Development Officer's role would be to fully engage with all stakeholders in an area to ensure everyone, especially older and other vulnerable groups and those on low incomes have equal access to healthcare and are aware of the health services they are entitled to.

## **8. Health Needs Analysis and Rural Proofing**

With the development of a Regional Development and Rural Affairs Minister and Department, IRL call for any policies/strategies developed to encompass all aspects of rural life. The Department of Health, HSE and other agencies must now work with this department to rural proof any policy being developed that can impact on people living in rural Ireland and their access to healthcare.

IRL also recommends that not just an economic analysis but also a social and health needs analysis is carried out prior to closure of health services in an area and that the demographics of the area is also considered.

## **Irish Rural Link the Organisation**

Irish Rural Link (IRL), formed in 1991, is a national network of organisations and individuals campaigning for sustainable rural development in Ireland and Europe. IRL, a non-profit organisation, has grown significantly since its inception and now directly represents over 300 community groups with a combined membership of 25,000.

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<sup>517</sup> HSE 'Community Development Resource Pack'

[https://www.hse.ie/eng/services/yourhealthservice/SUI/Library/Guides/Community\\_Development\\_Resource\\_Pack.pdf](https://www.hse.ie/eng/services/yourhealthservice/SUI/Library/Guides/Community_Development_Resource_Pack.pdf)

The network provides a structure through which rural groups and individuals, representing disadvantaged rural communities, can articulate their common needs and priorities, share their experiences and present their case to policy-makers at local, national and European Level.

Irish Rural Link is the only group represented at the national social partnership talks solely representing rural communities' interests

***'Our vision is of vibrant, inclusive and sustainable rural communities that contribute to an equitable and just society'***

Irish Rural Link's aims are:

- To articulate and facilitate the voices of rural communities in local, regional, national and European policy arenas, especially those experiencing poverty, social exclusion and the challenge of change in the 21<sup>st</sup> century.
- To promote local and community development in rural communities in order to strengthen and build the capacity of rural community groups to act as primary movers through practical assistance and advice.
- To research, critique and disseminate policies relating to rural communities including issues such as sustainability, social exclusion, equality and poverty
- To facilitate cross-border networking between rural communities

***'Our mission is to influence and inform local, regional, national and European development policies and programmes in favour of rural communities especially those who are marginalised as a result of poverty and social exclusion in rural areas.'***

<http://www.irishrurallink.ie/>

## Irish Skin Foundation

The Irish Skin Foundation (ISF) is a national charity dedicated to improving the quality of life of people with all kinds of skin diseases and conditions, to promoting skin health and the prevention of skin disease by providing support, information, engaging in advocacy and raising awareness.

We operate a free helpline providing direct, accessible and specialist guidance about skin conditions. Throughout the year we run events, including health promotion meetings and dermatology education for nurses and pharmacists.

### Overview of skin disease in Ireland

Over half of the Irish population experience a skin condition each year; between 15-20% of GP consultations specifically relate to the skin. This represents up to 5 million GP consultations per year which generates a significant number of referrals for consultant dermatologist advice.<sup>518</sup>

There are 4,500 skin diseases, many can be managed at primary care level; secondary level dermatology is usually an outpatient specialty dealing with more complex or severe forms of skin disease. Most skin consultations with GPs concern a small group of the most common skin conditions. These include skin lesions, eczema, psoriasis, acne, wounds (including leg ulcers), contact dermatitis and viral warts.<sup>519</sup>

Psoriasis is one of the most common skin diseases in Ireland and affects at least 73,000 people; 20% of whom will require secondary care according to international standards.<sup>520</sup> Many skin disorders, such as eczema, are increasing in frequency; approximately 1 in 5 children and 1 in 12 adults have eczema.

Ireland has one of the highest incidences of skin cancer in the world with 984 new cases of melanoma and 9,786 new people diagnosed with skin cancer in 2013.<sup>521</sup> It is expected that diagnoses of these diseases will increase over 300% by 2040.<sup>522</sup> The increasing instance of skin cancer alone threatens to overwhelm secondary level dermatology services.

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<sup>518</sup> The Irish Medical Organisation estimates that there are 25 million GP consultations each year.

<sup>519</sup> Broadly speaking skin disease includes inflammatory diseases, such as acne, eczema and psoriasis; skin cancers, such as melanoma and squamous cell carcinoma; infections caused by bacteria, viruses, fungi and parasites; autoimmune conditions, such as lupus and vitiligo; and hereditary diseases, such as epidermolysis bullosa (EB) and ichthyosis.

<sup>520</sup> The Burden of Psoriasis: Epidemiology, Quality of Life, Co-morbidities and Treatment Goals, 2015.

<sup>521</sup> Figures quoted by the National Cancer Control Programme. The most common cancer in Ireland is non-melanoma skin cancer; the two main types are basal cell carcinoma (BCC) and squamous cell carcinoma (SCC).

<sup>522</sup> Non-melanoma: 303% increase in females and 364% in men. Melanoma: 296% in females and 335% in males, figures from the National Cancer Registry Ireland.

At secondary level, dermatology has the fourth-longest waiting list with 34,805 patients, and an average (and unacceptable), waiting time for routine assessment of 12-18 months.<sup>523</sup> Skin diseases cause over 180 deaths each year in Ireland, including 113 deaths due to malignant melanoma, the vast majority of which are avoidable through early detection and better resourced services.<sup>524</sup> Severe skin disease also is implicated in premature death.

Quality of life is significantly impaired by skin diseases, often to an extent that is as great as some life-threatening conditions such as cancer.<sup>525</sup> Many people report stigmatisation, a fear of contagion and a failure of others to appreciate the serious health, financial, social and personal impacts of their disease.

While new specialist posts have been established in the past six years, the HSE has not provided sustained resources for additional posts or adequate investment in clinic infrastructure and development. Consultant dermatologist staffing is 50% below international best practice.<sup>526</sup> Access to predominately outpatient based treatments early and easily, reduces the health and financial impact of skin disease for patients and for the health care system.

## **Executive summary of recommendations**

### **Recommendation 1: Tackling skin cancer**

Sun safe practices lead to a reduction in skin cancer incidence. To tackle the increasing prevalence of skin cancer, a concerted long-term strategy to educate the public about prevention is required, in addition to the importance of early detection.

Changes to legislation are needed to place a duty of care on local authorities, schools, recreation / sporting clubs and employers to protect the public, children and employees from UV damage. Sunbeds should be banned, completely, for public and private use.

### **Recommendation 2: Reduce out-of-pocket expenses for patients**

Reduce out-of-pocket expenses paid by patients for moisturisers, emollients, bandages, dressings, specialist clothing and sunscreens by eliminating VAT on these products. Expand the limited choice of products available via medical card and Drug Payments Scheme (DPS) for preventing, treating and managing skin disease. Provide sunscreens on prescription to patient groups at particular risk of sun damage and skin cancer (e.g. immuno-suppressed patients, such as transplant recipients).

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<sup>523</sup> National Treatment Purchase Fund data, July 2016.

<sup>524</sup> In Ireland between 2003-10 an average of 181 people died each year as a result of diseases of the skin and subcutaneous tissue (68) and melanoma (113); figures from the OECD.

<sup>525</sup> Skin Conditions in the UK: a Health Care Needs Assessment, NHS, 2009.

<sup>526</sup> International best practice is 1 dermatologist to every 50,000 population. To operate a basic service requires 1 to 80,000 population is required. Literature recommending 1 dermatologist to 100,000 population assumes good clinic infrastructure, a high level of support staff in hospital dermatology departments and a robust, free primary care system run by GPs with a higher level of dermatology training than is usual in Ireland. See [Staffing and facilities guidance for dermatology services](#), produced by Clinical Services Unit British Association of Dermatologists, June 2014.

**Recommendation 3: Supporting patients in primary care**

Support patients in primary care by resourcing dermatology training for all GPs, to provide universal access to the widest range of dermatology care to all patients in Ireland.

Policy makers must examine options in primary care in consultation with all healthcare professional representative bodies and other stakeholders.

**Recommendation 4: Supporting patients in secondary care**

Increased funding for secondary care dermatology should include, but not be limited to, an increase in consultant dermatologist numbers, but must include greater investment in the infrastructure, equipment, specialist nursing and support staffing in dermatology departments.

Service planning and development must provide sustained investment for consultant dermatology posts (to increase numbers of consultant dermatologists from 46 to 74, i.e. from 1 per 100,000 population, to 1 post per 62,500), dermatology clinical nurse specialists (CNSs) and advanced nurse practitioner (ANPs) roles,<sup>527</sup> along with the necessary administrative support.

**Recommendation 5: Medical and nursing education in dermatology**

Ensure medical, nursing and GP training (undergraduate and postgraduate) is sufficient so that doctors have a basic knowledge in dermatology for common and important diagnoses. Basic nurse and pharmacist training must include dermatology and those specialising in dermatology should have easy access to post-qualification training in Ireland. This will widen the pool of clinicians with some dermatology expertise and allow earlier diagnosis and treatment.

**Recommendation 1 - Tackling skin cancer**

Skin cancer is the most common cancer in Ireland. Yet in most cases, it is preventable and early detection leads to better outcomes. The majority of cases are caused by ultraviolet (UV) radiation which comes from the sun.<sup>528</sup> Sun safe practices lead to a reduction in skin cancer incidence.

Approximately 75% of the Irish population have skin type 1 or 2, which burns easily and is more prone to skin cancer. There is a prevailing culture in Ireland where people believe having a tan is healthy, and rush outside at the first hint of sunshine, often without adequately protecting their skin. Given that sun damage is cumulative, there is a time lag between overexposure to ultraviolet radiation and the development of skin cancer. This underscores the importance of developing sun safe habits at a young age, when children are most receptive.

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<sup>527</sup> Begley, C et al. (2010) Evaluation of Clinical Nurse and Midwife Specialist and Advanced Nurse and Midwife Practitioner Roles in Ireland (SCAPE) Final Report. National Council for the Professional Development of Nursing and Midwifery in Ireland, Dublin.

<sup>528</sup> Artificial sources of UV radiation includes sunbeds.

A new National Skin Cancer Action Plan is currently being devised by the National Cancer Control programme. The ISF agrees that a coordinated response with consistent messaging is necessary to address the escalating incidence of skin cancer. The rates are projected to treble over the next 25 years.

Research has demonstrated the effectiveness of well planned, resourced, executed and sustained campaigns to have a lasting impact. It has also highlighted the importance of the social and environmental context in enabling positive sun safe choices. Ireland should look to Australia for guidance on best practice as in 2014, Australia became the first country in the world to bring about a reduction in skin cancer rates (both melanoma and non melanoma) in the under 45 age group. Measures such as 'no hat, no play' have become mandatory in Australian schools and in terms of artificial ultraviolet radiation, sunbeds are now banned.

### **Recommendation**

Sun safe practices lead to a reduction in skin cancer incidence. To tackle the increasing prevalence of skin cancer, a concerted long-term strategy to educate the public about prevention is required, in addition to the importance of early detection.

Changes to legislation are needed to place a duty of care on local authorities, schools, recreation / sporting clubs and employers to protect the public, children and employees from UV damage. Sunbeds should be banned, completely for public and private use.

### **Recommendation 2 - Reduce out-of-pocket expenses for patients**

One in 5 children and 1 in 12 adults suffer with eczema. Regular application of over-the-counter medical moisturisers is the cornerstone of treatment for the condition (augmented by steroid creams, or topical immunomodulatory treatments as needed). Medical cards do not cover an adequate spectrum of treatments. A combination of barriers (including the limited product list available with a medical card or through the DPS, VAT levels and regulatory restrictions) make dozens of products expensive for patients. These barriers limit patient choice as well as access to new products, hampering self-management and leading to lower treatment adherence, which ultimately results in higher healthcare utilisation.<sup>529</sup>

For example, while emollients such as aqueous cream (a soap substitute), emulsifying ointment or Silcock's base (medical moisturisers), and steroid creams/ointments are covered on the medical card, no other over-the-counter soap substitutes or moisturisers are covered by either a medical card or the DPS.

The limited availability of emollients on the medical card and DPS, combined with the high cost of over-the-counter treatments, leads to under-use of emollients (medical moisturisers and soap substitutes) as patients and carers use expensive products too sparingly. Emollients are a safe and cost-effective treatment for a range of dry

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<sup>529</sup> Adults with eczema are on average 53% more likely to miss at least six workdays due to illness, more than three times likely to visit a physician 10 or more times a year, were 81 times more likely than eczema-free adults to have 10 or more urgent or emergency care visits annually 37% hospitalized: [A JAMA Dermatology study of U.S. 62,000 adults.](#)

skin conditions, and in the case of eczema, their primary role is to prevent the condition from flaring up. They have also been shown to reduce the requirement for topical corticosteroids.<sup>530</sup> Emollients used to treat eczema may need to be applied generously up to six times each day to large parts of the body (e.g. 500-600g/week for adults and 250g/week for children.<sup>531</sup> If patients give up using a standard emollient to moisturise because it doesn't work or doesn't suit them, they often find that they can't afford to try other or branded products.

In such cases, patients are tempted to use more steroid creams because they are available on the medical card or the DPS. This clearly exposes patients to the risks of steroid overuse and causes higher utilisation of costly prescription products covered on a medical card or the DPS.

The cost of bandages, dressings, special clothing or sun protection creams for thousands of children and adults with certain skin conditions (such as psoriasis, eczema and hidradenitis suppurativa (HS)) are not covered by the medical card or the DPS. These essential daily management items are all taxed at 23%. People with exudative skin conditions (e.g. HS) may require a range of specialised dressings to absorb the exudate, prevent maceration and ultimately promote healing. These should be available on prescription.

Sun creams are not available via medical card or DPS to patient groups at particular risk of sun damage and skin cancer – in particular immuno-suppressed patients, such as transplant recipients. Sunscreen should be provided on prescription to these patient groups. Beyond the direct health benefits (i.e. reducing the risk of skin cancer), measures such as this, have wealth benefits (i.e. healthcare savings) for the state.<sup>532</sup> This situation should be remedied as soon as possible. Likewise, with rising skin cancer levels in the general population VAT on sun creams should be reduced from 23%.

Adult patients with chronic skin disease that have become adept in managing their condition should be afforded access to a broader range of tried and tested prescription products, over-the-counter.

Many dermatology patients benefit from the off-license use of medications (for example fumaric acid esters in the treatment of psoriasis). Irish regulatory restrictions and the consequences of Brexit may negatively impact the availability of certain off-licence treatments. The ISF calls on the HSE to ensure the continued supply of such products.

### **Recommendation**

Reduce out-of-pocket expenses paid by patients for moisturisers, emollients, bandages, dressings, specialist clothing and sunscreens by eliminating VAT. Expand the limited choice of products available via medical card and Drug Payments Scheme (DPS) for preventing, treating and managing skin disease. Provide sunscreens on prescription to patient groups

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<sup>530</sup> Grimalt, R. et al (2007) The steroid-sparing effect of an emollient therapy in infants with atopic dermatitis: a randomized controlled study. *Dermatology* 214: 61-67.

<sup>531</sup> Kownacki, 2009.

<sup>532</sup> Slevin, T (2016) [The skin cancer low-down from Down Under](#), Irish Medical Times

at particular risk of sun damage and skin cancer (e.g. immuno-suppressed patients, such as transplant recipients).

### **Recommendation 3 - Supporting patients in primary care**

There is strong demand for dermatology services at primary care. Many patients consult their GP or pharmacist in the first instance, whilst others self-treat. The majority of skin consultations with GPs concern a small group of most common skin conditions.<sup>533</sup>

Although mortality rates from skin conditions are comparatively low, skin cancer rates in Ireland are projected to treble over the next 25 years, and half of all specialist activity in hospitals now relates to the diagnosis and management of skin lesions. As the population ages, there is likely to be a higher demand for dermatology services. Against this background additional capacity is needed in dermatology. One element in delivering such capacity lies in examining options within primary care, policy makers must do this in consultation with healthcare professional representative bodies, and with reference to agreed national clinical guidelines with robust accreditation and governance structures.

There is a need to integrate primary, secondary and tertiary services more closely to ensure a joined-up approach, continuity of care and holistic support (including specialist nursing, counselling and psychological services where appropriate). This requires better communication between the primary and secondary care including multi-disciplinary care team meetings for GPs.

There is also an urgent need to develop more educational opportunities for GPs so as to facilitate the provision of dermatological treatments not requiring referral to hospital-based specialists.

#### **Recommendation**

Support patients in primary care by resourcing dermatology training for all GPs, to provide universal access to the widest range of dermatology care to all patients in Ireland. Policy makers must examine options in primary care, in consultation with patients, all healthcare professional representative bodies and other stakeholders.

### **Recommendation 4 - Supporting patients in secondary care**

Ireland has a shortage of consultant dermatologists at a time when cases of skin cancer are increasing. Skin cancer is the most common cancer in Ireland. Yet in most cases, it is preventable, and early detection can be critical to saving lives. The increasing incidence of skin cancer alone threatens to overwhelm dermatology services. Patients referred to pigmented lesion clinics, with suspicious lesions, must be seen as soon as possible but this can have a negative impact in that it displaces other dermatology patients already on the waiting list. Furthermore, the systemic

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<sup>533</sup> These include skin legions, eczema, psoriasis, acne, wounds (including leg ulcers), contact dermatitis and viral warts.

understaffing also affects thousands of people with psoriasis, eczema and other difficult skin conditions such as HS, requiring hospital care.

Psoriasis is recognised by the WHO as a chronic, non-communicable, painful, disfiguring, and disabling disease for which there is no cure.<sup>534</sup> The 2015 *Burden of Psoriasis* report suggests that 73,000 people in Ireland have psoriasis; 20% of whom will require secondary care according to international standards.<sup>535</sup> The majority of people with psoriasis are also under 50 years of age. Approximately 6,000 new diagnoses are made each year and is likely to increase into the future.

People with psoriasis also have an elevated risk for a number of co-morbid conditions, namely, cardiovascular diseases, type-2 diabetes, obesity, heart attack, metabolic syndrome, stroke, liver disease, and even depression. Moreover, up to 42% of those with psoriasis also develop psoriatic arthritis, which causes pain, stiffness and swelling of the joints and can lead to permanent disfigurement and disability.

The evidence is clear that early diagnosis and timely treatment is linked to lower healthcare utilisation with fewer hospital admissions and clear cost savings. Yet delayed diagnosis, inadequate treatment options, centralisation of services in major cities and insufficient access to care are common barriers experienced of people with psoriasis in Ireland. Compounding this, dermatology departments have not been resourced to meet this increasing demand. Against this backdrop the case for additional capacity in dermatology clinics is apparent.

<b>Dermatology Service Levels</b>	<b>Dermatologists per population</b>	<b>Number of Dermatologists</b>
Best Practice Internationally	1: 50,000 population	92
Effective Service for Ireland	1: 62,500 population	74
Current Service in Ireland	1:100,000 population	43

Based on *Staffing and facilities guidance for dermatology services*, produced by Clinical Services Unit British Association of Dermatologists, June 2014.<sup>536</sup>

In recent years demand has outstripped capacity in hospital dermatology clinics. While new posts have been established in the past decade, the HSE has not provided sustained resources for additional posts or adequate investment in the necessary specialist nursing support (i.e. dermatology CNSs and ANPs), clinic infrastructure and development. Restricted space in departments also leads to restricted numbers of patients being treated.

There are currently only two dermatology ANPs in Ireland; they play a key role in chronic disease management and minor skin surgery within hospitals. Resources should be made available to expand this nursing grade.

With small numbers of specialist registrars in training and challenging working conditions, both locum and permanent posts in dermatology services have become difficult to fill. Efforts must be made to increase numbers of medical dermatology trainees (i.e. specialist registrars).

<sup>534</sup> Resolution adopted by the WHO at the 67th World Health Assembly in May, 2014.

<sup>535</sup> The Burden of Psoriasis: Epidemiology, Quality of Life, Co-morbidities and Treatment Goals, 2015.

<sup>536</sup> [Research by the King's Fund cites](#) examples in which the optimal means of managing skin disease, from a cost-effectiveness perspective, was to ensure initial diagnosis by a consultant dermatologist and ready access to specialist opinion.

The ISF has previously called for at least one dermatologist per 62,500 people to provide an effective service. With year-on-year increases in referrals, policy makers must plan to address the issues affecting services or patients will continue to experience even longer waiting times, delayed diagnosis and treatment.

### **Recommendation**

Increased funding for secondary care dermatology should include, but not be limited to, an increase in consultant dermatologist numbers but must include greater investment in the infrastructure, equipment, specialist nursing and support staffing in dermatology departments.

Service planning and development must provide sustained investment for consultant dermatology posts (to increase numbers of consultant dermatologists from 46 to 74, i.e. from 1 per 100,000 population, to 1 post per 62,500), dermatology clinical nurse specialists and advanced nurse practitioner roles,<sup>537</sup> along with the necessary administrative support.

### **Recommendation 5 - Medical & nursing education in dermatology**

Despite the clear and increasing demand for dermatology care at primary and secondary level, undergraduate medical training in dermatology does not receive enough attention. Many undergraduates will receive as little as 6 hours dermatology education (if any) throughout their entire training. Moreover, universities and medical schools have very limited personnel dedicated to clinical academic positions for medical undergraduate teaching in dermatology. Compounding this situation, nurses (including practice, public-health, hospital-based and community nurses) and pharmacists do not receive adequate basic dermatology training and education.

Secondary services are supported by a small number of dermatology clinical nurse specialists (CNSs) and dermatology advanced nurse practitioners (ANPs), but there is no established career pathway for RGNs nor is training available in Ireland. This should be addressed at a matter of urgency as nursing specialist support is critical to the efficient delivery of dermatology services.

In response to this, a number of organisations provide training, including the ISF which organises an annual dermatology study day for nurses and pharmacists, to provide better access to dermatology expertise.<sup>538</sup> There are a small number of GPs who have developed considerable expertise in dermatology. However, at present there is no recognised national competency and guidelines framework for accrediting and maintaining standards for dermatology skills acquired through such training.

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<sup>537</sup> Begley, C et al. (2010) Evaluation of Clinical Nurse and Midwife Specialist and Advanced Nurse and Midwife Practitioner Roles in Ireland (SCAPE) Final Report. National Council for the Professional Development of Nursing and Midwifery in Ireland, Dublin.

<sup>538</sup> These include the Irish College of General Practitioners (ICGP), Primary Care Dermatology Society (PCDS), the Primary Care Surgical Association (PCSA) and Dermcloud.ie.

For further information please contact: David McMahon, COO, Advocacy and Communications, Irish Skin Foundation; C/o Charles Institute of Dermatology, University College Dublin, Dublin D04 V1W8  
Email: [davidmcmahon@irishskin.ie](mailto:davidmcmahon@irishskin.ie)

More recently some secondary level dermatology clinics have begun to train GPs; which is a welcome development bringing badly needed skills to primary care.

**Recommendation**

Ensure medical, nursing and GP training (undergraduate and postgraduate) is sufficient so that doctors have a basic knowledge in dermatology for common and important diagnoses.

Basic nurse and pharmacist training must include dermatology and those specialising in dermatology should have easy access to post-qualification training in Ireland. This will widen the pool of clinicians with some dermatology expertise and allow earlier diagnosis and treatment.

Irish Skin Foundation, C/o Charles Institute of Dermatology, UCD, University College Dublin, Dublin D04 V1W8 Helpline (01) 486-6280 | Email: [info@irishskin.ie](mailto:info@irishskin.ie) | Web: [www.irishskin.ie](http://www.irishskin.ie)

## Irish Society for Colitis & Crohn's Disease

The Irish Society for Colitis and Crohn's Disease (ISCC) is a voluntary organisation providing information and patient –to-patient support for the 20,000 people who are living with Crohn's and colitis in Ireland.

As the leading IBD advocacy organisation we welcome the opportunity to provide a submission to the Joint Oireachtas Committee on the Future of Healthcare. We fully recognise and support the primary objective of the Committee in developing cross party consensus on a national health care strategy and policy over a ten year time frame.

Our submission reflects the primary objectives, work plan (particularly around access to chronic disease management and integrated healthcare) and the wider terms of reference outlined in the background to the Oireachtas Committee future of Healthcare document.

In drafting our submission we have incorporated all of the latest medical research in an Irish and international context focussing on sustainable models of care, integrated multidisciplinary teams and community based access to specialist IBD nurses. Our vision for creating fair and equitable models of IBD care builds on that research and best practise and is outlined in more detail in the IBD Manifesto 2016 – 2018 (attached for reference)

In our view the development of a National Healthcare Strategy should incorporate a specific set of policies on Crohn's and colitis as follows:

1. Equitable access to an IBD Nurse and multidisciplinary team
2. Self- care and patient empowerment
3. Sustainable funding model

The submission below outlines possible ways in which this can be delivered

### About IBD

Crohn's disease and Ulcerative Colitis (collectively known as Inflammatory Bowel Disease or IBD) are serious yet under-recognised health conditions affecting approximately 20,000 Irish people today. <sup>3</sup> Often starting in early childhood, both Crohn's disease and ulcerative colitis are life-long conditions for which there is currently no cure <sup>4</sup>. People living with Crohn's and colitis are at higher risk of developing colorectal cancer and dying prematurely <sup>5</sup>. Due to its remitting and relapsing pattern, IBD places a heavy burden on patient populations, resulting in reduced quality of life, reduced capacity for work and potentially increasing disability. <sup>1, 2</sup>

### Summary of key evidence based research

The IMPACT survey was commissioned by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) in late 2010. Its main aim was to get an international perspective of the impact of IBD on people's lives and it was conducted in 22 countries including Ireland.

The IMPACT Survey described the devastating impact these conditions can have on those affected, including complex medical and therapeutic needs, compromised emotional

wellbeing, education, productivity and overall quality of life. The key findings of this survey included:

- More than half did not get a diagnosis within the first year of onset of symptoms [4](#)
- 97% of respondents experienced one or more flare ups in the past two years [4](#)
- More than 90% of respondents had been hospitalised in the last 5 years and more than half will eventually need surgery [4](#)
- 49% say they have lost or had to leave their job because of their illness [4](#)

A recent survey conducted in Ireland by the Irish Society of Gastroenterology (ISG) illustrated several key gaps in services to patients. These include:

- Lack of specialist IBD nurses throughout the country [6](#)
- Lengthy waiting times for tests [6](#)
- Lack of access to a gastroenterology specialist [6](#)
- Limited access to psychologist treatment [6](#)

### **The economic consequences**

The fluctuating nature of Crohn's and colitis means that people with these conditions have a lower rate of participation in the workforce than the general population [7](#). 23% said that they are unemployed or underemployed due to the condition [4](#). The IMPACT report shows that 77% of Irish respondents have had time off in the past year due to their condition; 59% stating that they had five or more day's off [4](#). Alarmingly, just under half of all respondents (49%) say they have lost or had to leave their job because of their illness [4](#).

One in four believe that they have been discriminated against in the workplace with many feeling stressed or pressured about taking time off due to their illness. The Gut Responses Survey outlined that patients reported missing on average between 16 and 17 days a year from work/college/School.

More specialist nurses are needed to ensure people with bowel conditions such as Crohn's disease and ulcerative colitis can stay in employment, according to a new report [22](#).

An Italian study demonstrated that Crohn's disease may have a profound impact on an affected person's quality of life and a substantial economic impact for both them and the healthcare system [8](#). The cost of illness per patient with Crohn's disease in the study was estimated to be €15,521 per year, [8](#).

### **The Impact of IBD on patients' lives**

When a flare up occurs, it really impacts the life of someone living with IBD. Almost half (48%) of people with IBD said that even between flares their lives are still negatively affected by their symptoms. Some 16% say that their condition is always flaring – these people are more likely to be aged 19 to 34 and in the group that is unemployed due to IBD. During their last flare:

- 47% of people experienced gastrointestinal tract bleeding for four or more days

- 76% experienced abdominal cramping, and
- 92% were tired, weak and worn out for four or more days
- 97% of people have experienced one or more flare ups in the last two years, meaning it is a real presence in their lives.(the EU average is 87%)

### **Creating sustainable models of care - Summary of international and local initiatives**

Building on these findings, the ISCC recognises that to improve the lives of those living with Crohn's and colitis, we must adopt a holistic policy framework that supports an increase in vital services. This can only be achieved through the collaboration of all relevant healthcare stakeholders in creating concrete solutions that will increase access to, and improve models of care.

The ISG survey and the IMPACT report demonstrate significant gaps in service delivery in the Irish healthcare system. . In this section, we highlight a number of international models with proven success as well as local innovations which, if applied nationally, have the potential to significantly change the course of the management of Crohn's and colitis in this country.

#### **The IBD integrated multidisciplinary team**

In its 2009 report *Preventing Chronic Diseases: A Vital Investment*, the World Health Organization identified a multidisciplinary team as: "...a highly effective approach to improving chronic disease care **9**"

As chronic, lifelong diseases, Crohn's and colitis require interventions at numerous points and levels of the healthcare system. Experts worldwide agree that a multidisciplinary team is the most effective structure for managing these conditions. The first recommendation of the UK IBD Standards Group is that high-quality clinical care delivered by a multidisciplinary team that includes specialist nurses **10**.

The UK IBD Standards Group recommends that the multi-disciplinary team include the following members:

- Consultant gastroenterologist (physician specializing in the digestive system) **10**
- Consultant colorectal surgeon **10**
- Clinical nurse(s) with an identified role and competency in Crohn's and colitis **10**
- Clinical nurse(s) with an identified role and competency in stoma therapy and pouch surgery **10**
- Dietician allocated to gastroenterology **10**
- GI pathologist (physician specializing in cellular abnormalities) with special interest in gastroenterology **10**
- Radiologist with special interest in gastroenterology **10**
- Pharmacist with special interest in gastroenterology **10**

Accesses to the following supporting services are identified as critical:

- Psychologist, Rheumatologist, Ophthalmologist, Dermatologist, Obstetrician, Nutrition Support team 10
- Consultant Paediatrician 10
- An established link with a GP to provide a liaison and educational role with local GPs 10
- Evidence from the IMPACT Report and the ISG survey indicate that minimum requirements in Ireland should include a gastroenterologist, colorectal surgeon, specialist nurse, psychologist, dietician, GI pathologist, and radiologist, all available for consults as needed 4,6

### **The case for the specialist IBD nurse**

Given the chronic nature of Crohn's and colitis, the importance of disease-specific and self-management education, the need to fine-tune therapy and encourage drug compliance, and the need to monitor patients for colorectal cancer, involvement of specialist nurses in the multidisciplinary team is critical. Within the context of the Irish shortage of gastroenterologists and the regional inequities in timely access to quality care, the specialist nurse can be a resource-sparing and cost-effective member of the IBD team. Increasing evidence suggests that specially trained nurses can perform as safely and effectively as doctors across a range of conditions and procedures 7. However, the number of dedicated nurses (12) is of serious concern to the ISC against the backdrop of close to 1,000 new cases of IBD per year.

IBD nurses serve as the first point of contact for patients, and they provide frequent and easy access to education, advice, and support aimed at improvement in outcomes. The effect of the introduction of an IBD nursing role on the delivered quality of care within an IBD referral centre was investigated 23. The role of IBD nurses as first point of contact and counselling is evident from a high volume of nurse-patient interactions that increased threefold within the first 6 months. Avoidance of emergency room and unscheduled clinic visits, and improved access to procedures were associated with these contacts 23.

A recent KPMG report states that the specialist nurse provided continuity of care for patients, educating them on their disease and giving them support and advice across the disease cycle 11. The report highlights the three key roles performed by these nurses:

- Care Co-ordinator: Supports patients to navigate the complex care pathway
- Treatment Expert: Nurse led clinics manage aspects of treatment including the administration and prescription of biologics
- Case Manager: Specialist nurses take on the role of case manager and support the patient through the medical and non-medical aspects of their disease

An Australian study showed that intervention with a specialist nurse leads to a reduction of hospital admission, fewer A&E presentations and clinic reviews 12. The specialist nurses provided sustained direct cost reductions to health services. Additional benefits were accrued through better patient knowledge, earlier presentation and increased compliance. The use of specialist nurses to carry out roles for which they have been specially trained

makes obvious health-economic sense: it alleviates the burden on gastroenterologists and primary care physicians while enabling a high level of continuity, streamlining the flow of care and minimising bureaucratic inefficiencies. In a Halifax experiment, analysis demonstrated a 50% reduction in patient wait times for IBD care following the introduction of an urgent access clinic led by a specialist nurse 7. Patients reported that attending the nurse-led clinic enabled them to avoid a more costly visit to the emergency room 6. Reducing avoidable hospital admissions, increasing the proportion of people with IBD to self-manage and the ability to offer choice of care are recognised as quality aspects of an IBD service. The presence of an IBD nurse, within the IBD team, correlates with fewer admissions, the availability of self-management programmes and greater overall choice in care provision and new modes of care delivery 20.

### **Community based chronic disease management**

The incidence of Crohn's and colitis has increased markedly over the last few years including a threefold increase in new paediatric cases since 2000 24. Primary care can be a key factor in providing early diagnosis 13. Shared care with primary care can also play a significant role in the on-going management of people with Crohn's or colitis. Patients can then migrate between secondary care and primary care according to the severity and complexity of their disease. In fact, at the University of Liège, Belgium, the specialist nurse links in with the primary care physician by following up each appointment with a letter to make them aware of the medications prescribed and any decisions made 11. This can be rolled out to enable a system which allows for the flow of information between primary and secondary care which can significantly reduce the burden on the patient, by allowing for local care while their disease is stable.

### **Virtual clinics**

Due to the fluctuating nature of Crohn's and colitis, a responsive and timely follow up is critical to best manage patient outcomes. In the UK, a nurse led virtual telephone follow-up clinic was trialled and questionnaires were sent to the first 50 patient's reviewed 14. Of the 34 returned questionnaires, 91% were happy with the nurse led telephone clinic, stating it met their needs. Most of these patients continued under the telephone clinic which increased the clinics capacity for patients who were in need of traditional outpatient review. This is a model that is currently being adopted locally and has the potential to deliver value to the healthcare system while improving patient outcomes.

Conclusions of a study in 2000 were that the use of the telephone helpline reduced visits to medical outpatient clinics and length of stay measured in bed days also declined, which may have been a result of the nurse enhanced outpatient support allowing earlier discharge 19.

Several patients have- in connection with flare ups of their Inflammatory Bowel Disease (IBD)- expressed lack of knowledge about their medical treatment for IBD. Some patients also admit that they have not taken all of the prescribed medication. Nurse consultations have the ability to change compliance for the patients 2. After the consultation the patients are informed of their medical treatment and they achieve knowledge of the medical treatment. The consultation gives them influence in choice of their medicine 21.

In addition, IBD nurses are best placed to ensure that patients are compliant with their treatment regime which includes turning up for appointments if required. It has been recently reported that patients failed to attend for one out of every six hospital appointments made in the health system last year. New figures show that almost 500,000 outpatient appointments resulted in a "did not attend", resulting in huge financial costs for hospitals and delays for other patients. An outpatient appointment costs an estimated €129 per person, with the cost of a "did not attend" put at €44. This could be prevented if a Nurse Specialist were in place.

## The Beaumont hospital “Better Health Better Living” programme

Chronic diseases make people more vulnerable to mental health problems <sup>23</sup> IBD has a significant impact on mental health of its sufferers, with studies showing a 30% rate of comorbid depression during remission of IBD. During relapse of the disease, over 60% of patients report anxiety and depression. In addition, in IBD depression and psychological stress have been found to have a significant impact on the disease course or are at least associated with the course of the disease <sup>23</sup>.

At Beaumont Hospital, Dublin, The *Chronic Disease Self-Management Programme* (CDSMP) was identified as a leading model of psychosocial intervention. In development since 1992 at Stanford University, studies of the CDSMP demonstrate an improvement in both the behaviours and health status of patients. The Stanford CDSMP was launched under the name of *Better Health Better Living* in 2013 in Beaumont. It is a course for people with Crohn’s and Colitis that runs over six weeks with 9 to 15 participants and two trained leaders – one of whom must have a chronic condition. Each session lasts 2½ hours and includes modules on:

- Understanding and managing common symptoms
- Cognitive strategies for managing symptoms
- Exercise methods
- Communication skills
- Nutrition
- Decision making in medical care and medication adherence.

The project covers a variety of learning topics taught through action plans, group discussion and educational lecturettes. The program includes:

- Techniques to deal with problems such as frustration, fatigue, pain and isolation
- Exercise methods
- Communicating effectively with family, friends and medical professionals
- Nutrition
- Relaxation
- Appropriate use of medication
- Decision making in medical care.

The effectiveness of the programme was assessed with pre- and post-intervention follow up assessments using questionnaires composed of three measures and a waiting-list control group <sup>15</sup>:

- **Hospital Anxiety and Depression Scale**
- Significant reduction in anxiety levels over time (treatment group 22% to 3%; control group 38% to 26%)
- **SF -36 Health Survey** Significant improvements in energy/ fatigue and general health perception in treatment group over time
- **Short Quality of Life in Inflammatory Bowel Disease Questionnaire (SIBDQ)** Statistically significant improvement on the SIBDQ in the treatment group over time

### **Access to IBD nurse led service in Ireland**

#### **Current Service:**

It is unfortunate that currently according to the Gut responses Survey, access to IBD health services is an issue for some with 34% of those patients who required an IBD nurse reporting limited or no access to such a service while 72% report inadequate access to a psychologist/counsellor. As per the UK IBD standards, the recommended number of IBD nurses is 1.5 whole time equivalent IBD nurses per 250,000 population set out in the IBD standards **10**

#### **Best Practice:**

The UK IBD Audit aimed to demonstrate the impact of the IBD nurse in terms of quality of care. The results of this revealed that there was a:

- Significant reduction in the number of patients admitted to hospital with an IBD nurse in post
- A difference in the range and choice of care delivery more patient education was offered in the presence of the IBD nurse,
- More patient involvement in service development,
- Clearer guidance for patients to seek a second opinion
- Clinical data more likely to be captured **16**

The NHS White paper states reducing avoidable hospital admissions, increasing the proportion of people with a long term condition to self-management and the ability to offer choice of care are High Level Outcomes which lead to commissionable services. The presence of an IBD nurse, within the IBD team, correlates with fewer admissions, the availability of self-management programmes and greater overall choice in care provision and new modes of care delivery **16**

The literature overwhelmingly reports positive findings in relation to the IBD nursing role. Benefits identified include **18**:

- Increased access for patients to specialist IBD nurses via telephone helplines and nurse-led clinics, especially at times of disease exacerbation

- The ability of specialist nurses to appropriately assess, investigate, modify treatment, monitor and review IBD patients via treatment guidelines; provision of emotional and physical support
- Increased patient satisfaction in a variety of areas including nurse-led management of disease, patient education and advice, and facilitation of self-help practices
- Reduction in outpatient attendances and waiting times
- Short-term effectiveness of specialist IBD nurse counselling intervention

### **Mercy university hospital Cork advanced nurse practitioner in Crohn's and Colitis:**

The Mercy University Hospital, Cork undertook an audit over a twelve week period from May to July 2013. The aim was to establish the potential impact of an Advanced Nurse Practitioner (ANP) post in working with Crohn's and colitis patients at the Gastroenterology Department.

Findings showed that 40% of patients had mild to moderate IBD and could effectively be managed by an ANP. This would result in reduced current waiting times in outpatient department, reduced A&E presentations, reduced SDU waiting lists, improved access to endoscopy as well as freeing up Consultant time to deal with more complex IBD cases. To date more than 50 patients have been admitted through triage or outpatient review who otherwise may have been admitted through A&E. In addition, the nurse spends time with each patient to ensure that they are confident in the management of their treatment and their condition

### **Conclusions**

The Colitis rate in Ireland is one of the highest in the world. With the incidence of Crohn's disease and ulcerative colitis increasing in children and young people, it has never been more important to ensure that we take action to plan and develop specialist services to meet the current and growing needs of those affected by ensuring optimal care is in place. New and innovative models of care that provide significant value for money for the healthcare system -as well as improved health outcomes for patients –are already in place for us to adapt and improve.

The Gut Decisions Report, (mentioned above) highlights some of these innovations – like the Advanced Nurse Practitioner initiative in Mercy Hospital Cork; the 'Better Health Better Living', chronic disease self-management programme in Beaumont Hospital with ISCC involvement; and the virtual clinic and electronic database initiative at St Vincent's Hospital

A critical first step in realising this plan is to achieve a commitment from the Minister that the Department of Health will carry out a rapid review of specialist IBD nursing resources in Ireland with a view to creating greater capacity and outcomes for patients through leveraging their proven expertise.

<http://www.iscc.ie/about>

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## **Irish Society for Disability and Oral Health**

People with disabilities have more untreated oral disease, missing teeth and difficulty obtaining oral health care than the general population in Ireland. Contributing factors include a lack of resources for dental services (1), limited access to General Anaesthesia (2), a lack of appropriately designed service models (3) and inconsistent and variable targeting of “Special Needs” groups across primary dental care services (4). Health Policy in Ireland has long recognized that there is a need to provide equitable health care “to disabled and institutionalized” (5). An updated, coherent National oral health strategy is currently in development (6). This new policy should lead to evidence based service models for people with disabilities and vulnerable groups (4, 6). The development of future healthcare policy gives an excellent opportunity to design and fund a service that will deliver equitable healthcare for people with disabilities in Ireland.

The Irish Society for Disability and Oral Health (ISDH) represents dental and other healthcare professionals in advocating for the oral health of people with disabilities. The ISDH advocates for the development of a strategy that delivers a range of accessible and available services that meet individual needs and lead to positive experience and optimal outcomes. This will involve the development of Managed Care Networks across services and the lifespan. These networks require improved processes of care, provision of a diverse and skilled workforce, who have access to appropriate training and the development of integrated care pathways. The ISDH suggest incentivisation of preventive and restorative healthcare for people with disabilities by recognizing the realities of providing care to the spectrum of people with disabilities and direct payment by people with disabilities. The key recommendations of the Society are summarized in Box 1.

8. When developing policy, all government policies need to be underpinned by principles of equity and health proofed, acknowledging the changing demography of the Irish population, the increasing advocacy for patient-centered care, shared decision-making and the right to cost-effective health care.
9. People with disabilities should be involved in the design and evaluation of dental services, which they use.
10. A national oral health service model with local flexibility should be developed that ensures equitable outcomes and access to a range of appropriate dental services for people with disabilities, informed by an Oral Health Needs Assessment.
11. Develop a strategy to embed integrated primary and secondary care into policy-making and service development processes, in order to place disability onto oral health agendas and oral health onto disability agendas.
12. A range of posts should be developed to create a workforce to deliver managed care networks for people with disabilities in Ireland and appropriate training in Special Care Dentistry should be available for the whole dental team.
13. Ensure that all people with a disability are offered early oral health assessment, whatever their age, as part of the wider healthcare team approach, and provided with a customized care plan that is implemented and reviewed.
14. Services should be evaluated to measure effectiveness, efficiency and patient experience

***Box 1. Key recommendations for action***

**Oral Health is important**

Poor oral health can affect how we look, feel about ourselves and enjoy our lives, grow and socialize. Oral health is so integral to general health that it is impossible to be healthy without a healthy mouth. The implications of oral disease on health can be demonstrated in the relationship between gum disease and adverse pregnancy outcomes, diabetes, cardiovascular events and stroke in susceptible subjects (7). Particularly in people with disabilities, poor oral hygiene can lead to respiratory disease, a leading cause of mortality (8). In contrast, oral health enables communication, nutrition, confidence and self esteem, among people with disabilities, promoting their participation and contribution (3).

**Oral disease is prevalent among people with disabilities**

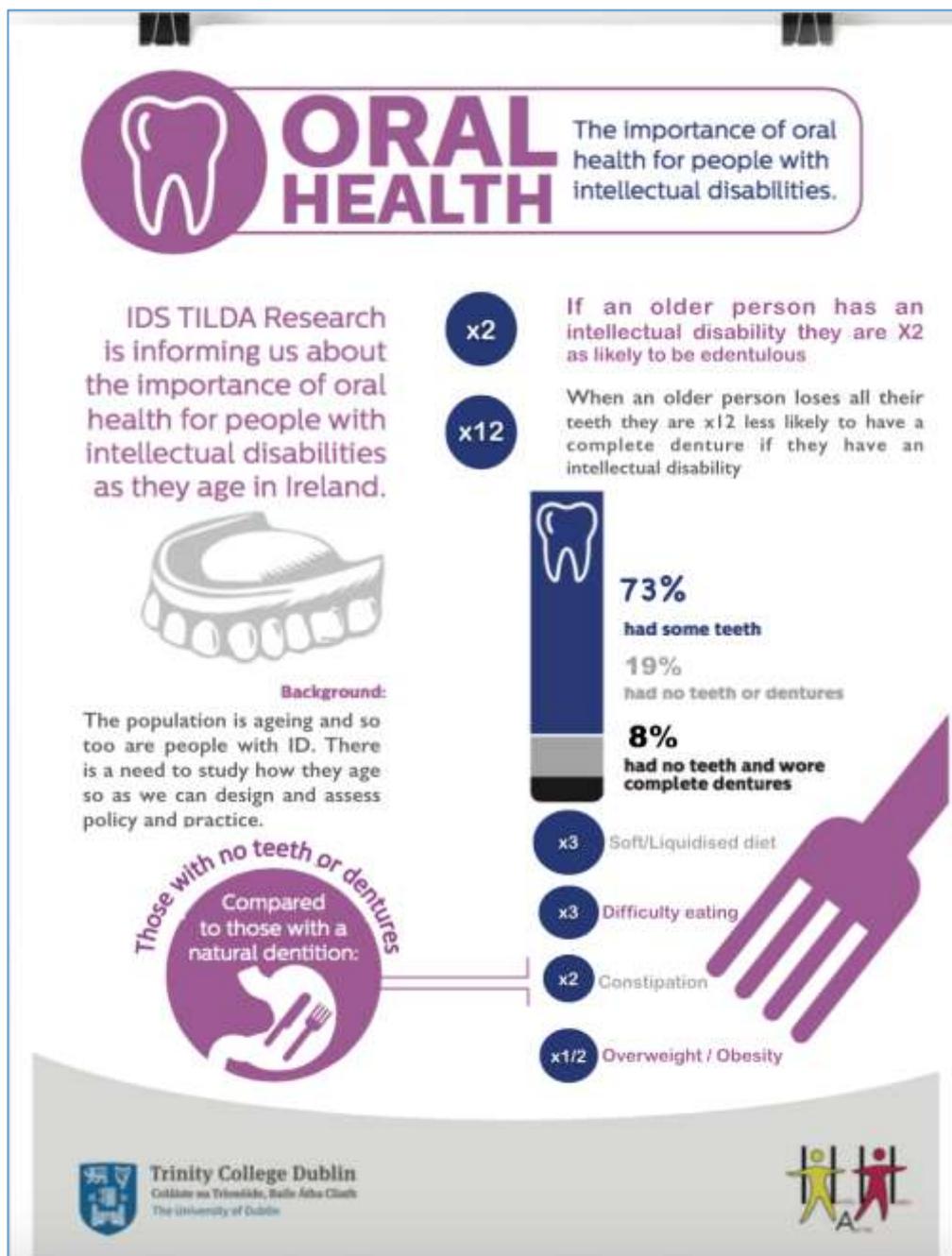
In Ireland, the oral health of people with disabilities is poorer than that of the general public. For example, people with Intellectual Disabilities (ID) are seven times more likely to have moderate or severe gum disease than the general public(1, 9). Oral health services result in poorer outcomes for those with disabilities because they are more likely to have their decayed teeth untreated or extracted, whereas people without ID are more likely to

have these treated with fillings (1, 9). Over the lifespan, the cumulative effect of the failure to prevent and manage oral disease is total tooth loss and oral disability (10). This is twice as prevalent amongst those with disabilities than the general population. Box 2 summarises evidence from the IDS-TILDA study, which explored total tooth loss amongst older adults with ID in Ireland, based on research presented at ISDH conference, Galway, June 2016.

### **Oral health services may inhibit outcomes and experience**

It is perhaps surprising that people with ID, with such poor outcomes, are found to access dental services far more regularly than those without ID, as one would assume a positive impact from frequent dental service use (11). This brings into question the benefits from accessing current services frequently. In contrast, appropriate dental care is often limited for people with disabilities. Unpublished research undertaken by the ISDH found long waiting lists for General Anaesthetic (GA) facilities nationally (Unpublished data, Irish Society of Disability and Oral Health, 2012). Reliance on GA services leads to increased waiting times, cost and treatment need (12, 13). Other barriers that contribute to access issues for people with disabilities are complex and lie mainly in addition to, rather than resulting from, the person's disability. Many access issues arise from within the structures and processes of oral health services, as they have been delivered in Ireland (1, 14-16). For example, the Public Dental Service, which is tasked with providing oral healthcare to people with disabilities (5) does so in an ad hoc manner. The proportion of Public Dental Service output, received by patients considered as having "Special Needs" varies from just 2% of overall output to 20% (4). This level of variation raises questions about the extent to which there is equitable access to services across Ireland.

**Box 2. Infographic exploring total tooth loss from the IDS-TILDA study**



**Summary**

The following sections outline the issues the ISDH feel are integral to improving Future Health Care to ensure that people with disabilities achieve equitable oral health. They are organized by heading outlined by the Committee: 1 Strategy; 2 Integrated Primary and Community Care and 3 Funding Model.

## Strategy

### Key priorities for inclusion in a ten year plan for the health service

It is crucial to identify priorities for oral health services for people with disabilities in Ireland. This will let those who plan, deliver, and use services in Ireland communicate the aims of services and also measure their outcomes. In Ireland, there is research, which has specifically looked at this crucial first step in healthcare delivery. A project called Project SMILE Ireland used an inclusive emancipatory approach to agree priorities for oral health services for people with disabilities in Ireland. A national project identified and ranked a list of priorities for oral health services in Ireland (17). This evidence should be included with further consultation to achieve a National vision for these services. Box 2 outlines the priorities agreed by oral healthcare planners, providers and service users recently.

### Box 3. Priorities for oral health services for people with disabilities in Ireland

Final Rank	Statement
1	Oral health services should raise awareness of oral health among people with disabilities, their families, carers and non-dental, health professionals
2	Oral health services should enable optimal outcomes for people with disabilities that meet individual need
3	Oral health services should be structured to enable the targeting of specific groups and deliver care based on individual need
4	Oral health services should be available and accessible
5	Oral health services should be designed using defined care pathways.
6	Oral health services should be acceptable to people with disabilities
7	Disability related training should be available to Dental Healthcare Professionals and students, appropriate to their need
8	Oral health training should be available for people, their families, carers and health professionals
9	Oral health services should be quality assured
10	Oral health services should be structured to enable frequency of care, appropriate to individual need
11	A range of Oral health services including emergency, preventive, primary and secondary care, should be available as appropriate to individual need
12	Oral healthcare should be available within an acceptable timeframe
13	Oral health services should be well resourced
14	Information and documentation should be accessible, and available in suitable formats where appropriate
15	Care pathways should be developed that allow people to choose Oral healthcare settings, appropriate to individual need
16	Oral health services for people with disabilities should be integrated both with general Oral health and non-Oral health services

### Current challenges and actions for future demographics

The key challenge currently facing oral health services in Ireland for people with disabilities is a lack of a national service model. There is therefore a need to develop a plan to deliver

equitable services. This should be developed following a National Oral Health Needs Assessment for people with disabilities. Future challenges and demographic features of Irish people with disabilities that will affect capacity and the actions required to manage these are summarized in Box 4.

**Box 4. Demographic features and actions required**

Feature	Issues	Appropriate policy response
Population with disabilities and rights	<p>The number of people with disabilities is increasing over time. Currently, between ten and twenty per cent of the Irish population report having a disability and according to the National Disability Authority, this number is growing (18). This parallels a heightened awareness of rights for people with disabilities (Ireland became a signatory of the UN Convention on the Rights of Persons with Disabilities on the 30th March 2007). The growing population of people with disabilities and the growing recognition of their rights to equitable health, mean that there is increasing pressure on the Health Services to provide equitable, quality health care. This is operationalized by part B of the Disability Act (2005).</p>	<p>Increase in capacity to deliver oral health care to people with disabilities.</p> <p>Ensure reasonable accommodation for people with disabilities by ensuring equitable outcome and access to treatment.</p> <p>The National Disability Authority has summarized actions required in this regard, previously. Many of these suggestions are still relevant today (3).</p>
Range of ability	<p>Within the cohort with disabilities, there is a spectrum of need to receive dental care from those with no additional needs and maintain their health, to those who will have massive barriers in maintaining health and accessing services (19). A contemporary definition of people requiring Special Care Dentistry is those with “a condition, disability, or activity restriction that directly or indirectly affects their oral health”. This recognises that individuals with the same medical diagnosis can have a wide spectrum of individual needs in order to receive dental care and achieve equitable oral health. The range of need within this group has implications for the design of care delivery for this group (20).</p>	<p>Build choice and options to a range of appropriate services, so as those who can access mainstream care can avail of this and those requiring secondary and tertiary care can do so accordingly (17). Therefore care networks should be able to deliver a range of care pathways depending on the needs of the individual.</p>

Older adults require additional time and care. Their treatment needs are likely to be complex. The prevalence of multiple and acquired disabilities such as arthritis, diabetes, dementia and Parkinsonism amongst our oldest is set to increase dramatically, leading to increases proportionally, of those living with acquired disabilities (21). The population with developmental disabilities is also ageing (22). Both cohorts are likely to retain their teeth for longer, meaning that oral function is challenged into older age. They may also have complex dental work to maintain and increasingly require more complex supports such as sedation, and general anaesthesia to maintain oral health and function, as they age. On top of this, social factors such as use of Long Term Care (LTC) facilities of the most frail introduce further complication in the delivery of appropriate care.

Oral health services will require a new skills mix, necessary to support this demographic. There will be a need to increase the availability of dentists skilled in the management of older adults (23). There is a need to increase the availability of and skills for dental treatment under sedation and general anaesthesia (3). There is a need to regulate the delivery of dental care to individuals in LTC facilities to ensure equity of care.

### **Integrated primary and community care**

For the majority of people with disabilities, oral/dental care delivered in the community, alongside their peers, is the preferred option. This is, provided that there is early assessment and access to appropriate services where necessary. For a minority, care within and across secondary or even tertiary clinical services will be required constantly or intermittently, in a shared care model. Similarly, some people will best attend publicly funded services and others may seek private dental care. This range of need means that a suite of care pathways are required constituting preventive care, routine care in both general and public dental services, specialist care and access to supports such as IV sedation and general anaesthetic. Therefore the ISDH recommends that policy leads to development of such integrated care pathways, so as patients can navigate services seamlessly.

### **A Model of good practice in integrated primary and community care**

Good practice in Special Care Dentistry (SCD) dictates that there is sharing of resources to greatest effect. The concept of managed clinical networks (MCNs) promotes this with mutual sharing of expertise, so that by professionals collaboration, patients receive appropriate care in a timely way (24). Such a network has been in place in Wales since 2012.

The membership of this network includes specialist and consultants in in SCD as well as other clinical disciplines, the wider oral healthcare team, managers of services as well as staff from postgraduate education centres and lay people. Such a construct enables sharing across health and other departmental boundaries for more effectual service delivery. Some of the advantages of this approach are listed in Box 5 (25).

**Box 5: Examples of outcomes from Managed Clinical networks in Wales 2012**

6. Review of workforce and services in a geographic area and identification of gaps in service provision
7. Development of dental referral pathways for adults requiring SCD, identifying the roles within the pathways from primary dental care teams through to consultants as well as more specific pathways, for example domiciliary and bariatric care pathways
8. Provision of local and regional information for patients
9. Development of training (and mentoring) of specialists and continuing professional development in SCD for the dental and wider multi-professional team
10. Establishment of MCN webpages and the mapping of information for the public and dental teams

**Integrated care across the lifespan**

As people with disabilities transition over their lifespan, oral health services should be designed to support people at these transitions. There is good evidence from Ireland that oral/dental disease becomes prevalent after three years of age (26) and that intensive preventive programmes can contain this (27). As vulnerable children transition into adulthood, a purposeful, planned movement to adult-orientated health care systems is required. With a focus on the person, throughout a lifetime, seamless, inter-agency collaboration has the potential to have a cumulative, additive and even multiplicative impact on health outcome in older age (28).

**Model of funding**

The majority of patients with disabilities receive dental treatment in the primary care setting, with approximately 20% requiring dental treatment under general anaesthesia, in a hospital-setting (1). Primary care dental services are provided either by general dental practitioners working in the Public Dental Service or in private dental practices, subsidized

by the DTSS scheme. There are also a proportion of patients with disabilities who receive self-funded private dental care. A number of issues have been identified with current dental service provision in Ireland resulting from funding deficits. Namely these include staff shortages in the public dental services, and the removal of funding for preventive dental treatment within the DTSS framework (29). These issues are likely to have impacted detrimentally on the oral health of patients with disabilities. Additionally, for those patients requiring specialist care, outside the remit of community care, there is an unclear referral pathway in Ireland (30) resulting in inequitable access to tertiary services Nationally (31).

### **Incentivize preventive and restorative treatment with appropriate supports**

Evidence based clinical guidelines state that health promotion and preventive care must be prioritized and services should promote preventive services for health gain, away from curative and clinical services (32). Effective preventive care can potentially save money by avoiding costly medical interventions for dental treatment, such as the use of general anaesthesia (31). Currently under the DTSS system payments for dentists are only available for clinical procedures, not preventive procedures. This means that many people with disabilities do not receive appropriate preventive dental care, which could prevent oral disease and the need for intervention. In addition, people with disabilities may require behavioural adjuncts, extra time or varying forms of sedation, at specific times or for specific procedures, in order to receive successful dental care. These adjuncts are not covered by current reimbursement schemes.

### **A tool to weight payments based on complexity rather than diagnosis or item of treatment**

The current extension of the DTSS scheme for individuals with specific medical conditions or disabilities (HSE 2010), whilst increasing the range of care available to a vulnerable group, is based on the medical model of disability. This means that entitlement to care is based on a medical diagnosis, instead of individual need, which can increase the time taken the cost to provide treatment. In the UK context the BDA Case Mix Tool (30) was developed as a commissioning tool. Case mix tools are used throughout medical service planning to take into account the characteristics of patients within a particular setting to predict and

distribute resources (33). A case mix model can aid commissioners and providers of dental services for people with disabilities to understand the challenges of caring for this patient group, in order to allocate appropriate funding. Indeed, emerging research has shown the BDA Case Mix Tool to be a reliable measure of cost of treatment for people with disabilities in UK.

## Summary

This document outlines the ISDH position in advocating for people with disabilities to maintain their oral health, function and independence.

Dr. Caoimhin Mac Giolla Phadraig, President of ISDH on behalf of the Irish Society for Disability and Oral Health

<http://isdh.ie/>

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## Irish Society for Prevention of Cruelty to Children

The ISPCC is pleased to make this submission to the Committee on the Future of Healthcare. As the national child protection charity, providing services to children all over Ireland, the ISPCC is well placed to provide insight into the experiences of some of the young people accessing health services. Identified roadblocks in accessing services and subsequent recommended priorities for the Future of Healthcare Plan have been addressed within the context of ISPCC's vision, mission and objective, as defined by its own strategic plan and within current policy contexts.

These are grounded in the principles of the UN Convention on the Rights of the Child.

Listed below are the ISPCC's key recommendations for consideration by the Committee for inclusion as priorities in the Future of Healthcare plan. These are based on;

- Our expertise as providers of services along the mental health continuum to children, and the direct information we receive from the 1,200 contacts a day from children in Ireland to our Childline service.
- Existing commitments in policy documents such as *A Vision for Change*,
- Principles in international law, such as the Convention on the Rights of the Child, and the key issues relating to health which were raised by the International Monitoring Committee on the Rights of the Child when Ireland gave its most recent report on its progress under the Convention on the Rights of the Child, in January 2016.

### **The ISPCC's Recommendations to the Committee are:**

1. Use this welcome reform agenda to deliver lasting change in the provision of health services to children in Ireland, by placing the voice of the child at the heart of health policy and practice. This will require fundamental and positive reform to how decisions are made, to resource planning and to skills development.
2. Establish a stand-alone fully-resourced national drug and alcohol rehabilitation service for children and young people which would allow consistently applied professional standards for treating children with addiction.
3. Implementation of the policies set out in *A Vision for Change* should be continued and in doing so, such policies should be tested against more recent data, evidence and best practice.
4. Ensure the recommended resources and staffing for the Child and Adolescent Mental Health Service (CAMHS) (as recommended by the current mental health strategy document *A Vision for Change*) to ensure that;
  - a. The needs of young people in need of CAMHS support are not further compounded by unacceptable waiting lists and
  - b. No matter where in the country a young person may be they have access to timely and appropriate mental health support.
5. Broaden the current referral pathway protocols to include other relevant professionals whose expertise and relationship with the child in need qualifies them to make a referral to CAMHS.

6. Undertake a review of current structures of service integration and communication across multiple agencies, most specifically between Health Service Executive, TUSLA and CAMHS to determine how best children's needs can be met.
7. Make a commitment to a child/person-centred approach in all interactions with children and families, placing the child's best interests at the heart of all interventions. Training and awareness raising for all relevant staff should be provided.
8. The voice of the child must be heard in all matters relating their care and treatment. This may be done in accordance with a child's age and maturity. An obligation must be placed on all medical and therapeutic professionals to meet and engage with all children before deciding on any course of treatment or intervention.
9. Establish a directly accessible 24-hour social work service for children and families across Ireland.
10. Eliminate the disparity between consent for medical and mental health treatment and implement the Expert Group's recommendations for children in mental health legislation.
11. The principle of placement of children in appropriate psychiatric units must be adhered to at all times. This will require an increase in the number of beds available in CAMHS inpatient units across the country to ensure that no child should be admitted to an adult unit, and no bed days spent in an adult unit, even in the short term.
12. Implement in full the Children First Act and ensure that all relevant staff are fully trained in child protection protocols.
13. Reinstate the publication of a comprehensive CAMHS Annual Report.

## **Introduction**

The ISPCC (Irish Society for the Prevention of Cruelty to Children) is the national child protection charity<sup>539</sup>. It provides a range of child-centred services including childhood support services, family support services and mentoring, all of which are focused on building resilience and coping skills. These services support children and young people and their families to develop their own skills and enable them to deal with challenges and situations in their lives, and to promote their well-being.

The ISPCC provides Childline, Ireland's only 24-hour listening service for children and young people. It is free, confidential and non-judgemental, providing support to children across Ireland. In 2015, we answered over 420,000 contacts from children and young people.

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<sup>539</sup> Further information about ISPCC services and financial statements can be found in the most recent Annual Report 2015 <http://www.ispcc.ie/campaigns-lobbying/publications/-ispcc-annual-report-2015/14783>

## **Our Vision**

An Ireland where all children are safe, heard, and valued.

## **Our Mission**

To make the protection of children everyone's priority

## **Our Work**

We listen, we support, we protect.

The ISPCC has confined its commentary to areas specifically within the scope of its vision, mission and objective, as defined by its own strategic plan. Issues within this submission have been addressed within this and current policy contexts.

Reform of the health service in Ireland is an enormously important proposition, with far-reaching consequences for the long-term health of the population. The recommendations made if acted upon will resonate for a generation, if not longer.

The population of Ireland under the age of eighteen stands at about one quarter of the total population. Too often in the preparation of reports and of legislation, and in committee hearings, the voice of the child is absent. This must not be the case in this process. The ISPCC would welcome the opportunity to further discuss these issues with the Committee, and to ensure that the voice of the child is given the audience it deserves in the preparation and the final content of the Committee's report.

## **Policy Context**

### *United Nations Convention on the Rights of the Child*

#### Article 3 – the best interests of the child

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

#### Article 12 – The child's opinion

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

#### Article 24 – Health and Health Services

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

#### Article 33 – Drug Abuse

States Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.

#### *UNCRC Concluding Observations*

In its recent review of Ireland's progress in the area of children's rights, in January 2016, the UN Committee on the Rights of the Child<sup>540</sup> made the following recommendations in the area of mental health;

54 . *The Committee recommends that the State party:*

- (a) *Enact legislation that explicitly and comprehensively provides for children's consent to and refusal of medical treatment, and ensure that this legislation should be in line with the objectives of the Convention and encompass clear recognition of children's evolving capacities;*
- (b) *Undertake measures to improve the capacity and quality of its mental health services for children and adolescents; in doing so, the State party should prioritise strengthening the capacity of its mental health services for in-patient treatment, out-of-hours facilities, and facilities for treating eating disorders; and,*
- (c) *Consider establishing a mental health advocacy and information service that is specifically for children, and accordingly accessible and child-friendly.*

#### *Better Outcomes Brighter Futures*

*Better Outcomes Brighter Futures: The national policy framework for children & young people 2014 - 2020*<sup>541</sup> has a vision for Ireland to be one of the best small countries in the world in which to grow up and raise a family, and where the rights of all children and young people are respected, protected and fulfilled; where their voices are heard and where they are supported to realise their maximum potential now and in the future. One of its five national outcomes is that children and young people are active and healthy, with positive physical and mental well-being.

#### *A Vision for Change 2006–2016*<sup>542</sup>

This policy makes important recommendations for children: for improving and expanding mental health services for children including addressing the glaring gap in provision for 16 and 17 year-olds; for promoting emotional well-being and the prevention of mental health

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<sup>540</sup> <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/039/97/PDF/G1603997.pdf?OpenElement>

<sup>541</sup> [http://www.dcyh.gov.ie/documents/cypp\\_framework/BetterOutcomesBetterFutureReport.pdf](http://www.dcyh.gov.ie/documents/cypp_framework/BetterOutcomesBetterFutureReport.pdf)

<sup>542</sup> <http://health.gov.ie/future-health/reforming-social-and-continuing-care-2/mental-health-a-vision-for-change/a-vision-for-change/>

difficulties; and for cross-departmental action, in particular regarding the crucial role of the formal and informal education system.

### **Key Principles for Policy Reform**

While many areas of Ireland's health system are reactive and in some cases in crisis, before undertaking reform of both policy and service a commitment to the following principles must be made.

#### **Voice of the Child**

A commitment must be made in the development of health care policy to place the child at the centre, to listen to the child's voice and to pre-empt and prepare for the impact of any policy on the child. A considered and broad approach must be taken to this, for example not only considering the impact on children in services provided directly to children but within any healthcare services being accessed by parents, including post-partum care. This principle of considering the voice of the child when developing services must be committed to at every level of service delivery; from recruitment and training right through to implementation and evaluation. Both the UNCRC and the Irish Constitution recognises children as individual rights holders and these rights must be to the front and centre of all policy decisions and service development.

#### **Prevention and Well-being**

In any policy reform there must be a commitment to sustaining and the growing practice of prevention and early intervention. A more effective balance must be struck between a system which responds to need in times of crisis, and a system which promotes proactive mental health and well-being. Investment in ongoing proactive mental health care delivers greater value for money in the long term. Investment and innovation in population health approaches deliver long term results, and children must be included and planned for in this regard.

#### **Access to Healthcare as a fundamental right**

Access to quality and effective healthcare and intervention is a fundamental right of all children, irrespective of the background or characteristics of the child. This principle should include access to mental health services for children and young people who are addicted to drugs and alcohol. It is of continued concern to the ISPC that young people struggle to access services on the basis of their addiction.

In any reform of the health system, a system of universal access to treatment and care, and universal access to a high standard of environment, based on need rather than ability to pay is a fundamental requirement.

#### **Investment in Children**

The long term benefits to children, to families, to society of early intervention are well documented.

The inverse is also true. The long-term damage of a failure of timely medical intervention, whether relating to acute, chronic management or as is frequently seen, in the mental health services is often forgotten. There is an urgent need to embrace the principles of early intervention across the health services and to relate this specifically to children.

### ***Roadblocks to Services & Recommended Priorities for Future of Healthcare Plan***

The ISPCC through its policy work and providing services to children and families has encountered and identified a number of key roadblocks in various parts of the health service, particularly in relation to child and adolescent mental health and well-being and drug and alcohol rehabilitation. These, as well as recommended priorities for inclusion in the health care plan are outlined below. These recommendations should be considered in addition to the Principles for Policy Reform outlined above.

***There is no nationally available drug and rehabilitation support service for young people under the age of 18.***

**Recommendation for Future of Healthcare Plan:** Establish a stand-alone, fully resourced national drug and alcohol rehabilitation service for children and young people which would allow consistently applied professional standards for treating children with addiction.

The ISPCC is aware of a high level of substance misuse among young people all around Ireland; in 2015 over 3,800 contacts to Childline were relating to alcohol or drug misuse. Despite these figures, there are very few options for young people to avail of support and a lack of clear referral pathways. Access to rehabilitation services is inconsistent, patchy and in some cases dependent on the value judgement of others. The ISPCC's team in the North East is aware of young people having to attend Oberstown to undergo detox due a lack of beds. These inconsistencies are unacceptable; young people in need have a right to these services.

The ISPCC has a dedicated Childhood Support team in the North East of the country, working solely on the issue of drugs and alcohol and young people. Last year, through consultation with adult services the ISPCC and the North East Regional Drugs Task Force identified over 100 additional young people in the North East Region aging from 12 to 17 who requested help for their substance misuse. In the experience of ISPCC Childhood Support workers, in the absence of specific HSE services many youth support and community based services are reluctant to engage with young people dealing with substance misuse and addiction due to a lack of knowledge and fear of the implications.

It has come to the attention of the ISPCC that in the absence of dedicated distinct rehabilitation services for under-18s, some young people suffering with addiction have been refused detox outright while others have been forced to make poor decisions such as engaging in criminal behaviour in order to receive appropriate support while serving judicial sentences.

Once a young person reaches the age of 18 they may then access a suite of resources that can help with their addiction. Many towns in Ireland have some form of adult addiction service run either through the Health Service Executive, the Regional Drugs Task Forces or on a voluntary basis. The ISPCC is aware of cases of 17 year olds with addiction issues being told to wait until they turn 18, when services will be available to them.

In some cases the ISPCC has contacted the HSE on behalf of specific clients in the North East who have presented with addiction issues. This has proven effective in some instances; a 17 year old girl was initially told to wait until she turned 18 before she could be seen however following the ISPCC's efforts the HSE has agreed to see under 18s and if assessment indicates a need for in-patient treatment, this may be provided.

***A Vision for Change has not been implemented fully within its designated timeframe***

**Recommendation for Future of Healthcare Plan:** Implementation of the policies set out in *A Vision for Change* should be continued and in doing so, such policies should be tested against more recent data, evidence and best practice.

*A Vision for Change* is the current national mental health strategy, and its implementation has been slow and behind pace. The vast majority of the recommendations and practices in *A Vision for Change* remain valid; however, it is worth noting that the report was published in 2006 and that the data and evidence on which it is based is now more than ten years old. In this context, it is important that as change is brought about, in accordance with *A Vision for Change*, it is tested against more recent data and evidence, with new developments in international best practice built in.

***The current situation of inconsistent service provision and long waiting times for assessment and intervention with Child and Adolescent Mental Services is unacceptable***

**Recommendation for Future of Healthcare Plan:** Ensure the recommended resources and staffing for the Child and Adolescent Mental Health Service (CAMHS) (as recommended by the current mental health strategy document *A Vision for Change*) to ensure that;

- a. The needs of young people in need of CAMHS support are not further compounded by unacceptable waiting lists and
- b. No matter where in the country a young person may be they have access to timely and appropriate mental health support.

In April 2016 it was reported<sup>543</sup> that 214 young people were waiting more than 12 months for a Child and Adolescent Mental Health Services (CAMHS) appointment while 1,075 were waiting longer than three months. For young people without appropriate support their difficulties may worsen as they wait; this can be extremely distressing for both the young person in question and their parents/carers. In addition, there is no one person or agency responsible for caring for young people who are awaiting assessment or intervention.

The availability of services is patchy across the country and in some cases there is still a specific lack of sufficient mental health services for 16 and 17 year olds. At the end of 2014 it was reported<sup>544</sup> that the number of clinical staff in post in CAMHS was 521.5 whole time equivalents; this is 51.6% of the level recommended in *A Vision for Change*.

- While the HSE has published figures indicating that the numbers of young people waiting more than 12 months for an appointment are decreasing, the ISPCC is aware of some young people who have had to wait up to 18 months for a CAMHS appointment.
- A client of ISPCC Childhood Support service who was in urgent distress waited four weeks for an emergency appointment with CAMHS. Emergency appointments are required where a child is in crisis and there is a serious concern for his/her wellbeing. Such appointments should be made available swiftly and in response to a child's specific needs.

<sup>543</sup> <http://www.hse.ie/eng/services/publications/performance/marchaprpr.pdf>

<sup>544</sup> <http://www.childrensmentalhealth.ie/wp-content/uploads/2015/03/Children%E2%80%99s-Mental-Health-Coalition-report1.pdf>

- A former ISPCC Childhood Support service client having previously accessed CAMHS was re-referred back to CAMHS due to a concern that she was anxious, suffering extreme fears and low mood. This young person had to attend her GP to request this referral which resulted in being re-waitlisted; effectively put to the back of the queue before receiving further support.

The impact of constrained resources in this area directly affects other services. ISPCC Childhood Support service workers report increased complexity in their caseloads, as a direct impact of pressure on mental health services. The knock-on impact is that the ISPCC receives referrals for children who are in need of mental health services, and in turn is less able to accept referrals from children with less acute needs, who would benefit from prevention and early intervention services. As a result, the limited resources that are available are not always resulting in the right children receiving the right services.

***The referral pathway to access Child and Adolescent Mental Services is too limited***

**Recommendation for Future of Healthcare Plan:** Broaden the current referral pathway protocols to include other relevant professionals whose expertise and relationship with the child in need qualifies them to make a referral to CAMHS.

In the current system, if a child presents with any form of mental health difficulty, be that experiencing suicidal thoughts or self-harming, a referral for further specialised and assessment and support via Child and Adolescent Mental Health Services is required by a General Practitioner (GP). Disclosing personal feelings, particularly when in a vulnerable state can be hugely challenging for young people and may be more difficult again when it is necessary to disclose to someone who is not well known to the young person. Young people accessing support services and engaging with other professionals very often have built up trust and rapport and are comfortable discussing their feelings and thoughts. It would be hugely beneficial to young people such as these if the referral pathway to CAMHS was broadened to include other professionals such as guidance counsellors, childhood support workers and other relevant professionals. This approach would place the child at the centre of the process and allow them to seek the right support through whichever avenue they have come to trust.

It was noted in a recent report by the Children's Mental Health Coalition that in some parts of the country CAMHS teams may accept a referral without GP sign-off; this has resulted in some confusion and inconsistent service provision<sup>545</sup>. While this broadening of referral pathway would be welcomed, clarity is needed to ensure that those in need of CAMHS intervention can access it.

A further issue with GP as the only referral pathway has been communicated to the ISPCC on numerous occasions via the Childline service. While any young person may attend a GP without parental consent from the age of 16 years, this service is not free and as a result may be a barrier for some young people accessing adequate and suitable support. Allowing for referrals to come from other professionals, some of whom may be providing free support services would contribute to removing this barrier.

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<sup>545</sup> Anecdotal evidence from the Children's Mental Health Coalition indicates that some CAMHS around the country only accept referrals via medical professionals while others do not require this. <http://www.childrensmentalhealth.ie/wp-content/uploads/2015/03/Childrens-Mental-Health-Coalition-report-final.pdf> pg. 9

***There is a lack of integration and cooperation between services and agencies and as a result many young people are not being provided with support specific to their needs***

**Recommendation for Future of Healthcare Plan:** Undertake a review of current structures of service integration and communication across multiple agencies, most specifically between the Health Service Executive, TUSLA and CAMHS to determine how best children's needs can be met.

Appropriate and timely service delivery is imperative when it comes to meeting the mental health needs of young people. A key roadblock in achieving this is inadequate inter-agency communication and lack of integration of services. This issue was highlighted again most recently in the reports published by the National Review Panel in August 2016<sup>546</sup> which indicated a lack of communication and coordination where multiple professional services and departments are involved. Health (including mental health and disabilities) and child protection services sitting in separate departments is reportedly causing difficulties in terms of budgeting and coordination.

Some children have communicated to the ISPCC that upon discharge from CAMHS no other avenues of support were explored with them and they were effectively left without any other support; low-level, at community level or otherwise.

Teenage boy D presented with low mood, was self-harming and was in a relationships with a teenage female that was cause for concern. He has recently been accused of sexually assaulting another female his age and comes from a background of alcohol abuse and maternal mental health issues. He was also suffering with an eating disorder. CAMHS met with him twice and reported that the issues he was experiencing were a reaction to recent life events as opposed to as a result of mental ill-health. He was discharged without further or alternative support being offered for the difficulties he was experiencing.

***There is a lack of child/person-centred approach in some hospital and mental health services***

**Recommendation for Future of Healthcare Plan:** Make a commitment to a child/person-centred approach in all interactions with children and families, placing the child's best interests at the heart of all interventions. Training and awareness raising for all relevant staff should be provided.

In most if not all cases, young people who are in need of medical or psychological intervention may already be in a vulnerable state. The best interests of the child should be central to all interventions and services interacting with children and young people and this should include child-centred approaches, allowing for the difficulty a child may have in engaging with services, and any circumstances over which they have no control which may impact on their ability to engage. Placing children at the centre of planning, assessment and intervention ensures that the child gets the best out of any approach which can be tailored to suit his/her specific, individual needs.

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<sup>546</sup> <http://www.tusla.ie/national-review-panel/individual-reports>

In some cases known to the ISPCC young people have felt unable to fully participate in interventions due to feeling disconnected from the process. In addition, some parents have reported feeling judged and in some cases blamed for their child's behaviour/diagnosis.

One young person, "E" was experiencing higher levels of anxiety and anger management issues. A referral to CAMHS was made by a GP and this referral was subsequently rejected by CAMHS. The reason given for this was that the child's parent had not engaged with CAMHS following a previous referral.

Other issues which have been communicated to the ISPCC by young people accessing its services include:

- Several children accessing ISPCC services have said they have found CAMHS to be quite clinical with no opportunity to allow for the building of trust or rapport with their contact.
- Young people have reported that the level of interaction with their contact is often limited and the link in time with service is often short term.
- Some young people have reported feeling judged and distrustful of health professionals with some callers to Childline stating that they have felt judged by the staff in A&E, when they have presented having self-harmed or some cases attempted suicide. In one case a medical professional told parents that the child was 'attention seeking'.

#### ***Voice of the child absent from assessments and interventions***

**Recommendation for Future of Healthcare Plan:** The voice of the child must be heard in all matters relating to their care and treatment. This may be done in accordance with a child's age and maturity. An obligation must be placed on all medical and therapeutic professionals to meet and engage with all children before deciding on any course of treatment or intervention.

In any assessment or intervention a child must be recognised as the expert on his/her own feelings. It is imperative that the young person be not only listened to but consulted on the plan for their care. Listening to the voice of the child, allowing them to share their experience and what they are going through is imperative to identifying the best course of treatment/intervention.

A teenaged boy K who was linked in with the ISPCC had become withdrawn and depressed following the deaths of two close family members. He was displaying challenging behaviours, violent outbursts and had stopped eating. His parents engaged with CAMHS and were told that no mental health issues were identified here and that K's behaviour was as a result of parenting. As K was not currently residing in the family home his parents were advised by CAMHS to take particular courses of action to bring him home. This was met with resistance from K and resulted in a physical altercation. Subsequent similar incidents occurred over the proceeding months and in that time CAMHS did not meet with K.

Some parents engaging with the ISPCC have indicated that full explanations of the assessment or the conclusions drawn as to why a particular course of action has been

decided upon is not always provided either to them or the child; whether this be the prescription of medication, a particular course of therapy or the decision to discharge.

***There is no directly accessible 24-hour social work service for children and families***

**Recommendation for Future of Healthcare Plan:** Establish a directly accessible 24-hour social work service for children and families across Ireland.

A directly accessible 24-hour social work service is essential for both crisis and early intervention in child protection and welfare concerns as well as family support. The ISPCC's experience of working with children and families demonstrates that there needs to be a more effective balance between a system which responds to need in times of crisis, and a system which promotes proactive family support and mental health. The ISPCC welcomed the introduction of a national Out-of-Hours Social Work Support Service to An Garda Síochána in early 2016; this is a positive first step however it is not sufficient. The ISPCC believes that such a 24-hour service must be directly accessible to children and families.

The recent annual report from TUSLA<sup>547</sup> shows the level of need among children and young people merits a directly-accessible 24-hour social work service for children and families.

The ISPCC Childline service received over 420,000 contacts in 2015. The majority of contacts are received out-of-hours, indicating support is needed outside of the traditional social work support systems of Monday to Friday, nine to five.

***Disparity of ages of consent for treatment***

**Recommendation for Future of Healthcare Plan:** Eliminate the disparity between consent for medical and mental health treatment and implement the Expert Group's recommendations for children in mental health legislation.

As touched on above, young people aged 16 years and over are permitted to give their consent for medical treatment. In the case of mental health treatment any person under the age of 18 must have consent from parents. This disparity may be challenging for some young people seeking CAMHS support, via their GP, as required. In 2015, the Report of the Expert Group Review of the Mental Health Act, 2001<sup>548</sup> was published. This Expert Group recommended that children aged 16 and 17 should be presumed to have capacity to consent/refuse admission and treatment.

A number of other recommendations pertaining to children were made by the Expert Group including that provisions relating to children should form a stand-alone part of the Mental Health Act and that advocacy services for children and families of children in mental health services should be made available.

***Young people being admitted to adult psychiatric units***

**Recommendation for Future of Healthcare Plan:** The principle of placement of children in appropriate psychiatric units must be adhered to at all times. This will require an increase in the number of beds available in CAMHS inpatient units across the country to ensure that no child should be admitted to an adult unit, and no bed days spent in an adult unit, even in the short term.

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<sup>547</sup> [http://www.tusla.ie/uploads/content/Tusla\\_Annual\\_Report\\_2015\\_WEB.PDF](http://www.tusla.ie/uploads/content/Tusla_Annual_Report_2015_WEB.PDF)

<sup>548</sup> <http://health.gov.ie/blog/publications/report-of-the-expert-group-review-of-the-mental-health-act-2001/>

While improvements are being made in the cessation of placing young people under the age of 18 in adult units, figures from the HSE<sup>549</sup> show that this practise is still occurring. Many of these children are already in a vulnerable position and placing them in a setting not specific to their needs is unacceptable.

### ***Implementation of Children First***

**Recommendation for Future of Healthcare Plan:** Implement in full the Children First Act and ensure that all relevant staff are fully trained in child protection protocols.

All services and agencies have a role to play in protection children. Clear and robust child protection policies must be in place and all staff must be well-briefed on protocols for responding to any child protection concerns. The ISPCC continues to call for urgent implementation of all aspects of the Children First Act. If Ireland is to meet its obligations to children the national standards on child protection must be placed on a statutory footing. It is essential that the protection of children is recognised as everyone's priority.

### ***CAMHS reporting***

**Recommendation for Future of Healthcare Plan:** Reinstate the publication of a comprehensive CAMHS Annual Report.

The most recent comprehensive annual report from Child and Adolescent Mental Health Services was published in 2014. This report outlines progress made in CAMHS in line with Government commitments and policies. Basic figures regarding admission of children to CAMHS units and the number of children on waiting lists are published throughout the year via HSE Performance Reports. This information is not comprehensive and does not adequately illustrate the developments or indeed the shortfalls in CAMHS which may require additional policy decisions and resourcing. A culture of transparency and accountability must be undertaken if services are to meet the needs of young people and be fit for purpose.

### ***Conclusion***

The recommendations which have been set out in this document if acted upon will resonate for a generation, if not longer, and ensure a health system that is inclusive and person-centred. The ISPCC appreciates the opportunity to make a submission to the Committee to provide insight into the experiences that many young people have had accessing the health service. The ISPCC would very much welcome the opportunity to address the Committee further to ensure that the voice of the child is given the audience it deserves in the preparation of the Committee's report.

If any further information is required please don't hesitate to get in contact.

Lisa Collins

Policy Co-Ordinator, ISPCC [lcollins@ispcc.ie](mailto:lcollins@ispcc.ie) Ph: 01 2342024

<https://www.ispcc.ie/>

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<sup>549</sup> <http://www.hse.ie/eng/services/publications/performance/marchaprpr.pdf>

## Irish Society of Chartered Physiotherapists

The Irish Society of Chartered Physiotherapists (ISCP) is the sole professional body for chartered physiotherapists in Ireland. It is the Member Organisation for Ireland on the World Confederation for Physical Therapy (WCPT) which is the world professional body for physical therapists/physiotherapists.

As such it is a major stakeholder in regard to health care provision, reform and models of delivery.

The ISCP advocates for the provision of a person-centred quality service that is accessible, effective, and humanitarian while advancing health and social gain.

*Physiotherapy provides services to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan. This includes providing services in circumstances where movement and function are threatened by ageing, injury, pain, diseases, disorders, conditions or environmental factors.(WCPT 2011)<sup>1</sup>*

Physiotherapy is an effective, comparatively low-cost, value for money high quality option. The benefits of social inclusion, prolonged independence and quality of life justify the costs when treatment is adequately provided, within an integrated care structure. It can lead service innovation, improvement and integration to maximise quality, productivity and patient choice by co-ordination of available resources. Physiotherapy services can be provided in a variety of settings that ensure timeliness and accessibility and that optimise impact and benefit for individuals' health and well-being.

As autonomous practitioners who can manage the continuum of care for many conditions, physiotherapists are well positioned to face the challenges of evolving health needs and care models in Ireland. In addition, those working in advanced practice are extending boundaries of practice in areas that were once the preserve of other health professionals. This increasing flexibility in delivery of new and extended services results in better patient outcomes and experiences and fits in with the integrated care model.

The evidence for positive health outcomes and the cost effectiveness of physiotherapy is included throughout the submission.

The ISCP supports in principle the universal single tier health service but has reservations about its implementation. It fully supports the Integrated Care Model. The submission focuses specifically on the questions asked by the Committee (in red). It draws largely from two documents; Optimising Physiotherapy Services in Ireland (ISCP 2015)<sup>2</sup> and Budget Submission to Government 2017 (ISCP 2016)<sup>3</sup>

<http://www.iscp.ie/>

## 1. Strategy

The ISCP has identified seven main priorities.

### PRIORITIES 1-3

A healthy population achieved through a health service that delivers the highest quality care combining the medical model with the biopsychosocial approach to health and well-being

A paradigm shift in emphasis, in both approach and resourcing, to prevention

A partnership (client centred) approach to health care.

The World Confederation for Physical Therapy (WCPT) states the physiotherapy profession is uniquely qualified to have an impact on the growing global epidemic of diseases related to lifestyle<sup>4</sup>. Physical inactivity is now identified as the fourth leading risk factor for global mortality<sup>5</sup>. The benefits of regular physical activity on primary and secondary prevention of several chronic diseases, many of which are lifestyle related, and lowering the risk of conditions such as depression, metabolic syndrome, colon cancer and breast cancer are now widely established<sup>5</sup>. The evidence also suggests a relationship between physical activity and reduced risk of falls in the older population<sup>5</sup>. As a result of the overwhelming evidence for physical activity, the focus has now moved to identifying evidence for optimal doses. Physiotherapists are the health professionals with the expertise in prescribing exercise for health as part of a structured, safe and effective programme. Combined with their training in the health promotion approach of involvement and empowerment, they are well placed to enable individuals to adopt a healthier lifestyle through optimal physical activity.

There is a need to increase focus on prevention through health promotion by;

- Promoting healthy living - with the aim of achieving illness prevention
- Delivering accessible services responsive to population needs
- Placing emphasis on quality of life; addressing health inequalities
- Early intervention which is a key factor in determining successful outcomes for patients.
- Early diagnosis and effective management of conditions in early stages of disease
- Roll out of effective screening programmes (Women who have already been treated for breast cancer should not be excluded from the free screening programme).
- Helping individuals to manage their symptoms
- 'Fit for work' initiatives

Health Promotion is not one-off initiatives, but rather is a systematic approach by dedicated trained staff. To be effective, all initiatives must include empowerment and participation and must bring about sustained and meaningful behaviour change.

Physiotherapy is a key component of health promotion with programmes in primary care e.g. mental health, bone health, obesity, chronic disease management including COPD, diabetes, cardiovascular conditions, frail elderly at risk of falls, palliative care, chronic pain and fatigue. In general, these programmes deliver self-management strategies, education and evidence based exercise prescription.

Physiotherapists as the health professionals with the expertise in movement and exercise throughout the lifespan across the health spectrum (WCPT) <sup>4</sup> can:

- Provide support for those managing mainstream exercise options for non-complex conditions;
- Promote wellness in those with, and at risk of, chronic disease;
- Prescribe safe exercise for those with morbidity and co-morbidity;
- Facilitate every service user to achieve improved health through participation in exercise; and
- Undertake screening in the areas of bone health and neurodevelopment in children and a preventative role in falls risk, obesity, low back pain and continence.

Physiotherapists should be the first point of referral for Health and Wellbeing related pathways such as the GP Exercise Initiative. They are well placed to design, train others to provide, and evaluate exercise programmes. The Northern Ireland Health Department outlined the role of Allied Health Professions in improving Health and Well-being through partnerships<sup>6</sup>, the 10-year Health Plan should include a similar approach.

The Health Plan needs to focus on prevention, the biopsychosocial model and client centred care in order to improve population health and reduce reactive and inefficient costs.

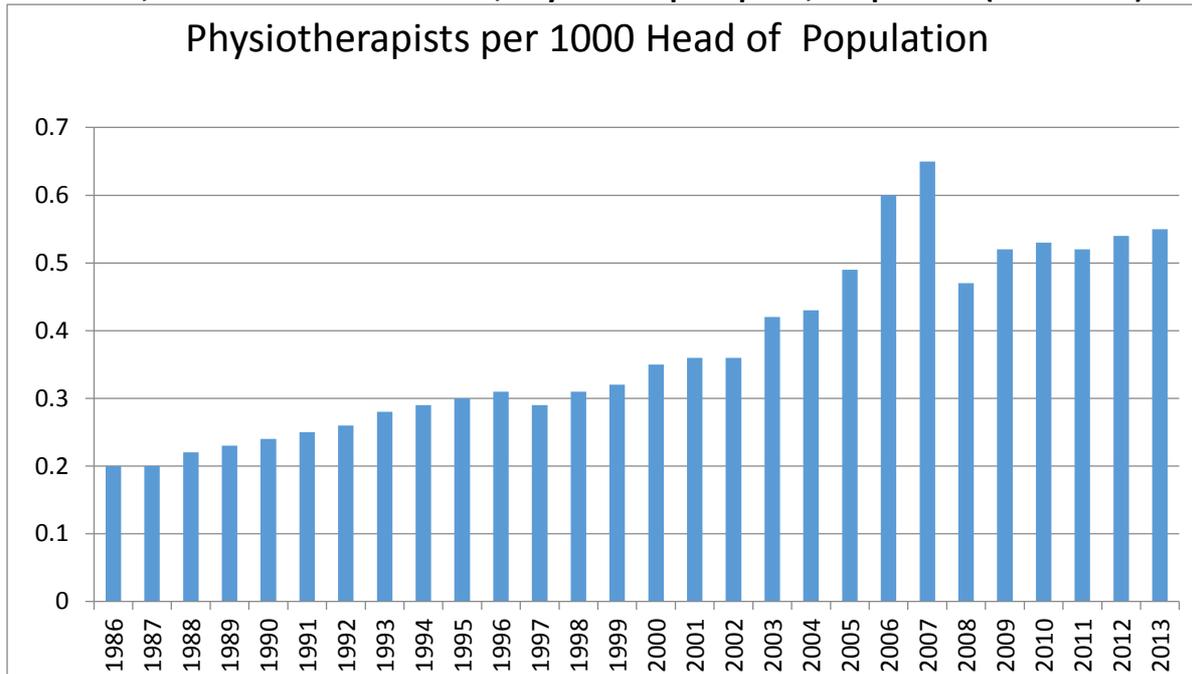
#### **PRIORITY 4**

A funding model that enables an adequately resourced and appropriately managed health service with the workforce capacity to meet the health needs of the population

The development of an optimum physiotherapy workforce was still in its infancy, when recruitment embargoes and reductions in staffing numbers were introduced in recent years. The physiotherapy workforce is therefore relatively low in number and cannot meet current demands.

There are 55 Physiotherapists per 100,000 population in Ireland, (OECD, 2014)<sup>7</sup> which is among the lowest per capita in European countries along side Estonia, Greece, Hungary, Slovakia and Slovenia. The ratio has decreased from a maximum in 2007 of 65 per 100,000.

OECD, National Statistical Office, Physiotherapists per 1,000 persons (1985-2013)<sup>7</sup>



**PRIORITY 5**

**A health service that promotes only the regulated health professions that use an evidence-based approach**

The ISCP always supported statutory regulation of the profession for public protection and has worked with successive governments for its implementation.

The world professional body for physiotherapists/physical therapists (WCPT) uses the two titles *physiotherapist* and *physical therapist* interchangeably, and these titles are the sole preserve of Member Organisations of the WCPT<sup>8</sup>

Protection of both titles in one register in line with international standards is essential for public protection and safety in Ireland.

The ISCP welcomed the previous Minister's decision in January 2016 to implement the above but was shocked to discover he subsequently diluted the decision by extending the grandparenting agreement from current physical therapy students to a cohort of students who had not yet begun a physical therapy course.

The Department should ensure that health care delivery is only provided by regulated health care professionals and is evidence-based in its approach to ensure safety and best outcomes.

## PRIORITY 6

### Full implementation of the Integrated Care model that includes Direct Access to Physiotherapists as First Contact Practitioners

#### Integrated Care Model

The benefits of physiotherapy services in an integrated care model are that they can:

- be delivered in a variety of sectors and settings
- integrate care to facilitate individual journeys, optimise outcome and satisfaction levels;
- optimise health, wellness promotion and illness prevention across the lifespan;
- support the population to stay well (long term “value add”) and continue to participate in work/school/ community life by prevention strategies or early treatment to minimise the effects of injury/illness;
- assist in addressing the current acute: chronic health spend mix and ensure services are delivered in line with a healthcare policy that focuses on prevention and reduces risk of chronicity due to direct and timely access to treatment
- span the entire Irish health and well-being economy, by maximising the existing network of physiotherapy private practices, staff and equipment which would reduce investment requirements in physical resources by the public sector.
- address the inequity of service provision and implementation of the clinical care pathway that exists across the country.
- reduce costs through locally delivered services closer to home, where this is clinically appropriate and conducive to the quality and outcome of the services provided;
- be open-access services, including self-referral and enable people to choose physiotherapy services at first point of contact
- include social care (including care homes) to integrate services and facilitate access to all those who can benefit from physiotherapeutic intervention;
- enable individuals to maximise their capacity for self-management and facilitate peer group support and behaviour change;
- be focused on meeting user need and enhancing clinical outcomes;
- optimise the use of new technologies to enhance access and support to individuals

(e.g. their engagement with self-management and behavioural change programmes), minimise hospital admissions and reduce length of hospital stays; and

- maximise efficiency of care by eliminating waiting times.

Physiotherapists are members of the core Primary Care Team delivering services in primary care. They are already supporting patients in managing their health, promoting continuity and co-ordination of care and making referrals to specialist services. The emphasis is on providing services in patients' homes and community settings (e.g. GP practices, Primary Care Centres; walk-in centres, day units, local community facilities such as gyms, pools). Specialist physiotherapy services should be in place at network level to support the delivery of more specialised services, in addition to the general services, at primary care team level.

In addition to the physiotherapy-led services aligned to Consultant services in acute units and the follow-through of patient pathways of care (e.g. supporting the planning of elective and emergency post-operative rehabilitation) needs to be co-ordinated at local level. This would include close collaborative working between the Advanced Practitioner/Clinical Specialist/Senior physiotherapist at secondary level and those in the Primary Care settings.

Among the 10 key elements identified by the King's Fund and Nuffield Trust<sup>9</sup> to enable integrated care is the development of new types of contracts with providers. The 10-year Health Plan should include the integration of private practitioners into the provision of local services. A model of shared services between public and private sector physiotherapy providers would enhance the services available to the public and help to address the disparity of access to essential physiotherapy services compared with other European countries. Refer to Section 2.

#### Direct Access (Self-Referral)<sup>10</sup>

The Primary Care Strategy (2001)<sup>11</sup> included a commitment to services that are "fully accessible by self-referral".

Direct access (self-referral) to chartered physiotherapists has been in place in Ireland since 1978. It is well established in private practice where a recent survey of countries showed the self-referral rate in Ireland was 82.8%<sup>12</sup>. The survey also showed that in countries with a higher rate of self-referral, there were lower rates of diagnostic intervention<sup>12</sup>. Self-referral in the public sector has been established in some Primary Care areas and fits with the HSE "choice and personal control agenda" by encouraging personal responsibility.

#### **Evidence for self-referral**

In Scotland, by 2009 60% of services were accessible thorough self referral and the average cost benefit to NHS Scotland (of self referral) is estimated at £2.5million annually (CSP, 2009)<sup>13</sup>.

Alan Johnson, the Health Secretary in England, stated that patients who self-refer access services more quickly and are more likely to complete their treatment. In the long term self-referral is more cost effective (CSP, 2009)<sup>13</sup>.

- lower rates of medical investigations were found in pilot studies in the UK and 75% of patients who self-referred to musculoskeletal physiotherapy services did not require a prescription for medicines<sup>14</sup>.
- reduced delay for patients in accessing physiotherapy, providing a shorter pathway of care
- facilitated the earlier management of injury/condition, so improving health gains<sup>15</sup>
- improved outcomes for patients with musculoskeletal conditions<sup>16,17</sup>,
- less absence from work<sup>18,19</sup>
- high patient satisfaction levels<sup>20</sup>.
- an important role in chronic disease prevention and control, keeping patients active and independent at work or returning to work and out of hospitals and long term care facilities<sup>21</sup>.
- reduced costs in areas such as x-rays and MRIs
- does not increase overall referral rate to physiotherapy<sup>16,18</sup>.

Self-referral also has a place in secondary care, especially to facilitate patients with chronic disease to access specialised outpatient physiotherapy services in a timely manner.

#### PRIORITY 7

Extension of the Advance Practice Physiotherapy initiatives which combine greater efficiencies and cost savings with improved delivery to service users (including Independent Prescribing)

### Advanced Practice

Advanced Practice (AP) physiotherapy roles first developed in the UK in 1986. Since then physiotherapists have become first contact practitioners in the musculoskeletal area within secondary care, in musculoskeletal clinics and the Emergency Department<sup>22,23,24</sup>. There are also a number of initiatives in the area of rehabilitation<sup>25,26</sup>.

Physiotherapists in advanced practice roles in Ireland contribute to the implementation of many programmes, bringing efficiencies to the system and expediting the patient pathway e.g. Oxygen clinics, Diagnostic Ultrasound and Injection Therapy in Rheumatology. Many are driving the roll out of the changes in patient pathways e.g. musculoskeletal (MSK) triage, COPD Outreach, heart failure clinics and stroke early supported discharge. There is further potential for AP physiotherapists to work in new ways to support the programmes facilitating admission avoidance and early discharge.

Key Challenges to achieving a “universal single tier health service, where patients are treated based on health need rather than the ability to pay”

One of the most fundamental responsibilities of the Department of Health (and its designates) is to decide what services will best meet the needs of patients and local communities and to engage these services in ways that ensure high-quality outcomes, maximises patient choice and secures efficient use of available resources.

The ISCP supports, in principle, the concept of a universal single tier health service, which will ensure equal access to care based on need, not income and designed in accordance with the principles of social solidarity outlined in Department’s *Future Health (2013)*<sup>27</sup>

### **General challenges**

It has however serious reservations about the feasibility of implementation and believes a transition of such magnitude would require major capital and structural investment to support it. The experience in the Netherlands when it transformed to such a model provides some indication of the challenges involved.

The Dutch Model has been in existence for several years but evaluations completed to date only reflect the initial years<sup>28</sup>. There is however a worrying trend in non-compliance with payment of the mandatory standard package .

The rising numbers (80,000) of non-compliance with mandatory basic cover payment in an affluent country like the Netherlands, the current economic climate in Ireland, the difficulties people have encountered in paying additional mandatory charges in recent years and the large numbers who have discontinued their private health insurance would all mitigate against successful implementation. In addition If people do not see a concomitant improvement in the health services, the government will face increasing opposition.

### **Physiotherapy related challenges**

In terms of physiotherapy services provided, the situation in the Netherlands is not comparable with that of Ireland;

- The Netherlands’ population is 3.7<sup>29</sup> times that of Ireland<sup>30</sup> but their physiotherapist-to-person ratio is nearly seven times greater (with a 3:1 community to hospital ratio).
- Access to all Dutch physiotherapy services is by direct access.
- There are purpose-built dedicated rehabilitation centres/clinics throughout the Netherlands, specialist in nature and committed to ongoing clinical research. (generally affiliated with local hospitals and universities).
- Dutch physiotherapists reported that increased funding resulted in increased access to treatment and rehabilitation services and the move away from hospital-based treatment.

The insurance companies identified early intervention schemes, through physiotherapy as a way of keeping inpatient costs down. However there are concerns in the Netherlands that the physiotherapy cover in the basic (mandatory) package does not facilitate the incorporation of health promotion and prevention when such interventions would reduce

the burden of non communicable lifestyle conditions on the health service in the long term. Patient responsibility is becoming a cost control initiative through incentives to reduce risks, but the supports through health promotion (such as empowerment) for people to take this responsibility are not available.

Actions needed to plan for, and take account of, future demographic pressures and their impact on the health system

Refer to Strategic Priorities above

- Move the health emphasis to Prevention
- Extend Direct Access and Advanced Practice Physiotherapy initiatives to address waiting lists
- Increase support /care packages to maintain people in their own homes for as long as possible
- Increase step- down facilities to facilitate earlier discharge from acute hospitals and transition to home
- Develop rehabilitation facilities to deliver short multi-disciplinary rehabilitation programmes for those in the community at risk of physical deterioration
- Implement advances in health care technologies that will impact on service delivery

## **2. Integrated Primary and Community Care**

2.1 Steps needed to move from the current model towards a model based on integrated primary, secondary and community health care

2.2 Key barriers to achieving this, and how might they be addressed

Refer to Strategic Priority 6

2.1 and 2.2 are answered together.

### **Changing demographics, disease patterns and inequities**

- An ageing population, with the fastest population increase in those aged 85 years and over,
- Projected rise in people with chronic and long-term conditions – accounting for 70% of healthcare spend in Ireland(2012)<sup>31</sup>
- Changing disease patterns, e.g. increasing rates of NCDs across the lifespan, e.g. obesity/diabetes in children/adolescents

- Increasing significance of migratory patterns on health and well-being trends
- Significant change is likely in the next 10-15 years, driven by advances in gene and drug therapies (e.g. management of cystic fibrosis and vaccination against some cancers)

Inequity of available services and service provision across the country needs to be addressed. While the Clinical Care Programmes strives to address this problem to some degree, the patient care pathway may continue to be negatively influenced by geography unless each piece of the pathway is well defined and implemented equally in all areas.

### **Health Care reform**

- Central focus on quality and innovation – clinical and cost effectiveness, patient satisfaction and patient-reported outcomes, and demonstrable patient value and benefit
- Innovative thinking to strengthen effectiveness and productivity in service design/delivery
- Design and implementation of care pathways.
- Reform fatigue – being experienced by public sector staff

**Staffing Levels** – See Priority 4 and Section 2.3 below

### **Changing perspectives of the public and professionals**

- More accessible information available to inform choice and decisions
- Increased focus on professional responsibility, patient autonomy and public responsibility to use healthcare services effectively

### **Regulation**

- Essential need for stronger regulatory requirements and accountability to enhance public protection, safety and confidence

### **Wider political, economic and sociological factors**

- Resistance to moving from a reactive led health service to a preventative led service
- Lack of real leadership to drive such a change
- A sustained period of fiscal constraint and public expenditure cuts which directly impacted on service delivery

Key roadblocks encountered by the ISCP and physiotherapists ( i.e. in your particular area of the health service)

**Road blocks and how they can be addressed are included. Refer also to Key Priorities**

## **Workforce capacity is unable to meet demands**

Delivery of physiotherapy and physiotherapy services are challenged and influenced by changing demographics, health needs of the population, the increase in co-morbidities in the general population as well as in complex ageing and special needs population, the increasing need for management of chronic and long term diseases, increasing dependency, developing treatment technologies, patient expectations and the need to improve health at a population level. Other challenges include reform fatigue and inadequate staffing levels.

The Primary Care strategy (2001)<sup>11</sup>, stated that 90% of care can be delivered locally. The demographic predictions for local populations indicate that this situation will deteriorate (ageing populations; increased survival rates for children and adults with disability; greater demand for “walk-in” (OPD) services for musculoskeletal services; people’s knowledge of the value of physiotherapy in enabling them to remain at or return quickly to work).

HealthStat information (2014)<sup>32</sup> within the public service indicates that the demand on out-patient services is a cause of frustration for both the patients and the physiotherapists within those services.

The development of an optimum physiotherapy workforce was still in its infancy, when recruitment embargoes and reductions in staffing numbers were introduced in recent years. The physiotherapy workforce is relatively low in number and cannot meet current demands.

- It is primarily a female population which has impact on actual availability at any given time (e.g. Maternity Leave, which is not currently covered in the public sector)
- Significant numbers of graduate physiotherapists are available for work but unemployed
- Restrictive HR practices within the public sector meant less sustained expansion (if any) in the public physiotherapy workforce in the short term and restricted opportunity for building capacity/maintaining competency.

### **Required :**

A mapping of need and supply of effective physiotherapy services (as outlined previously) in an Integrated Care model and correcting the workforce capacity to meet the needs.

### **Legislation**

#### **Maximising public protection – See Priority 5**

**Required:** the decision by the former Minister to protect both physiotherapy titles in one register along with the agreement on grandparenting timelines needs to be finalised in law without any further dilution to public protection.

**Independent prescribing** - Injection Therapy is part of scope of some physiotherapists’ advanced practice and though legally covered to administer the medication, the existing

legislation prevents physiotherapists from prescribing it. In the UK legislation in 2013 enabled specialist chartered physiotherapists to have full prescribing rights.

**Required:**

Legislative changes to facilitate independent prescribing.

**Other changes required:**

Amendments to the Nursing Homes Act to legislate for registered providers to provide a standard and equal level of access to physiotherapy for residents

Policy decision from the Department of Health in relation to eligibility for physiotherapy by people who are not entitled to a medical card;

**Lack of involvement of Physiotherapists in relevant national consultations, strategic planning committees and healthcare management**

The Framework (2011)<sup>27</sup> referred to widespread consultation with relevant stakeholders (including professional bodies) on reforming the health service. The ISCP was not included in several strategic committees\* on which it could have made significant contribution.

\* e.g. National Strategy on Dementia, A Vision for a Healthy Ireland, National Positive Ageing Strategy

Healthy Ireland Council, Special Action Group on Obesity (SAGO) and National Physical Activity Plan.

The absence of Health and Social Care professions at the highest management level has resulted in many of the roadblocks. To be fully effective, a genuine Integrated Care Model requires equal input from all stakeholders in the planning and implementation stages. The ISCP has made several requests to the Department to address this gap. (See ISCP Position Statement, 2015 Appendix 6)

**Required:**

- 1.1 A Health and Social Care Professionals' stream throughout the entire Health Management structure
- 1.2 The reinstatement of the Therapy Advisor in the Department of Health
- 1.3 The ISCP should be invited to appoint a representative to strategic committees
- 1.4 A position should be created for an ISCP nominee on the Healthy Ireland Council
- 1.5 If the proposed Action in the Framework<sup>27</sup> for a *National Task Force on Prescribing and Dispensing Practice* is established, membership should include a chartered physiotherapist .

**Contribution of physiotherapy in the Intergrated Care Model (ICM)**

Refer to Priority 6

## Required

- 1.6 The potential and the evidence for health improvement by physiotherapists in an ICM is clearly outlined in Section 2 above. The potential must be implemented.
- 1.7 A co-ordinated service delivery plan for physiotherapy within a local healthcare area, incorporating all available resources (staff and physical resources, public and private) to include all elements of service required for a population is achievable. The skill set to deliver appropriate services should be mapped out in line with demographics. There should be flexibility in budget allocation for Physiotherapy Managers to contract/purchase private services to address patient waiting lists.
- 1.8 Extension of Advance Practice Physiotherapists, roles and initiatives (refer to Priority 7 and 2.5 below)
- 1.9 Involvement of Physiotherapist Managers in planning and implementing Integrated Care
- 1.10 Professional line management structures ensure active training needs analysis and skills development to meet service need.

Ensuring buy-in from health care professionals to progress towards an integrated health care model

The ISCP fully supports the concept of an integrated model of care (See Section 2.1 for details) that treats patients at the lowest level of complexity that is safe, timely, efficient, as close to home as possible and where the emphasis is based on needs and evaluation is based on its impact on outcomes. It also supports clinical and service level integration.

It welcomes the opportunity to be involved in fully implementing the Integrated Care Model

Examples of best practice that the Committee should consider (with refer to evidence to support this).

There are long established areas of integrated physiotherapy services in some parts of the country. In developing a 10 year plan the outcomes of joint initiatives undertaken by physiotherapists from hospitals and community working collaboratively should be reviewed. Some examples are outlined below. Refer also to Appendices 1,3,4&5

**A modest deployment of resources to physiotherapy services is capable of having a significant impact on the treatment of musculoskeletal disorders.**

A national initiative supported by both the Rheumatology and Orthopaedic Clinical Programmes to achieve “significant reduction in OPD waiting lists through the use of physiotherapy-led Musculoskeletal (MSK) clinics” (HSE, 2011)<sup>32</sup> resulted in 24 Specialist

Physiotherapists removing over 50,000 patients from the Orthopaedic and Rheumatology waiting lists in 18 months up to 2015.

**Required:** The potential to extend this initiative and to replicate it in other services exists and must be implemented.

### **Chronic Obstructive Pulmonary Disease (COPD)**

Physiotherapy and pulmonary rehabilitation can reduce COPD admissions by 26% and reduce hospital length of stay thus significantly reducing the health cost - the second largest cause of emergency bed admission in UK/Ireland. (See Appendix 1 ).

#### Case Study

A Canadian study reported that pulmonary rehabilitation was associated with reduced usage of public health resources, decreased direct costs, and improved health status in COPD patients<sup>33</sup>. The average reduction of total costs before and after the programme was approximately \$344 CAD (€242) per patient per annum.

### **Rheumatology**

#### Case Study

Manning et al. (2015)<sup>34</sup> examined the effectiveness and cost-efficiency of upper-limb self-managed exercise programmes for people with Rheumatoid Arthritis. Results showed that participants in an eight week exercise programme gained 0.0296 Quality Adjusted Life Years (QALY), at a cost of £82 (€117). This equates to £2,770 (€3,950) per QALY, far below the NHS's guide threshold of £20,000 - £30,000 (€28,521 - €42,781) per QALY gained. The self-managed programme therefore represented a cost-effective use of resources in comparison to usual care methods, and led to lower healthcare costs and work absences.

### **Physiotherapists working within early supported discharge teams - Cerebrovascular**

#### **Accident (CVA/Stroke)**

It has been shown to be more cost effective where physiotherapists provide stroke rehabilitation in the home or in the community rather than the hospital, reducing long term dependency, length of hospital stay and reduced admission to institutional care.

In 2014, the Economic and Social Research Institute (ESRI)<sup>35</sup>, in conjunction with the Irish Heart Foundation (IHF) and the Royal College of Surgeons in Ireland (RCSI), undertook a substantial body of research centred on improving outcomes and lowering healthcare costs for people who have suffered strokes<sup>550</sup>. The study found that the current approach to

treating people with stroke involves relatively low amounts of therapy and a relatively low availability of therapists in Ireland. The research examined the impact of Early Supported Discharge (ESD), which aims to accelerate discharge from hospitals by providing

rehabilitation while the patient lives at home. It found that a 44% take-up rate for ESD would result in costs of between €5m and €10m per annum, and savings from shorter hospital stays of €12m; in other words, a net saving of between €2m and €7m.

#### **Other examples of Evidence of Good Practice in Physiotherapy:**

- Health Economic Impact of Physiotherapy - examples -Appendix 1
- Unique Role of Physiotherapy in Weight Management - Appendix 2
- Integrated working between PCCC services and acute hospitals in the network in city areas where traditionally physiotherapists worked independently e.g. St James's and Tallaght and PCCC Physiotherapy Departments - Appendices 3-5;
- Occupational Health - Early intervention can reduce the amount of time people are off sick and can stop people going off work in the first place by enabling people to understand prevention of chronic disease, re-occurrence, and strategies to self-manage effectively
- Functional Capacity Evaluations and work hardening – Fit for Work interventions;
- Training the Trainers for Moving and Handling (HASAW Act) to recognised QQI Level; and
- Aquatic physiotherapy provided by HSE physiotherapy staff in local public Leisure Centres for people with lifelong conditions.

#### **Funding Model**

Which health service funding model would be best suited to Ireland?

Improvements are needed in both the standard of health and the provision of health services in Ireland. This requires adequate and properly managed funding.

Countries that appear to have the best health services (e.g the Nordic countries), are funded directly from higher taxes. A percentage is absolutely ring fenced for health service provision (and cannot be diverted in any circumstance). The result is free at the point of access, no waiting lists, and consultant heavy/junior doctor light delivery of services. Private medicine is not required and all staff are on salary payment.

If implemented in Ireland, it has the potential to bring about real improvement in delivery, outcome and population health.

The specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating

Emphasis and planning at national level based on prevention, conservative (non-invasive) interventions first and where required high tech ambulatory/day surgery interventions.

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What are the main entitlements that patients will be provided under your funding model?

All I healthcare requirements including access to preventative measures would be included. Options such as cosmetic surgery, private rooms would be excluded.

Examples of best practice, or estimated costs of such models if available.

The model used by the Nordic countries to fund their health service.

Although the costs of such a model is not provided – examples of best practice that indicate the health economic impact of physiotherapy are **included (Appendix 1)**

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## Irish Society for Parenteral and Enteral Nutrition (IrSPEN)

The Irish Society for Parenteral and Enteral Nutrition (IrSPEN) is dedicated to advancing the science and practice of clinical nutrition and metabolism within the Irish healthcare system as a means of improving patient outcomes and healthcare utilisation. Founded in 2010 with the support of the Irish Society of Gastroenterologists (ISG), the Nutrition Society (NS) and the Irish Nutrition and Dietetics Institute (INDI), IrSPEN is a multi-disciplinary organization whose 400 members include dietitians, nurses, physicians, scientists, students, health economists and other health professionals from every facet of nutrition support clinical practice, research, education and delivery.

In the six years since its establishment, IrSPEN has conducted or participated in research initiatives to establish the clinical and health economic impact of malnutrition within the Irish healthcare system, the cost benefits associated with good nutritional care models and the dissemination of knowledge and best practice nutritional care amongst healthcare professionals. It has partnered with patient organisations in launching its campaign in 2013 – Every patient deserves good nutritional care – and worked with the HSE and HIQA in national working groups in 2015 / 2016 to advance best practice in Nutrition and Hydration.

### Board and Management Committee

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- Professor John V Reynolds, Head of Clinical Surgery, Trinity College, St. James's Hospital.
- Professor Carel le Roux, Head of Pathology, University College Dublin
- Dr. Orla Crosbie, Consultant Gastroenterologist, Cork University Hospital (Irish Society of Gastroenterology)
- Carmel O Hanlon, Clinical Nutrition Specialist Dietitian, Beaumont Hospital (Irish Nutrition and Dietetic Institute)
- Professor Maria O Sullivan, Senior Lecturer, Trinity College
- Niamh Rice, Consultant in Nutritionist and Medical Affairs (Corresponding author)
- Dr. Eileen Gibney, Assistant Dean of Nutrition Studies, University College Dublin
- Dr. Declan Byrne, Consultant in Acute Medicine/ Geriatrician, St. James's Hospital (MC)\*

Given that the background to the establishment of the Joint Committee is the severe pressures on the healthcare system, the unacceptable waiting times for public patients, and the poor outcomes relative to healthcare cost, it is clear that a one tier, universal health model can only be achieved if care gaps within the existing services with known, adverse effects on outcome and healthcare utilisation are addressed within the ten year plan. In this context, IrSPEN urges the Committee to commit greater efforts towards the prevention and effective treatment of undernutrition (primarily disease related) and obesity, both major and costly public health problems likely to place increased pressure on scarce healthcare resource within the next decade.

Disease related malnutrition is a major source of avoidable risk to patients and an unsustainable source of cost to the health service, with malnourished patients currently using in excess of one third of acute care inpatient bed capacity in Irish hospitals each year, over 90% of whom are admitted from their own home. As most malnutrition is preventable and screening programmes and models of good nutritional care capable of delivering net cost savings, the high prevalence of malnutrition (averaging 30% of inpatients on admission to Irish hospitals) and low priority placed on its prevention merit immediate attention by the Committee. Earlier detection and treatment of community patients with malnutrition could release as many as 450 inpatient bed days per day or 168 000 per year (6% total capacity), yet so far, primary care screening programmes are lacking and community dietetic access severely limited. Future healthcare strategy must focus increased efforts at preventing malnutrition in primary as well as community and secondary care settings.

Contrary to the principle of supporting patient self- management, treatment at the lowest level of complexity and the integration of care pathways across care settings, IrSPEN has identified major deficits in the configuration and delivery of clinical services and support for patients discharged from acute care settings on home enteral nutrition (approximately 2800 each year) and on home parenteral nutrition (approximately 35 to 40 per year), both of which IrSPEN urges the committee to address. Current 'ad hoc' services and failure to provide specialist support required by patients on

home therapies results in delayed discharges, excess acute admissions for routine problems (eg. tube misplacement, site infections) that could be safely managed at home and in the case of parenterally fed patients managed by non-specialist centres (see below), potentially life threatening line sepsis.

Whereas a key deliverable of the Committee is to establish a basis for more equitable access to services based on need, we would draw the Committees immediate attention to the current lack of any suitable service capable of meeting UK / International minimum commissioning standards for patients that develop prolonged / permanent intestinal failure (IF) in Ireland each year (80 – 100), and for those awaiting transition from the national paediatric IF specialist unit based at Our Lady's Hospital for Sick Children. IrSPEN has highlighted this to the HSE as an entirely unacceptable situation that is contrary to all international recommendations and at odds with all developed healthcare systems, including NI (12 bedded unit), the UK and across Europe, costing an estimated 20 lives each year.

Given the strategic importance of obesity and diet related disease to healthcare planning, the Committee should align policy and services according to best available evidence regarding the most effective strategies for prevention on the one hand, and treatment of those with severe and complex obesity on the other. In the case of severe and complex obesity, surgical intervention is by far the most clinically and cost effective solution, offering return on investment of 2 – 3 years. In Ireland, access to bariatric surgery is less than 0.1% of the demand based on criteria established by NICE / cost effectiveness data.

The costs associated with malnutrition and obesity are substantial and growing, putting added pressure on services. However, many of the problems are avoidable and large savings achievable. Hence, IrSPEN urges the Committee to address the current gaps in the provision of nutritional care within their ten year plan.

**Recommendations included:**

A national malnutrition steering group or task force should be established at Department of Health level, involving HSE members, patient representatives and relevant expert groups and individuals to ensure that implementation is effective and produces the anticipated outcome and cost benefits.

**Given the strategic importance of this area and the large potential for savings, IRSPEN is seeking an oral hearing to present its proposals in full and the activities already underway, incorporating health economic modelling on investment costs and potential for savings.**

IRSPEN urges the committee to address the gaps in service provision and models of care required to support patients discharged from hospital on home enteral and parenteral nutrition therapies. As part of its planning, greater funding and streamlined services and funding arrangements must be put in place to support the ambitions outlined by the Committee for integrated, equitable and efficient healthcare delivery.

Patients with intestinal failure in Ireland deserve the same access to specialist dedicated units as

those in Northern Ireland, the UK and in developed healthcare systems throughout Europe and beyond. We urge the Oireachtas Committee to support the establishment of a national service, capable of meeting minimum commissioning standards within the UK/NHS as deemed necessary to give this small group of patients with highly complex and challenging requirements the best chance of survival and health. St. James's hospital is proposed as the ideal location for this a national adult specialist unit, and is the subject of a business plan for which the support of this Committee is being sought.

Healthcare policy in the area of obesity and malnutrition must differentiate between strategies for prevention and effective treatment, both being important. We urge the Committee to establish a public bariatric programme to allow access to 400 public patients annually with immediate effect, rising to at least 1000 by year ten (2026). Recognizing that allocating limited resources must take budget as well as cost effectiveness into account, a self-funding model is proposed with planned expansion of services subject to delivery of predicted returns on investment over the 10 year plan.

The Oireachtas Committee should support specific reporting measures and audit data to highlight the prevalence and impact of malnutrition on outcomes and on the quality of nutritional care provided by healthcare providers.

### **Strategic Priorities over the next 10 years**

**Action Area 1:** National strategy aimed at significantly reducing the scale and impact of malnutrition on patient outcomes and healthcare costs.

Malnutrition and dehydration are known causes and consequences of illness that have significant adverse impacts on health outcomes. As such, their prevention and effective treatment must be integral to all care pathways. However, in practice in Ireland, nutritional care - from detection of risk to the earliest possible correction of any deficits or imbalances and access to nutrition services - is still given low priority relative to its impact across our healthcare system, undermining the effectiveness of medical and surgical interventions and delaying recovery, driving up overall healthcare costs.

At any time, malnutrition affects more than 140,000 chronically ill patients' over half being over 65 years. Although most malnutrition occurs in the community (approximately 97% of those with malnutrition are living in their own home or community settings), most of the €1.4billion annual care costs associated with malnutrition are borne by acute care services, due to more frequent and longer hospital episodes. Without greater focus and resources to achieve consistently high standards of nutritional care and timely access to dietetic services for assessment, treatment and review as appropriate to the patient's needs rather than their ability to pay or geographical location, the cost burden and impact on scarce healthcare resources will only increase further.

### **Strategy: why malnutrition must be given significantly greater priority within the 10 year plan :**

- The prevalence of malnutrition is currently around 3.3% of the population but is predicted to increase to between 190 000 and 200,000 (3.7% of population) by 2026, of which 60% will be >65y.

- A secondary analysis of prevalence data obtained from two annual surveys conducted in 27 Irish hospitals applied to 2013 HIPE inpatient data indicates that 36% of the entire acute bed capacity usage was associated with malnourished patients, despite this group representing just 3.3% of the general population. This disproportionate use of healthcare resources by malnourished is predictable, unless systems are in place to ensure early detection and treatment throughout the healthcare system, which they are not.
- Applying results from recent systematic reviews, early treatment of community malnutrition could release 168,000 inpatient bed days arising from reduced hospital admissions. The relative impact would be greater in adults aged over 65 years (4% of bed days) than younger adults (2% of bed days), given that the average LOS for an older malnourished patient is approximately 11.5 days, almost twice that of younger malnourished patients and significantly greater than non-malnourished patients.
- National Screening programmes to detect malnutrition risk factors in old and/or chronically ill and socially isolated patient populations have been shown to be effective in reducing the prevalence and severity of malnutrition, improving outcomes and delivering cost savings.
- Ireland lags behind countries such as the UK and Netherlands in implementing national screening programmes across and within care settings.

**Delivering services as part of an integrated model across primary, secondary and community care:**

- Most malnutrition arises in adults living in their own home (92 – 93%), with the remainder of those affected living in nursing or residential care (around 5%) and hospitals (2 - 3%), on any given point in time. Conversely, an estimated 56 and 58% of the care costs of malnourished patients arise in hospitals, due to higher rates of hospitalisation, higher risks of infection once there and longer average length of stay and up to 90% higher readmission rates. Thus, the greatest potential to avert costs arising from malnutrition related health or functional deficits arise in the primary care settings, supporting the need for investment in nutrition education of primary care team members, dietetic services, with emphasis on groups at highest nutritional risk, and care pathways and support services for patients receiving nutrition support at home.
- IRSPEN supports the establishment of workstreams within the HSE to improve nutrition and hydration of patients. We welcome the valuable role HIQA has played in establishing a framework for self- assessment of nutritional care in both hospitals and nursing homes. However, in establishing a new framework for the future of healthcare, we believe it imperative that policies and quality standards be fully integrated across care settings and sufficiently resourced to address some major gaps and inequities in the current access of patients to appropriate nutritional care. This will have major implications for community /primary care services, which are insufficiently resourced to take pressure of acute care services.
- The vast majority of patients who receive nutritional support are first identified in hospitals and discharged into the community, where dietetic services are lacking to ensure follow up and timely review. If savings are to be achieved and malnutrition prevented or treated at the earliest opportunity, patients should be identified through screening by the GP or practice nurse, and referred to community dietetic services for assessment and treatment if required.

## **Funding Model and implications**

Without any regular, large scale survey or auditing of malnutrition prevalence and / or its relationship on outcomes or to differences in the quality of nutritional care, there is no accountability and the HSE is unlikely to invest in its prevention and treatment or to ensure access to dietetic services for those in community / primary care as well as hospitals. Hence, to guide service development and resource allocation as nutrition services are put in place, key performance indicators and metrics should be measured. These metrics should reflect service activity and outcomes.

In recent years, low priority placed on nutritional care of patients coupled with severe pressure on healthcare expenditure produced an environment in which the costs of nutrition support and the need for savings overshadowed the clinical and cost impact of malnutrition or the efficacy and cost effectiveness of medical nutrition. Dietetic services were drastically impacted by an extended moratorium, leaving large areas of the country without any community service for patients requiring assessment or review of their nutrition support.

Given the overwhelming evidence base supporting the efficacy and cost effectiveness of nutritional support, once targeted appropriately and the patient reviewed at regular intervals by a dietitian, it is important that community funded schemes for nutrition support place greater emphasis on value and outcomes and that reimbursement systems ensure access of all patients, including those on LTI schemes, to required nutrition support.

### **Recommendation to Joint Committee**

**Given the strategic importance of this area and the large potential for savings, IRSPEN is seeking an oral hearing to present its proposals in full, incorporating health economic modelling on investment costs and potential for savings.**

**Action Area 2:** Urgent need to address the deficits in community support and coordination of services for patients requiring home enteral (and parenteral) nutrition.

### **Background**

Currently in Ireland, c.2000 adults and children are receiving home enteral nutrition (HEN), with c.2900 patients discharged home on tube feeding each year. Clearly, it is in the interests of both patients and healthcare system to ensure streamlined transition of suitable patients from hospital to their own home / community as soon as they are clinically stable, and data consistently shows that HEN can have a transformative impact on quality of life, allowing restoration of normal family life. Compared with the costs of keeping patients in hospital to receive enteral nutrition (average bed day cost of €825 to €1300 in level 4 hospital), care at home delivers major savings for the health service, yet currently, the supports available to maintain patients safely in the community are lacking in the vast majority of areas. In particular, access to community dietetic staff with expertise in enteral feeding is a major problem for patients following discharge, resulting in avoidable admissions for routine procedures that could be managed safely and considerably more cost effectively in the patient's home. Medical nutrition companies play a significant role in patient training in both hospital and home and in providing free of charge equipment (pumps, stands, initial supply) in many areas of the country and this is undoubtedly propping up services where they are non-existent and masking care gaps in community services. Surveys by IRSPEN have confirmed major

gaps in services and inconsistencies that all patients on home enteral nutrition and will publish their findings and recommendations later this year.

**Strategy: why this is a strategic priority within ten year planning**

- The number of patients on tube feeds is likely to rise to between 2600 and 3000 by 2026, with discharges on tube feeding rising to over 3900 per year.
- A recent IrSPEN survey of HEN patients has confirmed major gaps in service provision at community level for many patients, with highly variable practices and community arrangements for funding and supply according to the discharging hospital and the area. There is a lack of 'joined up' thinking in both service planning and resourcing by the HSE to ensure safe care for this small but vulnerable patient group, contrary to the principle of supporting patient self-management at home.
- Due to the absence of standards of practice for service providers nationally, the quality of service and support are highly variable and inconsistent.
- Supply arrangements vary greatly across the country, resulting in frequent problems ensuring continuity of supply or in obtaining emergency supplies.
- The failure to ensure adequate care for patients following discharge from acute settings into community care is entirely at odds with an integrated care model, and highlights the urgent need to operate a more effective community care model that keeps patients out of hospital.
- There are clearly missed opportunities for cost saving and improved clinical outcome, as well as quality of life benefits.

**Integrated primary and community care:**

*A Best Practice Example for HEN from INDI (Irish Nutrition and Dietetic Institute) and a model for adoption nationally:*

- In Dublin North City and County, a very successful Community Adult HEN service has been established since 2008.
- Up to the end of 2014, 276 patients have been referred to the service, with an average of 40 new referrals a year. At any one time a caseload of 110 patients are being seen.
- All adult patients on HEN are initially seen within one week of discharge by a dietitian, who is assigned as their main / single point of clinical contact.
- Each patient is reviewed regardless of their location in the community (home, private or public nursing home), at least 3 monthly and ongoing training is provided to each patient/ carer, as well as to their public health nurse/ nursing home staff, GP and professional carers.
- The community dietitians involved have an extended scope of practice that involves changing tubes when necessary at a patient's bedside.
- It has been estimated based on a similar service in the UK, in which patients discharged under the supervision and with access to a community dietitian and speech and language therapist were compared with those discharged home to community services without home visits and specialist dietetic / SLT access. Over a six month period, admissions to hospitals were reduced by over 21%, with significant annual savings possible if applied nationally.

*Unfortunately this ideal level of community based HEN service is not available elsewhere.*

## Funding Model

Funding of feed: Enteral feeds are available through retail pharmacy through the GMS (General Medical Services), LTI (Long Term Illness), or DPS (Drugs Payments) schemes. The product needs to be reimbursed under the PCRS scheme to be available under these schemes.

Funding of feeding equipment: Inequities exist in the funding and provision of associated feeding equipment (e.g. giving sets, Y-adaptors, replacement tubes, syringes). This process varies according to local procedures and is not standard across the country. Equipment is funded for medical card holders, but not for non-medical card patients which then results in a significant financial burden for these patients.

Gaps in services: Lack of community services are resource dependent. A workforce planning report in the acute and community setting would help identify where staffing shortfalls are impeding service delivery. Education programmes may help to upskill existing staff, where this is needed.

## Recommendations to the Joint Committee

A systematic approach to discharge from hospital to community services should be in place nationally, meeting criteria and best practice international guidelines which will shortly be issued by a special report and guidelines developed by IrSPEN.

Services must be streamlined and adequately funded to ensure consistent delivery of quality care for all patients receiving home nutritional therapies, irrespective of discharging hospital or healthcare area, aligned to the principles outlined by the Joint Committee.

All home enterally fed patients should have care provided by an experienced multidisciplinary team, both in hospital but especially at home. The committee should ensure that primary care services are configured and resourced to give patients on home therapies equal access to services provided by multidisciplinary team, in this case, the Dietitian being the main clinical point of contact. A skilled workforce with access to appropriate training and CPD is needed to provide this service

Funding processes should be streamlined across the country and made easier for HEN patients and carers. Currently, patients above the medical card threshold are likely to face significant financial hardship under existing arrangements (eg. obtaining suppliers of ancillaries not covered within prescription DPS scheme).

**Action Area 3:** Establishment of a national specialist unit for adults with Intestinal Failure in Ireland.  
**(Special case to be addressed)**

## Background

Intestinal failure is defined as “the reduction of intestinal function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth”. This reduced intestinal function can arise for a wide variety of medical and surgical reasons. Between 80 and 100 of these patients will require specialist inpatient care and intensive outpatient care as they are often discharged on home parenteral nutrition (long term intravenous feed at home). Currently in Ireland, no specialist adult service exists for these patients, contrary to standard practice and all international expert recommendations. Thus, they are dispersed across hospitals lacking the expertise, training or service configuration necessary to provide safe care.

**Strategy: why this should be included as a priority within the 10 year plan:**

- The current absence of a National Intestinal Failure Service represents a major risk for patients and a concern for current service providers, with ethico-legal as well as cost implications.
- INDI data indicates that this small but highly complex patient group are dispersed throughout the country across at least 21 hospitals, none specialised or adequately resourced.
- Our Lady's Hospital in Crumlin is the national paediatric centre for IF for the last 16 years, headed by Professor Billy Bourke, yet no adult service has been established to which they can transition or which offers a similar standard of care for those over 18 years of age.
- Based on available evidence, the lack of adult services might be anticipated to be associated with 18 to 20 avoidable deaths each year in Ireland.
- The risks for patients transitioning from a specialist paediatric unit to a non-specialist adult service have already been brought to light by Our Lady's Children's Hospital, Crumlin (OLCHC). Of the three patients that were transitioned to adult acute services, two have subsequently died, resulting in the suspension of transfers pending suitable specialist care being made available.
- In NI, Belfast City Hospital operates a **12 bedded IF specialist tertiary referral unit** for a population of just over 1.6 million.
- The case for establishing a national IF unit for the Republic of Ireland (ROI) is supported by findings from specialist units internationally of dramatically improved morbidity and mortality when compared with treatment at non-specialist hospitals.

**Current Status:**

IrSPEN supports the establishment of a national unit at St. James's Hospital as the ideal location for reasons outlined in a full business case, currently submitted to the HSE for review and urgent consideration.

**Integrated care model**

Establishing a national centre for IF will also facilitate the streamlining of services for HPN patients, which should ideally be managed under the care of a specialist centre.

**Recommendations for Joint Committee**

Patients with intestinal failure in Ireland deserve the same access to specialist dedicated units as those in Northern Ireland, the UK and in developed healthcare systems throughout Europe and beyond. We urge the Oireachtas Committee to support the establishment of a national service, capable of meeting minimum commissioning standards within the UK/NHS as deemed necessary to give this small group of patients with highly complex and challenging requirements the best chance of survival and health. St. James's hospital is proposed as the ideal location for this a national adult specialist unit, and is the subject of a business plan for which the support of this Committee is being sought.

**Action Area 4:** Establishment of national bariatric programme as a component of its strategy to reduce obesity related disease.

## **Background**

Whilst the 10 year strategy must address both prevention and treatment of obesity, this submission focuses specifically on the urgent need to increase access to specialist bariatric services for the treatment of severe and complex obesity:

### **Strategy: why bariatric services must be prioritised within the 10 year plan**

- Obesity already affects more than a million people and Diabetes more than a quarter of a million people in Ireland, whilst obesity causing diabetes being one of the most serious health problems within the Irish population. By 2026, the proportion of adults classed as obese could reach 37%, with a concomitant rise in type 2 diabetes (T2DM) and other related conditions.
- Bariatric surgery offers the most successful and cost effective treatment option for the treatment of severe and complex obesity, being associated with a 65% remission rate for those with T2DM and complications () and a two to three year return on investment ().
- Despite its clinical and cost effectiveness, bariatric surgery is severely under-resourced in Ireland, with just two public clinics – one in Galway and one in Dublin. This imbalance between service availability and current demand has created long waiting lists for access to bariatric services.
- Given that obesity and related diseases are projected to increase and that bariatric surgery offers the most clinically and cost effective treatment option for severe and complex obesity, it is imperative that provision is made for more patients to gain access to services. Therefore, there will need to be enough bariatric surgeons, physicians and allied health professionals with sufficient experience to provide this care over the lifetime of this plan.
- The €90,000/hour (€730 million per annum)() that the Irish healthcare system currently spends on diabetes is a major burden on existing services, whereas the costs of bariatric surgery for obese patients with T2DM (est €10,000) are recouped within three years from reduced prescription costs().
- An estimated 10,891 (95%CI: 8,228 – 14,416) people aged  $\geq 50$  years would meet the criteria for bariatric surgery based on BMI and presence of T2DM. Almost 8 times that number would meet criteria based on a BMI alone. Provision of bariatric surgery to those with both severe obesity and diabetes could potentially result in an estimated 7,079 patients having acceptable glycaemic control not requiring medication() whereas at present, less than 1% of suitable candidates have access to treatment, with significant cost implications for the healthcare system.

### **Delivering services as part of an integrated model across primary, secondary and community care:**

- To achieve the best outcomes for patients and have sufficient volumes to develop the experience and expertise of the MDT, it is important to centralize surgical bariatric services in high-volume centres that are geographically located to optimize access to the national population. We support proposals by the IES Bariatric Interest Group that one centre be established in each of the six hospital groups alongside one national paediatric bariatric centre with a full MDT, with associated assessment clinics provided nationally within each of the HSE Hospital Groups. The MDT in each centre should include at least an upper GI surgeon, bariatric physician, a dietician, a specialist nurse, a clinical psychologist, a physiotherapist, and a liaison psychiatrist.

- To ensure access to specialist medical and surgical care for this complex patient group, it is important that centres be based in model 3 or model 4 hospitals with a well-integrated pathway from primary care services to secondary care and back. These pathways should include preventative care, community based interventions, specialist multi-disciplinary bariatric services that include bariatric physicians, and a bariatric surgical service. For those who are referred onto surgical services, post-operative care should be delivered in a chronic disease model of care.
- It is recognised that these care pathways may have different structures in distinct geographical areas. For example in the west of Ireland, the hospital-based bariatric service links with Croi, the West of Ireland Cardiac Foundation, for the delivery of specific domains of bariatric care involving structured lifestyle modification, whereas in Dublin, these services tend to be delivered within the hospital campus.
- To guide service development and resource allocation as the bariatric services develop, key performance indicators and metrics should be measured. These metrics should reflect service activity and outcomes. The development of this data collection strategy should agree with the aims of the National Obesity Strategy. Strong consideration should be given to the development of a National Registry integrated between primary and secondary care to allow regular audit and to ensure appropriate service development

### **Funding Model and implications**

The decision to invest in the establishment of a national service model capable of treating a minimum of 400 public patients per annum year one rising to 1000 by year 10 (see proposals below) must take into consideration the cost effectiveness of bariatric surgery versus non-surgical treatments. A UK health technology assessment found that for patients with a body mass index (BMI)  $\geq 40$ , the incremental cost effectiveness ratios for surgery ranged between £2000 and £4000 per quality adjusted life year (QALY) gained over 20 years. This was well below the £20 000 per QALY threshold for cost effectiveness used by the National Institute for Health and Care Excellence (NICE) and the range historically used by the HSE (between €20000 and €45,000). For patients with diabetes and a BMI of 30-39 the incremental cost effective ratio fell to £1367 per QALY gained, resulting in a probably of cost effectiveness over 20 years of 100%.

Notwithstanding that even with the investment outlined below, services will continue to fall short of demand and pose ongoing challenges in offering equity of access to patients that will benefit from surgery, we propose the following:

### **Recommendation to Joint Committee**

1. Sufficient upfront investment to establish 4 additional adult bariatric centres across Ireland in addition to expansion of existing public specialist services in Dublin and Cork, thereby improving access to services in areas where there are none.
2. Service planning to provide access to 400 patients in year 1, 400 in year 2 (2017 and 2018), increasing by 200 patients annually thereafter to 2000 patients by year 10 (2026), subject to

being able to demonstrate a return of investment within two years of treatment for patients that received bariatric surgery in preceding years.

3. Access to patients should be offered preferentially to those with complications arising from severe obesity, such as those with T2DM.

**(IRSPEN recommends an oral representation with the committee by the main submitting group / Dr. Francis Finucane / Professor Carel le Roux)**

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Contact <http://www.irspen.ie/>

## Irish Society of Chartered Physiotherapists (ISCP)

The Irish Society of Chartered Physiotherapists (ISCP) is the sole professional body for chartered physiotherapists in Ireland. It is the Member Organisation for Ireland on the World Confederation for Physical Therapy (WCPT) which is the world professional body for physical therapists/physiotherapists.

As such it is a major stakeholder in regard to health care provision, reform and models of delivery.

The ISCP advocates for the provision of a person-centred quality service that is accessible, effective, and humanitarian while advancing health and social gain.

*Physiotherapy provides services to individuals and populations to develop, maintain and restore maximum movement and functional ability throughout the lifespan. This includes providing services in circumstances where movement and function are threatened by ageing, injury, pain, diseases, disorders, conditions or environmental factors.(WCPT 2011)<sup>1</sup>*

Physiotherapy is an effective, comparatively low-cost, value for money high quality option. The benefits of social inclusion, prolonged independence and quality of life justify the costs when treatment is adequately provided, within an integrated care structure. It can lead service innovation, improvement and integration to maximise quality, productivity and patient choice by co-ordination of available resources. Physiotherapy services can be provided in a variety of settings that ensure timeliness and accessibility and that optimise impact and benefit for individuals' health and well-being.

As autonomous practitioners who can manage the continuum of care for many conditions, physiotherapists are well positioned to face the challenges of evolving health needs and care models in Ireland. In addition, those working in advanced practice are extending boundaries of practice in areas that were once the preserve of other health professionals. This increasing flexibility in delivery of new and extended services results in better patient outcomes and experiences and fits in with the integrated care model.

The evidence for positive health outcomes and the cost effectiveness of physiotherapy is included throughout the submission.

The ISCP supports in principle the universal single tier health service but has reservations about its implementation. It fully supports the Integrated Care Model. The submission focuses specifically on the questions asked by the Committee (in red). It draws largely from two documents; Optimising Physiotherapy Services in Ireland (ISCP 2015)<sup>2</sup> and Budget Submission to Government 2017 (ISCP 2016)<sup>3</sup>

<http://www.iscp.ie/>

### 3. Strategy

#### 1.1 Key Priorities for inclusion in a ten-year plan for the Health Service

The ISCP has identified seven main priorities.

##### PRIORITIES 1-3

1. A healthy population achieved through a health service that delivers the highest quality care combining the medical model with the biopsychosocial approach to health and well-being
2. A paradigm shift in emphasis, in both approach and resourcing, to prevention
3. A partnership (client centred) approach to health care.

The World Confederation for Physical Therapy (WCPT) states the physiotherapy profession is uniquely qualified to have an impact on the growing global epidemic of diseases related to lifestyle<sup>4</sup>. Physical inactivity is now identified as the fourth leading risk factor for global mortality<sup>5</sup>. The benefits of regular physical activity on primary and secondary prevention of several chronic diseases, many of which are lifestyle related, and lowering the risk of conditions such as depression, metabolic syndrome, colon cancer and breast cancer are now widely established<sup>5</sup>. The evidence also suggests a relationship between physical activity and reduced risk of falls in the older population<sup>5</sup>. As a result of the overwhelming evidence for physical activity, the focus has now moved to identifying evidence for optimal doses. Physiotherapists are the health professionals with the expertise in prescribing exercise for health as part of a structured, safe and effective programme. Combined with their training in the health promotion approach of involvement and empowerment, they are well placed to enable individuals to adopt a healthier lifestyle through optimal physical activity.

There is a need to increase focus on prevention through health promotion by;

- Promoting healthy living - with the aim of achieving illness prevention
- Delivering accessible services responsive to population needs
- Placing emphasis on quality of life; addressing health inequalities
- Early intervention which is a key factor in determining successful outcomes for patients.
- Early diagnosis and effective management of conditions in early stages of disease
- Roll out of effective screening programmes (Women who have already been treated for breast cancer should not be excluded from the free screening programme).
- Helping individuals to manage their symptoms
- 'Fit for work' initiatives

Health Promotion is not one-off initiatives, but rather is a systematic approach by dedicated trained staff. To be effective, all initiatives must include empowerment and participation and must bring about sustained and meaningful behaviour change.

Physiotherapy is a key component of health promotion with programmes in primary care e.g. mental health, bone health, obesity, chronic disease management including COPD, diabetes, cardiovascular conditions, frail elderly at risk of falls, palliative care, chronic pain and fatigue. In

general, these programmes deliver self-management strategies, education and evidence based exercise prescription.

Physiotherapists as the health professionals with the expertise in movement and exercise throughout the lifespan across the health spectrum (WCPT)<sup>4</sup> can:

- Provide support for those managing mainstream exercise options for non-complex conditions;
- Promote wellness in those with, and at risk of, chronic disease;
- Prescribe safe exercise for those with morbidity and co-morbidity;
- Facilitate every service user to achieve improved health through participation in exercise; and
- Undertake screening in the areas of bone health and neurodevelopment in children and a preventative role in falls risk, obesity, low back pain and continence.

Physiotherapists should be the first point of referral for Health and Wellbeing related pathways such as the GP Exercise Initiative. They are well placed to design, train others to provide, and evaluate exercise programmes. The Northern Ireland Health Department outlined the role of Allied Health Professions in improving Health and Well-being through partnerships<sup>6</sup>, the 10-year Health Plan should include a similar approach.

The Health Plan needs to focus on prevention, the biopsychosocial model and client centred care in order to improve population health and reduce reactive and inefficient costs.

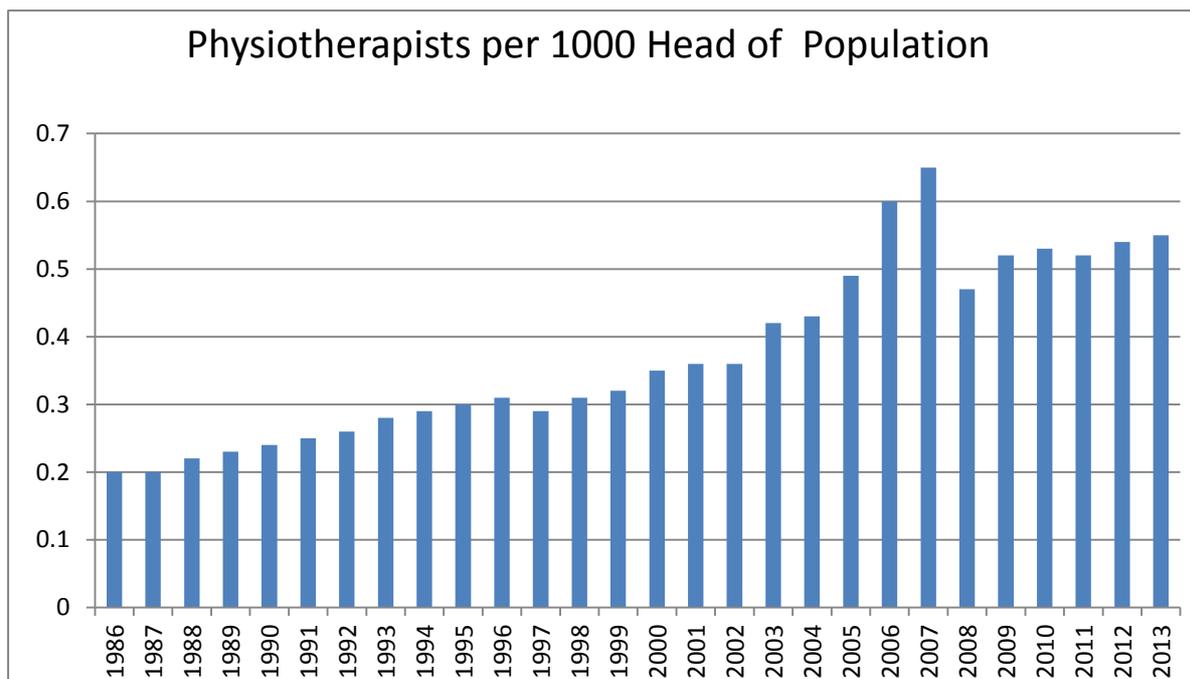
#### **PRIORITY 4**

A funding model that enables an adequately resourced and appropriately managed health service with the workforce capacity to meet the health needs of the population

The development of an optimum physiotherapy workforce was still in its infancy, when recruitment embargoes and reductions in staffing numbers were introduced in recent years. The physiotherapy workforce is therefore relatively low in number and cannot meet current demands.

There are 55 Physiotherapists per 100,000 population in Ireland, (OECD, 2014)<sup>7</sup> which is among the lowest per capita in European countries along side Estonia, Greece, Hungary, Slovakia and Slovenia. The ratio has decreased from a maximum in 2007 of 65 per 100,000.

**OECD, National Statistical Office, Physiotherapists per 1,000 persons (1985-2013)<sup>7</sup>**



#### PRIORITY 5

**A health service that promotes only the regulated health professions that use an evidence-based approach**

The ISCP always supported statutory regulation of the profession for public protection and has worked with successive governments for its implementation.

The world professional body for physiotherapists/physical therapists (WCPT) uses the two titles *physiotherapist* and *physical therapist* interchangeably, and these titles are the sole preserve of Member Organisations of the WCPT<sup>8</sup>

Protection of both titles in one register in line with international standards is essential for public protection and safety in Ireland.

The ISCP welcomed the previous Minister's decision in January 2016 to implement the above but was shocked to discover he subsequently diluted the decision by extending the grandparenting agreement from current physical therapy students to a cohort of students who had not yet begun a physical therapy course.

The Department should ensure that health care delivery is only provided by regulated health care professionals and is evidence-based in its approach to ensure safety and best outcomes.

#### PRIORITY 6

**Full implementation of the Integrated Care model that includes Direct Access to Physiotherapists as First Contact Practitioners**

## Integrated Care Model

The benefits of physiotherapy services in an integrated care model are that they can:

- be delivered in a variety of sectors and settings
- integrate care to facilitate individual journeys, optimise outcome and satisfaction levels;
- optimise health, wellness promotion and illness prevention across the lifespan;
- support the population to stay well (long term “value add”) and continue to participate in work/school/ community life by prevention strategies or early treatment to minimise the effects of injury/illness;
- assist in addressing the current acute: chronic health spend mix and ensure services are delivered in line with a healthcare policy that focuses on prevention and reduces risk of chronicity due to direct and timely access to treatment
- span the entire Irish health and well-being economy, by maximising the existing network of physiotherapy private practices, staff and equipment which would reduce investment requirements in physical resources by the public sector.
- address the inequity of service provision and implementation of the clinical care pathway that exists across the country.
- reduce costs through locally delivered services closer to home, where this is clinically appropriate and conducive to the quality and outcome of the services provided;
- be open-access services, including self-referral and enable people to choose physiotherapy services at first point of contact
- include social care (including care homes) to integrate services and facilitate access to all those who can benefit from physiotherapeutic intervention;
- enable individuals to maximise their capacity for self-management and facilitate peer group support and behaviour change;
- be focused on meeting user need and enhancing clinical outcomes;
- optimise the use of new technologies to enhance access and support to individuals (e.g. their engagement with self-management and behavioural change programmes), minimise hospital admissions and reduce length of hospital stays; and
- maximise efficiency of care by eliminating waiting times.

Physiotherapists are members of the core Primary Care Team delivering services in primary care. They are already supporting patients in managing their health, promoting continuity and co-ordination of care and making referrals to specialist services. The emphasis is on providing services in patients’ homes and community settings (e.g. GP practices, Primary Care Centres; walk-in centres, day units, local community facilities such as gyms, pools). Specialist physiotherapy services should be in place at network level to support the delivery of more specialised services, in addition to the general services, at primary care team level.

In addition to the physiotherapy-led services aligned to Consultant services in acute units and the follow-through of patient pathways of care (e.g. supporting the planning of elective and emergency post-operative rehabilitation) needs to be co-ordinated at local level. This would include close collaborative working between the Advanced Practitioner/Clinical Specialist/Senior physiotherapist at secondary level and those in the Primary Care settings.

Among the 10 key elements identified by the King's Fund and Nuffield Trust<sup>9</sup> to enable integrated care is the development of new types of contracts with providers. The 10-year Health Plan should include the integration of private practitioners into the provision of local services. A model of shared services between public and private sector physiotherapy providers would enhance the services available to the public and help to address the disparity of access to essential physiotherapy services compared with other European countries. Refer to Section 2.

### Direct Access (Self-Referral)<sup>10</sup>

The Primary Care Strategy (2001)<sup>11</sup> included a commitment to services that are "fully accessible by self-referral".

Direct access (self-referral) to chartered physiotherapists has been in place in Ireland since 1978. It is well established in private practice where a recent survey of countries showed the self-referral rate in Ireland was 82.8%<sup>12</sup>. The survey also showed that in countries with a higher rate of self-referral, there were lower rates of diagnostic intervention<sup>12</sup>. Self-referral in the public sector has been established in some Primary Care areas and fits with the HSE "choice and personal control agenda" by encouraging personal responsibility.

### Evidence for self-referral

In Scotland, by 2009 60% of services were accessible through self referral and the average cost benefit to NHS Scotland (of self referral) is estimated at £2.5million annually (CSP, 2009)<sup>13</sup>.

Alan Johnson, the Health Secretary in England, stated that patients who self-refer access services more quickly and are more likely to complete their treatment. In the long term self-referral is more cost effective (CSP, 2009)<sup>13</sup>.

- lower rates of medical investigations were found in pilot studies in the UK and 75% of patients who self-referred to musculoskeletal physiotherapy services did not require a prescription for medicines<sup>14</sup>.
- reduced delay for patients in accessing physiotherapy, providing a shorter pathway of care
- facilitated the earlier management of injury/condition, so improving health gains<sup>15</sup>
- improved outcomes for patients with musculoskeletal conditions<sup>16 17</sup>,
- less absence from work<sup>18,19</sup>
- high patient satisfaction levels<sup>20</sup>.
- an important role in chronic disease prevention and control, keeping patients active and independent at work or returning to work and out of hospitals and long term care facilities<sup>21</sup>.
- reduced costs in areas such as x-rays and MRIs

- does not increase overall referral rate to physiotherapy<sup>16,18</sup>.

Self-referral also has a place in secondary care, especially to facilitate patients with chronic disease to access specialised outpatient physiotherapy services in a timely manner.

#### PRIORITY 7

Extension of the Advance Practice Physiotherapy initiatives which combine greater efficiencies and cost savings with improved delivery to service users (including Independent Prescribing)

### Advanced Practice

Advanced Practice (AP) physiotherapy roles first developed in the UK in 1986. Since then physiotherapists have become first contact practitioners in the musculoskeletal area within secondary care, in musculoskeletal clinics and the Emergency Department<sup>22,23,24</sup>. There are also a number of initiatives in the area of rehabilitation<sup>25,26</sup>.

Physiotherapists in advanced practice roles in Ireland contribute to the implementation of many programmes, bringing efficiencies to the system and expediting the patient pathway e.g. Oxygen clinics, Diagnostic Ultrasound and Injection Therapy in Rheumatology. Many are driving the roll out of the changes in patient pathways e.g. musculoskeletal (MSK) triage, COPD Outreach, heart failure clinics and stroke early supported discharge. There is further potential for AP physiotherapists to work in new ways to support the programmes facilitating admission avoidance and early discharge.

### 1.2 Key Challenges to achieving a “universal single tier health service, where patients are treated based on health need rather than the ability to pay”

One of the most fundamental responsibilities of the Department of Health (and its designates) is to decide what services will best meet the needs of patients and local communities and to engage these services in ways that ensure high-quality outcomes, maximises patient choice and secures efficient use of available resources.

The ISCP supports, in principle, the concept of a universal single tier health service, which will ensure equal access to care based on need, not income and designed in accordance with the principles of social solidarity outlined in Department’s *Future Health (2013)*<sup>27</sup>

#### General challenges

It has however serious reservations about the feasibility of implementation and believes a transition of such magnitude would require major capital and structural investment to support it. The experience in the Netherlands when it transformed to such a model provides some indication of the challenges involved.

The Dutch Model has been in existence for several years but evaluations completed to date only reflect the initial years<sup>28</sup>. There is however a worrying trend in non-compliance with payment of the mandatory standard package.

The rising numbers (80,000) of non-compliance with mandatory basic cover payment in an affluent country like the Netherlands, the current economic climate in Ireland, the difficulties people have encountered in paying additional mandatory charges in recent years and the large numbers who have discontinued their private health insurance would all mitigate against successful implementation. In addition if people do not see a concomitant improvement in the health services, the government will face increasing opposition.

### **Physiotherapy related challenges**

In terms of physiotherapy services provided, the situation in the Netherlands is not comparable with that of Ireland;

- The Netherlands' population is 3.7<sup>29</sup> times that of Ireland<sup>30</sup> but their physiotherapist-to-person ratio is nearly seven times greater (with a 3:1 community to hospital ratio).
- Access to all Dutch physiotherapy services is by direct access.
- There are purpose-built dedicated rehabilitation centres/clinics throughout the Netherlands, specialist in nature and committed to ongoing clinical research. (generally affiliated with local hospitals and universities).
- Dutch physiotherapists reported that increased funding resulted in increased access to treatment and rehabilitation services and the move away from hospital-based treatment.

The insurance companies identified early intervention schemes, through physiotherapy as a way of keeping inpatient costs down. However there are concerns in the Netherlands that the physiotherapy cover in the basic (mandatory) package does not facilitate the incorporation of health promotion and prevention when such interventions would reduce the burden of non communicable lifestyle conditions on the health service in the long term. Patient responsibility is becoming a cost control initiative through incentives to reduce risks, but the supports through health promotion (such as empowerment) for people to take this responsibility are not available.

### **1.3 Actions needed to plan for, and take account of, future demographic pressures and their impact on the health system**

Refer to Strategic Priorities above

- Move the health emphasis to Prevention
- Extend Direct Access and Advanced Practice Physiotherapy initiatives to address waiting lists
- Increase support /care packages to maintain people in their own homes for as long as possible
- Increase step- down facilities to facilitate earlier discharge from acute hospitals and transition to home
- Develop rehabilitation facilities to deliver short multi-disciplinary rehabilitation programmes for those in the community at risk of physical deterioration
- Implement advances in health care technologies that will impact on service delivery

## **4. Integrated Primary and Community Care**

### **2.1 Steps needed to move from the current model towards a model based on integrated primary, secondary and community health care**

## 2.2 Key barriers to achieving this, and how might they be addressed

Refer to Strategic Priority 6

2.1 and 2.2 are answered together.

### **Changing demographics, disease patterns and inequities**

- An ageing population, with the fastest population increase in those aged 85 years and over,
- Projected rise in people with chronic and long-term conditions – accounting for 70% of healthcare spend in Ireland(2012)<sup>31</sup>
- Changing disease patterns, e.g. increasing rates of NCDs across the lifespan, e.g. obesity/diabetes in children/adolescents
- Increasing significance of migratory patterns on health and well-being trends
- Significant change is likely in the next 10-15 years, driven by advances in gene and drug therapies (e.g. management of cystic fibrosis and vaccination against some cancers)

Inequity of available services and service provision across the country needs to be addressed. While the Clinical Care Programmes strives to address this problem to some degree, the patient care pathway may continue to be negatively influenced by geography unless each piece of the pathway is well defined and implemented equally in all areas.

### **Health Care reform**

- Central focus on quality and innovation – clinical and cost effectiveness, patient satisfaction and patient-reported outcomes, and demonstrable patient value and benefit
- Innovative thinking to strengthen effectiveness and productivity in service design/delivery
- Design and implementation of care pathways.
- Reform fatigue – being experienced by public sector staff

**Staffing Levels** – See Priority 4 and Section 2.3 below

### **Changing perspectives of the public and professionals**

- More accessible information available to inform choice and decisions
- Increased focus on professional responsibility, patient autonomy and public responsibility to use healthcare services effectively

### **Regulation**

- Essential need for stronger regulatory requirements and accountability to enhance public protection, safety and confidence

### **Wider political, economic and sociological factors**

- Resistance to moving from a reactive led health service to a preventative led service
- Lack of real leadership to drive such a change

- A sustained period of fiscal constraint and public expenditure cuts which directly impacted on service delivery

**2.3 Key roadblocks encountered by the ISCP and physiotherapists ( i.e. in your particular area of the health service)**

**Road blocks and how they can be addressed are included. Refer also to Key Priorities**

**2. Workforce capacity is unable to meet demands**

Delivery of physiotherapy and physiotherapy services are challenged and influenced by changing demographics, health needs of the population, the increase in co-morbidities in the general population as well as in complex ageing and special needs population, the increasing need for management of chronic and long term diseases, increasing dependency, developing treatment technologies, patient expectations and the need to improve health at a population level. Other challenges include reform fatigue and inadequate staffing levels.

The Primary Care strategy (2001)<sup>11</sup>, stated that 90% of care can be delivered locally. The demographic predictions for local populations indicate that this situation will deteriorate (ageing populations; increased survival rates for children and adults with disability; greater demand for “walk-in” (OPD) services for musculoskeletal services; people’s knowledge of the value of physiotherapy in enabling them to remain at or return quickly to work).

HealthStat information (2014)<sup>32</sup> within the public service indicates that the demand on out-patient services is a cause of frustration for both the patients and the physiotherapists within those services.

The development of an optimum physiotherapy workforce was still in its infancy, when recruitment embargoes and reductions in staffing numbers were introduced in recent years. The physiotherapy workforce is relatively low in number and cannot meet current demands.

- It is primarily a female population which has impact on actual availability at any given time (e.g. Maternity Leave, which is not currently covered in the public sector)
- Significant numbers of graduate physiotherapists are available for work but unemployed
- Restrictive HR practices within the public sector meant less sustained expansion (if any) in the public physiotherapy workforce in the short term and restricted opportunity for building capacity/maintaining competency.

**Required :**

1.1 A mapping of need and supply of effective physiotherapy services (as outlined previously) in an Integrated Care model and correcting the workforce capacity to meet the needs.

**3. Legislation**

**Maximising public protection – See Priority 5**

**Required:**

2.1 the decision by the former Minister to protect both physiotherapy titles in one register along with the agreement on grandparenting timelines needs to be finalised in law without any further dilution to public protection.

**Independent prescribing** - Injection Therapy is part of scope of some physiotherapists' advanced practice and though legally covered to administer the medication, the existing legislation prevents physiotherapists from prescribing it. In the UK legislation in 2013 enabled specialist chartered physiotherapists to have full prescribing rights.

**Required:**

2.2 Legislative changes to facilitate independent prescribing.

**Other changes required:**

2.3 Amendments to the Nursing Homes Act to legislate for registered providers to provide a standard and equal level of access to physiotherapy for residents

2.4 Policy decision from the Department of Health in relation to eligibility for physiotherapy by people who are not entitled to a medical card;

**4. Lack of involvement of Physiotherapists in relevant national consultations, strategic planning committees and healthcare management**

The Framework (2011)<sup>27</sup> referred to widespread consultation with relevant stakeholders (including professional bodies) on reforming the health service. The ISCP was not included in several strategic committees\* on which it could have made significant contribution.

\* e.g. National Strategy on Dementia, A Vision for a Healthy Ireland, National Positive Ageing Strategy Healthy Ireland Council, Special Action Group on Obesity (SAGO) and National Physical Activity Plan.

The absence of Health and Social Care professions at the highest management level has resulted in many of the roadblocks. To be fully effective, a genuine Integrated Care Model requires equal input from all stakeholders in the planning and implementation stages. The ISCP has made several requests to the Department to address this gap. (See ISCP Position Statement, 2015 Appendix 6)

**Required:**

4.1 A Health and Social Care Professionals' stream throughout the entire Health Management structure

4.2 The reinstatement of the Therapy Advisor in the Department of Health

4.3 The ISCP should be invited to appoint a representative to strategic committees

4.4 A position should be created for an ISCP nominee on the Healthy Ireland Council

4.5 If the proposed Action in the Framework<sup>27</sup> for a *National Task Force on Prescribing and Dispensing Practice* is established, membership should include a chartered physiotherapist .

**5. Contribution of physiotherapy in the Intergrated Care Model (ICM)**

Refer to Priority 6

**Required**

5.1 The potential and the evidence for health improvement by physiotherapists in an ICM is clearly outlined in Section 2 above. The potential must be implemented.

- 5.2 A co-ordinated service delivery plan for physiotherapy within a local healthcare area, incorporating all available resources (staff and physical resources, public and private) to include all elements of service required for a population is achievable. The skill set to deliver appropriate services should be mapped out in line with demographics. There should be flexibility in budget allocation for Physiotherapy Managers to contract/purchase private services to address patient waiting lists.
- 5.3 Extension of Advance Practice Physiotherapists, roles and initiatives (refer to Priority 7 and 2.5 below)
- 5.4 Involvement of Physiotherapist Managers in planning and implementing Integrated Care
- 5.5 Professional line management structures ensure active training needs analysis and skills development to meet service need.

#### 2.4 Ensuring buy-in from health care professionals to progress towards an integrated health care model

The ISCP fully supports the concept of an integrated model of care (See Section 2.1 for details) that treats patients at the lowest level of complexity that is safe, timely, efficient, as close to home as possible and where the emphasis is based on needs and evaluation is based on its impact on outcomes. It also supports clinical and service level integration.

It welcomes the opportunity to be involved in fully implementing the Integrated Care Model

#### 2.5 Examples of best practice that the Committee should consider (with refer to evidence to support this).

There are long established areas of integrated physiotherapy services in some parts of the country. In developing a 10 year plan the outcomes of joint initiatives undertaken by physiotherapists from hospitals and community working collaboratively should be reviewed. Some examples are outlined below. Refer also to Appendices 1,3,4&5

- 1. A modest deployment of resources to physiotherapy services is capable of having a significant impact on the treatment of musculoskeletal disorders.**

A national initiative supported by both the Rheumatology and Orthopaedic Clinical Programmes to achieve “significant reduction in OPD waiting lists through the use of physiotherapy-led Musculoskeletal (MSK) clinics” (HSE, 2011)<sup>32</sup> resulted in 24 Specialist Physiotherapists removing over 50,000 patients from the Orthopaedic and Rheumatology waiting lists in 18 months up to 2015.

**Required:** The potential to extend this initiative and to replicate it in other services exists and must be implemented.

## 2. Chronic Obstructive Pulmonary Disease (COPD)

Physiotherapy and pulmonary rehabilitation can reduce COPD admissions by 26% and reduce hospital length of stay thus significantly reducing the health cost - the second largest cause of emergency bed admission in UK/Ireland. (See Appendix 1 ).

### Case Study

A Canadian study reported that pulmonary rehabilitation was associated with reduced usage of public health resources, decreased direct costs, and improved health status in COPD patients<sup>33</sup>. The average reduction of total costs before and after the programme was approximately \$344 CAD (€242) per patient per annum.

## 3. Rheumatology

### Case Study

Manning et al. (2015)<sup>34</sup> examined the effectiveness and cost-efficient of upper-limb self-managed exercise programmes for people with Rheumatoid Arthritis. Results showed that participants in an eight week exercise programme gained 0.0296 Quality Adjusted Life Years (QALY), at a cost of £82 (€117). This equates to £2,770 (€3,950) per QALY, far below the NHS's guide threshold of £20,000 - £30,000 (€28,521 - €42,781) per QALY gained. The self-managed programme therefore represented a cost-effective use of resources in comparison to usual care methods, and led to lower healthcare costs and work absences.

## 4. Physiotherapists working within early supported discharge teams - Cerebrovascular Accident (CVA/Stroke)

It has been shown to be more cost effective where physiotherapists provide stroke rehabilitation in the home or in the community rather than the hospital, reducing long term dependency, length of hospital stay and reduced admission to institutional care.

In 2014, the Economic and Social Research Institute (ESRI)<sup>35</sup>, in conjunction with the Irish Heart Foundation (IHF) and the Royal College of Surgeons in Ireland (RCSI), undertook a substantial body of research centred on improving outcomes and lowering healthcare costs for people who have suffered strokes<sup>xxv</sup>. The study found that the current approach to treating people with stroke involves relatively low amounts of therapy and a relatively low availability of therapists in Ireland. The research examined the impact of Early Supported Discharge (ESD), which aims to accelerate discharge from hospitals by providing rehabilitation while the patient lives at home. It found that a 44% take-up rate for ESD would result in costs of between €5m and €10m per annum, and savings from shorter hospital stays of €12m; in other words, a net saving of between €2m and €7m.

## 5. Other examples of Evidence of Good Practice in Physiotherapy:

- Health Economic Impact of Physiotherapy - examples -Appendix 1

- Unique Role of Physiotherapy in Weight Management - Appendix 2
- Integrated working between PCCC services and acute hospitals in the network in city areas where traditionally physiotherapists worked independently e.g. St James's and Tallaght and PCCC Physiotherapy Departments - Appendices 3-5;
- Occupational Health - Early intervention can reduce the amount of time people are off sick and can stop people going off work in the first place by enabling people to understand prevention of chronic disease, re-occurrence, and strategies to self-manage effectively
- Functional Capacity Evaluations and work hardening – Fit for Work interventions;
- Training the Trainers for Moving and Handling (HASAW Act) to recognised QQI Level; and
- Aquatic physiotherapy provided by HSE physiotherapy staff in local public Leisure Centres for people with lifelong conditions.

## 5. Funding Model

### 5.1 Which health service funding model would be best suited to Ireland?

Improvements are needed in both the standard of health and the provision of health services in Ireland. This requires adequate and properly managed funding.

Countries that appear to have the best health services (e.g the Nordic countries), are funded directly from higher taxes. A percentage is absolutely ring fenced for health service provision (and cannot be diverted in any circumstance). The result is free at the point of access, no waiting lists, and consultant heavy/junior doctor light delivery of services. Private medicine is not required and all staff are on salary payment.

If implemented in Ireland, it has the potential to bring about real improvement in delivery, outcome and population health.

### 5.2 The specifics of the financing, payment methods and service delivery (purchaser and provider) of the model you are advocating

Emphasis and planning at national level based on prevention, conservative (non-invasive) interventions first and where required high tech ambulatory/day surgery interventions.

### 5.3 What are the main entitlements that patients will be provided under your funding model?

All I healthcare requirements including access to preventative measures would be included. Options such as cosmetic surgery, private rooms would be excluded.

#### 5.4 Examples of best practice, or estimated costs of such models if available.

The model used by the Nordic countries to fund their health service.

Although the costs of such a model is not provided – examples of best practice that indicate the health economic impact of physiotherapy are included (Appendix 1)

1. World Confederation of Physical Therapy (2011) Policy statement; Description of Physical Therapy
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7. OECD (2014), National Statistics Office, *Physiotherapists per 10,000 persons 1985-2013*)
8. World Confederation of Physical Therapy (2011) Policy statement; Protection of Title
9. The Kings Fund and Nuffield Trust 2011 What Next for the NHS Reforms? The Case for integrated Care
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24. Anaf S. and Sheppard L.A. Physiotherapist as a clinical service in emergency departments: a narrative review. *Physiotherapy;* 2007: 93; 243-252.

25. Ramaswamy B. Therapy led bed evaluation: July 2004- June 2006, Derbyshire County PCT, UK.
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## APPENDIX 1

### Health Economic Impact of Physiotherapy

“*Physiotherapy Works v*” is a series of information papers produced for the Chartered Society of Physiotherapists (UK) in conjunction with health economists that outline the beneficial health economic impact of physiotherapy on a number of conditions.

The **cost savings** included **reductions in admission and readmission rates, length of hospital stays, use of prescription medicines and health staff absenteeism**

The following is a summary of a sample of the research based findings that show where physiotherapy has reduced the cost burden (improved clinical outcomes are implicit).

#### **1. Reduction in length of hospital stay through early mobilisation of patients in ICU<sup>4</sup>**

A Physiotherapy led early mobility protocol showed a decrease in ICU and hospital length of stay (average 14.5 v 11.2 days) and an average cost savings of 7% on standard patient care costs.

#### **2. Reduction in length of hospital stay in people with COPD<sup>3</sup>**

Intensive multidisciplinary outpatient pulmonary rehabilitation programme including physiotherapy is an effective intervention in the long and short term and resulted in reduced length of hospital stay.

#### **3. Reduction in length of hospital stay in patients following pulmonary lobectomy<sup>3</sup>**

Intensive respiratory physiotherapy following pulmonary lobectomy reduced mean hospital stay from 8.3 to 5.7 days. Further findings included a reduction in rates of mortality, pneumonia and lung collapse.

**4. Reduced length of hospital stay and admission to institutional care in people with strokes<sup>15</sup>**

Physiotherapy in the very early stage for people with strokes (mobilising within 24 hours) and at high intensity leads to better outcomes.

In the UK, physiotherapy stroke rehabilitation is increasingly based in the community in specialist stroke services. Early supported discharge (within 24 hours) has been shown to be clinically effective in people with mild or moderate disability. It has also been shown to reduce long term dependency, admission to institutional care and length of hospital stay.

**5. Reduced length of hospital stays and future hospital admissions in people with Dementia<sup>5</sup>**

An intensive physiotherapy in-patient service and follow up home service for people with dementia showed reductions in length of hospital stays and future hospital admissions.

( 58% of the people were able to return home).

**6. Reduced length of stay in patients with cancer<sup>12</sup>**

Physiotherapy has been shown to reduce length of inpatient stays

**7. Reduction in hospital admissions and IV antibiotics through physiotherapy outreach programmes in people with Cystic Fibrosis<sup>14</sup>**

The programme resulted in substantial health care savings by significantly reducing the need for IV antibiotic treatment and hospital admissions. Increased participation rates were also found.

**8. Reduction in readmissions through pulmonary rehabilitation post COPD exacerbation<sup>3</sup>**

Showed a 26% reduction in readmission rate with cost effectiveness demonstrated

**9. Reduced admissions with Physiotherapist-led Falls Prevention programme in the community<sup>10</sup>**

The programme showed a reduction in admission due to falls in the home (32%), in institutional care (27%) and in the street (nearly 40%) over a 10 year period in Glasgow.

**10. Reduction in admissions, GP and hospital consultant visits through a Physiotherapy-led MDT service for people with Multiple Sclerosis (MS)<sup>9</sup>**

Introduction of the above resulted, over a 6 month period, in decreased GP and hospital consultant visits and hospital bed days in 38 people with MS, thereby reducing the inappropriate use of inpatient beds.

**11. Cost savings in managing early stage breast cancer related Lymphoedema prospectively<sup>11</sup>**

A cost comparison study showed that the cost of managing early stage breast cancer related lymphoedema was 80% less per patient when using a prospective physiotherapy surveillance model compared with reacting to symptomatic presentation.

**12. Reduction in prescription medicines in self-referral programmes<sup>2</sup>**

Self referral pilots in 6 NHS sites in England between 2006 and 2008 reduced the number of associated NHS costs particularly for investigations and prescribing; 75% didn't require prescription medicines. It also reduced work absence among patients. The average cost benefit to the NHS in Scotland of self referral (2009) was estimated as £2.5million p.a. <sup>1</sup>

### **13. Reduced health service staff absenteeism<sup>2</sup>**

Triaging to facilitate easy access to staff for musculoskeletal physiotherapy rehabilitation (consistently the most common reported type of work related illness since records began in UK and half of sick absence in the NHS is caused by musculoskeletal disorders (MSD) and 30% of primary care referrals) meant 53.3 % could stay at work, 21.7% returned to work within 8 days and the remainder within 30 days resulting in substantial savings on agency staff. Two government departments in Northern Ireland offered this service to staff and 80% indicated that physiotherapy prevented their absence from work.

### **14. Physiotherapy as the more cost effective option:**

- i. Cheaper and more clinically effective than drug treatment for urinary incontinence<sup>6</sup>
- ii. Health Technology Assessment showed that intensive pelvic floor training and lifestyle changes were the most clinically and cost effective first line strategy<sup>6</sup>
- iii. Recent NICE review found 5 studies on cardiac rehab were cost effective when compared with traditional care. Physiotherapy exercise focused cardiac rehab programmes are more effective than other cardiac interventions<sup>7</sup>

Extracts from Physiotherapy Works have been summarised by the ISCP (January 2014) with kind permission of CSP (UK).

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## APPENDIX 2

### The Unique Role of Physiotherapy in Weight Management

This document provides a summary overview of the unique and important skill set that chartered physiotherapists provide to optimise the outcome of weight management patients.

#### **Physical Activity Promotion:**

In tandem with the rising levels of obesity (NANS, 2011, Tanne, 2011, NHS, 2011) a dramatic decline in levels of physical activity (PA) has been reported (Brownson et al, 2005, Church et al, 2011). A strong inverse relationship has been shown to exist between physical activity and obesity (Ekelund et al, 2011, Slattery et al, 2006).

Goodpastor et al (2010) recently showed a significant positive effect for a conservative weight management programme that included physical activity intervention over a programme that did not recommend changes in physical activity. This finding underlines assertions made by several international organisations including the World Health Organisation's (WHO) (2010) and the American College of Sports Medicine (ACSM) (2010) that increasing physical activity directly influences both weight loss and weight maintenance. Assimilating these statements into clinical weight management strategies requires continued development of interventions to increase physical activity within the obese population. The delivery and development of such strategies is best done by university trained professionals with the capacity to analyse and interpret data in both theorised and practical ways.

#### **Professional Care**

The ability to appropriately manage patients in a holistic and professional manner is vital to best outcome and the patient care experience. Established professional bodies such as the Irish Society of Chartered Physiotherapists ensure high quality professional standards are met. Chartered physiotherapists are among the most established group of allied health care professionals within the multidisciplinary team, as such they help to set standards of patient care and to ensure issues such as audit, research and continued professional development are adhered to in order to ensure high standards in the delivery of care.

#### **Physical Fitness Assessment**

The physiotherapy assessment of individuals attending for weight management is intended to evaluate global fitness in order to identify the existence of structural impairments which may limit time spent in the activity required for weight management. The aims of physical testing are to: assess symptoms, exercise tolerance and the cardiorespiratory response to exercise intensity\* in a controlled setting. Furthermore testing is used as an outcome measure to assess the effectiveness of the weight management programme in improving the fitness profile of patients referred.

Structural impairments such as reduced muscle strength, muscle inflexibility, reduced range of movement and impaired balance are reported in this population and each of these factors can contribute to reduced function and an increased risk of falls and injury (O'Malley et al., 2012; Bell et al., 2011). Physiotherapy assessment and management of these concerns are vital in order to treat primary complaints, prevent secondary injury and promote optimal function.

#### **Pain Management and Biomechanical Analysis**

It is well established that weight management patients have a much higher rate of pain compared to a healthy weight population (Stone and Broderick, 2012). A recent audit of 147 adult patients who attended the weight management clinic at St. Columcille's Hospital found that 73% of patients reported significant levels of pain often in multiple locations. The most common source of pain is low back pain (52%), followed by knee pain (43%) and least frequent but still increased at other locations (29%). Similarly, in paediatrics, up to 72% of children who are obese report pain and up to 40% have sustained fractures (O'Malley et al., 2012; Bell et al., 2011; and Krul et al., 2009). Physiotherapy plays a strong and unique role here as experts in pain assessment and triage, diagnosis, biomechanical analysis, treatment and appropriate onward referral where necessary. As front line professionals, physiotherapists are undoubtedly providing the most cost effective means to manage obesity related pain issues. Without early point of contact to a physiotherapist physical function will not be optimised which dramatically influences exercise capacity, weight and overall health outcome.

#### **Respiratory Disease**

Approximately 10% of patients in obesity class III have a clinical diagnosis of type 2 respiratory failure (Audit data n=257), which is a serious respiratory disease characterised by a chronic decrease in blood oxygen levels and an increase in retained carbon dioxide levels. Type 2 respiratory failure is caused by inadequate pulmonary ventilation and is associated with chronic functional deficits and increased mortality.

Additionally, asthma and obstructive sleep apnoea are highly prevalent with weight management patients. These respiratory diseases must be managed professionally with graded therapeutic exercises and specific breathing exercises to maximise participation and functional improvement.

Physiotherapists are experts in respiratory disease and are well placed to manage these associated chronic respiratory diseases with respect to prescribed appropriate exercise in a weight management setting.

## **Type 2 Diabetes**

Another disease associated with obesity is Type 2 diabetes. The prevalence of the disease is rising dramatically. Some common problems facing this cohort of patients that require physiotherapy input are lifestyle and exercise counselling, peripheral neuropathy and pain, and increased musculoskeletal pain. Physiotherapy treatment of youth who are obese has been shown to be effective in reversing insulin resistance and pre-diabetes (Savoye et al., 2011).

## **Obesity Related Chronic Lymphoedema Like Skin Changes (ORCLLS)**

This is also a significant barrier to physical activity engagement and physiotherapists' knowledge of lymphoedema management is essential to the management of this symptom.

### **Defined role of physiotherapy**

The role of physiotherapy obesity management includes an evidence-based assessment and agreed treatment plan.

#### *Assessment:*

- 1) Beliefs around healthy growth and development;
- 2) Cardiorespiratory (exercises testing);
- 3) musculoskeletal (full musculoskeletal screen including assessment of range of movement; strength; flexibility; balance; coordination; posture; gait and bony alignment);
- 4) Sedentarism (screen-time); and
- 5) Physical activity level and associated perceived barriers to reaching recommended levels.

#### *Treatment:*

- 1) Education around general health literacy for patient;
- 2) Management of any associated conditions (painful flat feet; back pain; knee pain; weak core) identified in physical assessment;
- 3) Age-appropriate and fun therapeutic exercise training to increase physical fitness;
- 4) Assist family to make the necessary changes at home to prevent obesity developing or progressing through goal setting and motivational interviewing techniques; and
- 5) Appropriate liaison and onward referral within the interdisciplinary team.
- 6) Learning/engagement and goal setting would be part of the Adult programme

## **Patient Centred Lifestyle Education**

Adult education to facilitate lifestyle change requires specialised education and a high level of experience of patient contact and counselling. Physiotherapists are well versed in this area as it forms a routine part of almost every patient contact in routine care. Without such patient contact experience education and empowerment regarding sustained lifestyle change will not be optimal.

The area of weight management has inherent hazards with regard patient communication. It has been shown that if communication is not managed in a professional and empathetic manner with careful attention to language and realistic goal setting there can be undesirable consequences to lifestyle changes (Puhl and Heuer, 2009), which underlines to necessity for the delivery by qualified professional healthcare workers.

Patients who attend for weight management present with a broad spectrum of barriers and specific problems. Physiotherapist with a broad education and wide range of clinical experience are well placed to deal with the majority of patient specific problems in a timely and efficient manner. Results to date are promising whereby physiotherapy-led weight management has been effective in reducing body mass index (O'Malley et al., 2012).

## **Health Care Professional Centred Lifestyle Education**

Dissemination of new or changed practice across the multidisciplinary team, educating colleagues regarding the latest developments within the professions is important for the development of modern health care across the professions. Physiotherapists are well established in this role and already provide this important service across different health care settings. Physiotherapists working in the area of weight management are already very involved in the provision of new knowledge in this area which continues at pace.

\* Fitness testing focusses on using a modified BORG to encourage patients to work within an "easy to manage to a slightly challenging" range or 4-6/10

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Unreferenced data provided here are from audit data carried out by physiotherapists working in the area of weight management at St. Columcille's Hospital, Dublin and The Children's University Hospital, Temple Street.

Further details to specific areas mentioned in this document are available on request from the authors.

The ISCP acknowledges and thanks the authors; chartered physiotherapists Colin Dunlevy, Emer O'Malley and Grace O'Malley who prepared this document on its behalf., updated 08/14

## Appendix 3

### Community based pulmonary rehabilitation: a joint partnership between acute hospital and primary care physiotherapy services

M.Sammin<sup>1</sup>, P. Davis<sup>2</sup>, C. Gleeson<sup>2</sup> C. McNally<sup>1</sup>, and S. Shelly<sup>2</sup>

<sup>1</sup> PCCC Physiotherapy, HSE Dublin South West, 235 Crumlin Road, Dublin 12. <sup>2</sup> Respiratory Assessment Unit, St. James's Hospital, Dublin 8.

**Background:** Demand for outpatient pulmonary rehabilitation programmes (PRPs) outstrips availability in Ireland. A joint partnership was established between an acute hospital and a local primary care physiotherapy service to develop a community based PRP. The objectives were to increase service capacity and investigate its feasibility and efficacy.

**Methods:** Two separate programmes were run in two consecutive years. Patients were recruited from the PRP waiting list at the acute hospital. The eight-week programme consisted of twice weekly sessions of exercise and education at a parish hall supervised by staff from both settings. All patients were assessed at baseline and on programme completion on measures of exercise capacity (Six-minute walk test distance (6MWD)) and quality of life (Chronic Respiratory Disease Questionnaire (CRQ)). Data were analysed using Minitab Version 16.

**Results:** Twenty-five patients met the eligibility criteria for the PRP of which 21 patients (13 female) of mean age 70 +/- 8.35 years completed the programme. The mean number of classes attended was 12.9 +/- 2.8. No adverse incidents were reported during training. Patients had a diagnosis of COPD (n=19) and bronchiectasis (n=2). Subjects had moderately severe disease as indicated by a mean %predicted FEV<sub>1</sub> of 61.33 +/- 27.75% and median Medical Research Council Dyspnoea (MRCD) score of 2 (range 1-3). Following the programme there was a mean increase of 67.8 metres (95% CI: 24.1, 111.6) in 6MWD which was clinically significant. The improvement in CRQ

total score of 1.24 points (95% CI: 0.26, 2.22) also exceeded the threshold for clinical significance. Significant improvements were also seen in the fatigue and emotion domains of the CRQ.

**Conclusion:** This joint initiative between acute hospital and primary care was safe and feasible and led to clinically significant improvements in exercise capacity and quality of life. Findings support the development of community based PRPs nationally.

#### APPENDIX 4

##### The Feasibility and Effects of an 8-week Pilot Community Pulmonary Rehabilitation Programme

C. Baily<sup>1</sup>, M.Spencer<sup>2</sup>, N.Murphy<sup>1</sup>, P.Barron<sup>2</sup>

<sup>1</sup>Physiotherapy Department, St. James's Hospital (SJH) and <sup>2</sup>Physiotherapy Department Primary, Community and Continuing Care (PCCC) Area 3.

**Introduction** – Hospital gyms are common sites for pulmonary rehabilitation programmes, however they are high in demand and weekly availability can be limited (Ward et al 2002). Many clients may be prevented from attending hospital-based programmes due to transport issues. Pulmonary Rehabilitation in a community environment may enable more clients to access this essential component of care. The aim of this pilot community Pulmonary Rehabilitation programme was to examine its feasibility and effects on quality of life and exercise tolerance in a group of patients living in PCCC Area 3, Dublin.

**Participants** – Fifteen patients on the SJH pulmonary rehabilitation waiting list were identified as living in PCCC Area 3 and offered assessment for the programme. Seven patients (male n=4, female n=3) were recruited; however one was admitted to hospital with an exacerbation of COPD prior to commencement of the programme. Five had a diagnosis of COPD and one had Idiopathic Pulmonary Fibrosis.

**Methodology** – All clients underwent an 8-week programme (8 supervised sessions, 16 unsupervised home sessions) of exercise training and education. It was jointly run by staff from SJH and PCCC Area 3 and took place in a residential unit. The exercise component consisted of upper and lower limb strength training and endurance training as recommended by guidelines on pulmonary rehabilitation (Nici et al.) Subjects were assessed at baseline and on programme completion on measures of exercise capacity

(6 Minute Walk Test-6MWT) and quality of life (Chronic Respiratory Questionnaire-CRQ). Patients were given exercise diaries to record their unsupervised sessions at home and were telephoned on a weekly basis to ensure compliance.

**Analysis-** Descriptive Statistics (Excel) was used to analyse the statistics.

**Results** – Six patients (3 female, 3 male) completed the programme - mean age 66.6 years, mean % predicted FEV1 43.8%. The mean number of classes attended was 7 and mean number of home sessions completed was 9 as verified by the home exercise diary. On completion of the programme there was a significant increase in the 6MWT of 75.5metres, a significant decline in the fatigue domain of the CRQ (4.6 to 4.1) and no other significant changes in the CRQ.

**Conclusion** – Results of this pilot study support the feasibility and potential role of community pulmonary rehabilitation programmes in improving exercise tolerance in patients with chronic respiratory disease. Failure to see a change in the CRQ from pre to post rehab may have been due to clients receiving only 50% of the education received during a 16 session supervised programme. Randomised controlled trials with increased patient numbers are needed in the future. Directly

comparing a community rehabilitation programme with a hospital-based one would also be beneficial.

Key words –community, pulmonary rehabilitation

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## APPENDIX 5

### **Working together – a joint initiative between physiotherapists in the community and acute hospitals** (ISCP Clinical Innovation Prize, 2009)

Flynn, H. St James's Hospital

**Purpose** – Using the model of team based performance management (TBPM), physiotherapists from the Adelaide & Meath National Children's hospital (AMNCH), St. James' hospital and community areas 4 and 5 participated in a joint initiative in 2008/09. The project aimed to foster improved communication between services with an emphasis on quality, equity, person-centeredness and population health.

**Relevance** – The team was established as part of a broader drive to enhance service integration and promote a seamless transfer of care to community services.

**Description** – Following a brain-storming session with management, the following key performance areas (KPA) were established;

- 1 Quality:** Improve the quality and recording of referrals and appliance requests to community.
- 2 Equity:** Improve transparency of prioritisation system in the community.
- 3 Person-centred:** Establish a method of informing community physiotherapists of general in-services being held in St James' and AMNCH
- 4 Population Health:** Improved access to information regarding services in the hospital and the community.

Examples of specific developments include 1) creation of hospital filing systems for all referrals and appliance requests, 2) contribution to the development of a new appliance request form and 3) production of a leaflet, aimed at the healthy elderly, with information on local activities, such as walking clubs and active retirement groups.

**Evaluation** – In keeping with the model of TBPM, the team met quarterly to review each KPA. This proved an effective method of monitoring progress and all KPAs were achieved within the year.

**Conclusion** – Participation in this project led to increased understanding of the challenges facing both acute and community physiotherapy services. The referral process and communication between the hospital and the community has undoubtedly become more efficient, effective and transparent.

**Implications** – Integration of health services will play a key role in coming years. This may be the first joint initiative of its kind and it is envisaged that it will serve as a model for others to adopt in the future. **Key words** – service integration, community

## APPENDIX 6

### **Irish Society of Chartered Physiotherapists – Position Statement**

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#### **Health and Social Care Professions – Structured Representation in the Health Service**

The Irish Society of Chartered Physiotherapists (ISCP) is the sole professional body representing chartered physiotherapists in Ireland.

#### **Department of Health level**

The ISCP welcomes the stated intention of the Minister for Health to reinstate the position of Health and Social Care Professionals Advisor (formerly the Therapy Advisor's post) in the Department of Health.

#### **Health Service Executive level**

In the assumption that the above will be re-established, the ISCP calls for the creation of a Health and Social Care Professions (HSCPs) stream throughout the HSE structure to national level. This would ensure that collectively the HSC professionals would represent the HSC professions at the policy/strategic levels in each of the relevant directorates\* (i.e. Clinical Strategy and Programmes, Acute Hospitals, Primary Care, Social Care, Health and Wellbeing and Mental health) as well as managing the professions at the middle management levels.

HSCP personnel are required at a higher strategic and policy level (than currently) and can work across most clinical areas through one or other of the professions included in the group. HSCPs need to have direct representation at every level where there is other clinical representation, whether this is operational or strategic, sharing equal status with other clinical colleagues in the best interests of providing quality health services

In working on behalf of the best interests of patients and health care, the HSCP voice, views and approach can only be accurately articulated by Health and Social Care Professionals. Currently there is an obvious mismatch; although some HSCP professions are representatives for clinical strategy and programmes, HSCPs are not at Hospital Board level or at the new CHOs level, either nationally or regionally. The HSCPs can bring much to the table to positively change the health system, offer alternatives, reduce the health economic impact etc.

\* Looking at Directorate level in more detail the proposal would be to establish an Office of the Health and Social Care Professions Services Director. This office would have a Director and three divisions within that Office to lead for Therapy, Diagnostics and Social Care.

This is essential to influence the many streams in which the HSE is divided at national level, many of which impact on HSCP but none of which have HSCP input at that level.

The Office of the Health and Social Care Professions Services Director would have a primary focus in the strategic development of the Health and Social Care professions to provide optimum patient centered care, leadership, supporting excellence and innovation and building capacity in HSC professions to enhance patient care and service delivery. (2015)

## **The Irish Thoracic Society (ITS)**

The Irish Thoracic Society (ITS) is the representative body for respiratory healthcare professionals on the island of Ireland. Our work aims to advance the care of patients with lung disease through education, research, advocacy and public health information.

The ITS welcomes the establishment of the Committee on the Future of Healthcare and the prospect of a long term vision and strategy for healthcare in Ireland that is founded on cross-party agreement.

The ITS proposes that a National Strategy for Respiratory Healthcare should be a key component in plans for the Future of Healthcare in Ireland given our burden of respiratory disease in terms of disability and death together with the resultant health, societal and economic costs. A National Respiratory Strategy should encompass a cohesive approach to improving our population's lung health through better prevention, diagnosis and treatment of respiratory disease.

The following submission outlines the reasons for this. The statistics around respiratory disease in Ireland are stark and speak for themselves – Ireland has one of the highest death rates for respiratory disease in Western Europe and the highest rate of acute hospital admissions. Respiratory disease is the number one reason for emergency hospital admissions and is the most common reason for GP visits.

Respiratory healthcare is concerned with the management of 30 respiratory and related conditions. We outline in this submission in some detail the scale, complexity and challenges of current and future care for patients with these diseases.

### **Respiratory Disease in Ireland – Overview**

Respiratory disease refers to any disease that affects the lungs, the organs that allow us to breathe. Symptoms of respiratory disease include breathlessness, cough and wheeze. In many cases, these symptoms progress and lead to profound disability and often death. Respiratory diseases include diseases such as COPD and lung cancer that in many cases (but not all) are attributable to smoking tobacco products. Respiratory disease also includes conditions like Asthma, Tuberculosis, Obstructive Sleep Apnoea (OSA), Pulmonary Hypertension, Idiopathic Pulmonary Fibrosis (IPF), Sarcoidosis, Cystic Fibrosis and Pneumonia – all conditions that are very common in Ireland and lead to considerable illness, reduced quality of life and premature death in many cases.

Respiratory disease is a source of major pressure on the Irish health system. It is the most common reason for emergency hospital admission (acute lower respiratory infection and chronic obstructive pulmonary disease combined). In addition Ireland has the highest number of acute hospital admissions for respiratory disease (COPD and Asthma) in selected OECD countries.<sup>1,2</sup> Respiratory disease is also the most common reason for GP visits.

Ireland has one of the highest death rates from respiratory disease in Western Europe with rates of mortality from respiratory diseases 42% higher in Ireland than the EU-28 average in

2014.<sup>3</sup> Respiratory disease causes approximately 1 in 5 deaths in Ireland. Older age-groups are particularly affected, with 67% of deaths occurring in persons aged 75 and over.<sup>4</sup> Social inequality causes a higher proportion of deaths in respiratory disease than in any other disease area. For COPD the difference in mortality rates between the higher and lower occupational classes is 430%.<sup>5</sup>

### **Respiratory Disease in Ireland - Projections**

The population of Ireland is projected to increase from its current level of 4.75 million (based on preliminary results from the 2016 census) to between 5 million and 6.7 million by 2046. The older population (>65 years) is projected to increase significantly from the 2011 level of 532,000 to up to 1.45 million by 2046. The number aged 80 years and over is set to rise even more dramatically, from 128,000 in 2011 to between 484,000 and 470,000 in 2046. Life expectancy will also increase from: 77.9 years in 2010 to 85.1 years in 2046 for males and from 82.7 years in 2010 to 88.5 years in 2046 for females.<sup>7</sup> As respiratory disease is more common in an ageing population these data indicate that the burden of respiratory disease will increase over two-fold in the next 30 years.

At global level, the WHO estimates that by 2030, the four major potentially fatal respiratory diseases (pneumonia, tuberculosis, lung cancer and COPD) will account for about one in five deaths worldwide, compared to one in sixth of all deaths in 2008. There are also upward trends forecast in the prevalence of asthma, interstitial lung disease and sleep disorders. Respiratory diseases are therefore likely to remain a major burden on European societies for decades to come.<sup>8</sup>

### **Specific Respiratory Diseases**

The following is an overview of the main respiratory conditions.

#### *4.1 Chronic Obstructive Pulmonary Disease (COPD)*

COPD is progressive, life-limiting but treatable disease that affects an estimated 380,000 people in Ireland, yet only 110,000 people are diagnosed. The burden of care is substantial with 13,685 people hospitalised yearly and spending on average 9.5 days in hospital. The total cost of COPD hospitalisations was €70,813,040 in 2014.<sup>9</sup> The National Respiratory (COPD) Framework (2008) estimates that 10% of people over 50 years of age have COPD rising to 50% of those over 70.<sup>10</sup>

COPD is a major contributor to overcrowding in our hospitals. The National Healthcare Quality Reporting System (NHQRS) Report issued in June 2016 reports that Ireland has 394.9 COPD hospitalisations per 100,000 population, almost double the OECD average of 200.6, putting Ireland at the top of the OECD table for COPD hospitalisation. The report also shows that COPD is the most frequent case of acute medical admission. It also highlights major variations between counties in COPD hospitalisations nationwide (244.5 per 100,000 population in Kerry to 632.7 per 100,000 in Offaly).<sup>11</sup> In addition, as reported in Health in Ireland - Key Trends 2015, COPD is the most common disease-specific cause of emergency admissions of adults to hospitals.<sup>3</sup>

The Institute of Public Health (IPH) projects that by 2020 there is likely to be a 23% increase in the number of adults with clinically diagnosed chronic airflow obstruction with one third of this increase due to an increase in the size of the population and two thirds due to population ageing (including the increases in risk factor levels associated with ageing).<sup>12</sup>

The extraordinarily high level of hospitalisation for COPD in Ireland points to a dearth of resources in the primary and community healthcare sectors to adequately diagnose and treat people with COPD. This leads to increased suffering for patients as their condition deteriorates without early diagnosis or adequate management and also places unnecessarily high pressure on the acute hospital system.

Plans currently underway under the National COPD Programme to introduce integrated respiratory posts comprising of a Respiratory Clinical Nurse Specialist and Senior Physiotherapist to provide diagnostic services and advice in the community as well as plans to commence pulmonary rehabilitation programmes in the community should help alleviate the high level of COPD exacerbations that lead to hospitalisation. However it is important that these measures are implemented throughout the country and as speedily as possible.

### *Asthma*

It is estimated that 470,000 people in Ireland have asthma and we have the fourth highest prevalence of asthma in the world. This equates to 1 in every 10 adults and 1 in every 5 children. 60% of people with asthma in Ireland have uncontrolled asthma, meaning they are at risk of an asthma attack. More than one person dies every week in Ireland from asthma however 90% of asthma deaths are preventable. Asthma is responsible for over 5,000 acute hospital admissions and 20,000 emergency department attendances annually. The economic burden of asthma in Ireland is estimated to be €500m per year.<sup>13,14</sup>

The National Healthcare Quality Reporting System (NHQRS) Report issued in June 2016 reports an increase in hospitalisations for asthma from 40.6 per 100,000 in 2014 to 43.5 per 100,000 in 2015. The report also highlights major variations between counties in asthma hospitalisations ranging from 16.9 in Monaghan to 68.6 hospitalisations per 100,000 population in Longford, a four-fold variation nationwide.<sup>11</sup> International studies demonstrate that asthma and associated allergic disease is increasing (over 100% increase in a decade).

The National Clinical Programme for Asthma (NCPA) was set up to design and standardise the delivery of high quality asthma care to all who need it. Since its establishment, the NCPA has made significant progress in a number of areas including the following:

- A Model of Care (MoC) for Asthma has been developed with planned launch date in late 2016.
- A number of Guidelines have been developed for the management of Asthma:
  - *National Guidelines for the Management of an Acute Asthma Attack in Adults (launched by NCEC and developed by NCPA)*
  - Emergency Paediatric Asthma Guidelines
  - Asthma Control in General Practice Guidelines – (in collaboration with ICGP).

- The NCPA developed and has overseen the roll out of the Asthma Integrated Care Demonstrator Project across two initial sites which aims to improve the diagnosis and management of asthma patients in the primary care setting with links to specialist adults asthma services. Through the 2016 HSE Service Plan the service will be expanded to include six additional sites.
- An e-learning programme for healthcare professionals was developed by NCPA in conjunction with the Asthma Society of Ireland

It is essential that these initiatives continue to be implemented in full to ensure that adults and children with asthma receive the care and services required to meet their needs.

### *Lung Cancer*

Lung cancer is the second most commonly diagnosed cancer in Ireland, with over 2,300 cases per year.<sup>15</sup> It is also the most common cause of cancer death in both sexes and accounted for 20% of all deaths (n=1858) in 2015<sup>16</sup>.

While the high incidence and mortality of this disease has declined in recent years in men, there has been an increase in women. This trend is attributable to societal changes in cigarette smoking over the past 30 years and underlines the importance of smoking cessation and prevention efforts targeting women in particular.

Social deprivation is also a significant risk factor for lung cancer. The incidence of lung cancer is 60% higher in the most deprived compared to the least deprived fifth of the Irish population. Survival was also significantly poorer (mortality hazard 21 % higher) in the most compared with least deprived group.<sup>17</sup>

Management of lung cancer is complex and requires a multidisciplinary approach. The national cancer care programme with rapid access to lung cancer specialists has driven improved diagnostic pathways and outcomes. This together with evolving advances in diagnostics and therapies and targeted treatments for advanced lung cancer provides cause for optimism. In addition screening of high-risk individuals with low-dose CT scan may emerge further in the coming years and will become more cost-effective.

However Lung Cancer continues to result in high mortality with a detrimental impact on the quality of life of patients and their families. Given that over 90% of lung cancer in Ireland may be attributed to smoking tobacco, continued efforts to control tobacco dependence should remain central to lung cancer prevention.

### *Sleep Disorders*

Obstructive sleep apnoea syndrome (OSAS) is characterised by recurring episodes of upper airway obstruction leading to cessation of breathing during sleep. The resultant sleep fragmentation leads to daytime sleepiness and cognitive dysfunction, which can have profound adverse effects on patients' physical health and safety, quality of life, and work performance. OSAS is a major independent contributor to cardiovascular and metabolic co-

morbidities, and is also recognised to greatly increase the risk of motor vehicle accidents and injury, both of which have substantial implications for the health services.

Obstructive Sleep Apnea (OSA) is estimated to affect approximately one in five adults (approximately 100,000 adults in Ireland). One in 15 adults has moderate or severe obstructive sleep apnoea. The prevalence in children is 3%. Prevalence figures have been increasing over the past decade in adults and children, at least partly due to the growing prevalence of obesity.

Only 25% of OSA cases have been identified but as 75% are symptomatic and disease awareness has increased, it is expected that rates of OSA diagnosis will increase by 2-3 fold. UK estimates suggest that a population of 500,000 will generate 500 referrals and 200 new prescriptions for CPAP per year.

Sleep services in Ireland are currently inadequate for the management of the large volume of patients with OSAS, who currently may have to wait several years for effective therapy. Since OSAS is now a specified disorder in Irish driving licence applications where affected patients are precluded from driving until effective treatment is provided, the need to provide increased services in this area has become more pressing.

#### *Interstitial Lung Disease (ILD)*

Interstitial lung diseases such as sarcoidosis and Idiopathic Pulmonary Fibrosis (IPF) are conditions caused by damage to the interstitial space or the area around the tiny air sacs in the lungs. Ireland has the second highest prevalence of sarcoidosis in the world and recent data suggest IPF occurs at a higher frequency in those of British and Irish heritage. The diagnosis and management of these conditions requires specialist investigation and a multi-disciplinary approach. Treatments include new drugs such as pirfenidone, a drug that requires close monitoring for toxicity, and lung transplantation. Mortality rates for IPF in Ireland are higher than the EU average.

The Irish Thoracic Society has developed an ILD Registry designed to increase knowledge around the prevalence, incidence, and treatment of interstitial lung disease (ILD) in the Republic of Ireland. This will provide data on the long term prognosis of ILD in the Republic of Ireland and enable evaluation of novel treatments in ILD. It will also support research relating to the causes, distribution, treatment, and outcome of ILD in the Republic of Ireland as well as assisting in the planning and management of health services and essential resources for ILD in Ireland.

#### *Cystic Fibrosis*

Cystic Fibrosis is a genetically inherited disease that primarily affects the lungs and the digestive system. Ireland has the highest prevalence of CF in the world with 50 new cases diagnosed each year. The introduction of the newborn screening programme ensures earlier diagnosis. Around 55% of the CF patient population in Ireland is aged 18 or older. The predicted median age of survival for a person with CF is in the early and mid-30's in Ireland.

It is anticipated that the Irish CF population will continue to grow, particularly our adult population. A recent study published in the European Respiratory Journal analysed longitudinal data from 34 European registries and forecasted that in 16 countries including Ireland that by 2025 that the number of patients will increase by approximately 50%. The number of CF adults will increase by approximately 75% with children showing an increase of 20%. CF is and will continue to be a major respiratory illness in future years.<sup>18, 19</sup>

### *Pulmonary Hypertension*

Pulmonary Hypertension is a condition that occurs as a result of restriction of blood flow through the lungs that results in increased pressure on the right side of the heart. There are a number of novel therapies that have improved outcomes for patients and the disease is generally managed by specialist respiratory consultants. International guidelines recommend that the disease is managed in expert centres given the complexity of disease management. Ireland has one national treatment and referral centre located in the Mater University Hospital, Dublin.

### *Tuberculosis*

Tuberculosis remains a major infection in Ireland. While numbers have decreased over the last decade, the rates remain at 7-10 per 100,000 per year. The complexity of care has increased due to the increasing prevalence of drug resistant organisms, including multidrug resistance. Approximately 40% of cases occur in non-Irish born persons, creating a challenge in communication and follow up.<sup>20</sup> These data have necessitated a development of regional TB clinics. Management in specialised clinics improves compliance and outcome but also generates a significant workload.

The ITS has identified a number of principles that are central to tackling TB: These include education of healthcare professionals and members of the public in recognising the symptoms of TB; more rigorous implementation of WHO recommendations on Directly Observed Therapy (DOT) – where a healthcare professional is assigned to monitor treatment and support compliance with medication; control of the spread of multi-drug resistant TB (MDR-TB) and establish a national programme to screen for and treat latent TB in high risk groups.

### *Paediatric Respiratory Disease*

Respiratory disease accounts for almost half of all chronic disease in 9 year olds according to the 'Growing up in Ireland' Survey.<sup>21</sup> Respiratory disease is also the most common reason for hospital discharge for children aged 15 years and under accounting for 13.6% of total discharges in this age category in 2014.<sup>1</sup> In spite of this there is a lack of adequate respiratory paediatric manpower resources and respiratory paediatrics is increasingly being carried out by general paediatrics.

## **Risk Factors**

### *Smoking*

Recent years have seen a significant decline in smoking rates in Ireland from 29% reported in the 2007 Slan Report<sup>22</sup> to between 19.5% and 23% in 2015.<sup>23,24</sup> However smoking is still a significant risk factor for lung disease and other conditions and the health impacts of previously high rates are now being seen in the health system. In addition the Healthy Ireland survey of 2015 shows a strong link between smoking prevalence and social deprivation. Those living in the most deprived decile are more than twice as likely to smoke compared to those living in the least deprived decile. (35% and 16% respectively). Recruitment of younger smokers continues with 19% of 15-24 year olds smoking daily or occasionally. Encouragingly, 63% of the smoking population are trying to quit, planning to quit or thinking of quitting underlining the need for widespread access to adequate smoking cessation supports.

Despite significant tobacco control measures implemented over the last decade Ireland is still in the middle third performers, ranked 16 out of 34, for smoking in adults, in a table of OECD countries.<sup>2</sup> We are still some way off reaching a Tobacco Free Ireland by 2025 and efforts towards this must be sustained and unrelenting.

### *Obesity*

The Healthy Ireland Survey 2015 found that 60% of respondents are either overweight (37%) or obese (23%). The Growing Up in Ireland Survey found that one quarter of Irish nine year olds are either overweight or obese.<sup>21</sup> Compared to other countries Ireland is in the bottom third performers for obesity in adults (24 out of 34).<sup>2</sup> This has direct implications for respiratory health, in particular increased asthma and OSA rates.

### *Lack of Awareness and Under-diagnosis*

Research carried out by the Irish Lung Health Alliance in 2012 found that one in seven Irish people has a previously undiagnosed lung condition. The study concluded that undiagnosed respiratory disease is common, particularly airflow obstruction, and demographic and socioeconomic factors influence lung health in Ireland.<sup>25</sup> This high level of undiagnosed respiratory disease also points to another risk factor – low awareness levels amongst the general population of the causes and symptoms of lung disease.

## **National Respiratory Strategy for Ireland**

Given the significant burden that respiratory disease places on both patients and the health services in Ireland, it's clear that an integrated approach, supported by adequate resourcing across primary, secondary and community care is required to reverse downward trends in respiratory mortality and morbidity and to meet future needs as outlined above. We have seen the impact of both the Cardiac Strategy and the Cancer Strategy to their respective disease areas and it is now time to apply a similar approach to adult and paediatric respiratory healthcare.

A National Respiratory Strategy for Ireland should encompass the following over-arching aims:

**Prevention**

1. Increase public knowledge of the causes and symptoms of lung disease through targeted awareness campaigns.
2. Continue to develop effective policies around tobacco control and air quality.
3. Increase access to smoking cessation services nationally.
4. Reduce health inequalities

**Diagnosis**

1. Increase access to early diagnosis through greater availability of spirometry, particularly at primary care level.

**Treatment**

2. Continue to prioritise and implement the National Clinical Programmes for COPD, Asthma and Cystic Fibrosis.
3. Increase levels of respiratory healthcare staffing in line with international recommendations – including specialist nurses, respiratory physiologists and pulmonary physiotherapists.

These should be achieved through a programme to develop respiratory healthcare services as part of an integrated healthcare model taking into account the current and future healthcare needs in terms of workforce planning, population health initiatives and research.

*Workforce Planning*

Ireland has the lowest number of respiratory consultants in Europe after Macedonia at 1.3 per 100,000 population while the mean for Europe is 4.4. Ireland also has the lowest number of respiratory consultants as a percentage of total physicians in Europe ( 0.41).<sup>26</sup> Although international recommendations suggest a ratio of 1 respiratory consultant to 35,000 persons, in Ireland there is 1 consultant to every 80,000 people. At present there are approximately 54 public appointed respiratory consultants and approximately 6 respiratory WTE in private practice. The age distribution of consultants shows that 35 percent are 50 years or older and 35 percent are aged under 45 years of age. Although figures are not available for allied healthcare professionals, their distribution is proportionate to that of consultants and we can therefore extrapolate that clinical nurse specialists, respiratory physiologists and physiotherapists are also under-represented.

It is clear that respiratory disease will increase significantly (approximately 20%) in future due to population growth and aging. Based on international recommendations at present we should have at least 130 respiratory consultants in Ireland or 70 additional consultant posts. Based on population growth alone Ireland should have 200 respiratory consultants by 2046. This may reach 230 based on disease prevalence and evolving specialist respiratory care.

Increased skills and resources at primary and community level are also essential to support the diagnosis and treatment of a significant volume of respiratory disease outside the acute hospital setting.

### *Population Health Initiatives*

As outlined above risk factors for lung disease such as smoking, obesity and lack of awareness pose a significant challenge and should continue to be addressed through tobacco control, smoking cessation, promotion of a healthy diet and physical activity and public information and awareness campaigns. Health and social inequality is also a major risk factor for respiratory disease and healthcare services must become more effective at targeting the most vulnerable groups to prevent and treat respiratory disease.

### *Research*

Research has a vital role to play in helping to address the burden of respiratory disease through:

- Increasing knowledge around the causes, diagnosis and treatment of the disease
- Developing expertise and increasing the number of highly qualified and trained specialists in the area
- Providing evidence based data for increased and more efficient health services
- Increasing awareness amongst healthcare professionals and the general public around the causes and treatment of respiratory disease

Initiatives such as the ITS ILD Registry and development of other respiratory disease registries should be supported as well as the facilitation and funding of clinical and basic science research in respiratory disease and healthcare.

<http://www.irishthoracicsociety.com/>

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## Irish Vape Vendors Association

- Smoking remains one of the leading causes of death and disease in Ireland, with 19 people per day dying from smoking, and smoking is one of the largest preventable cost burdens to our health system.
- The use of e-cigarettes (vaping) has been found to represent no more than 5% of the risk to the user compared to the smoking of lit tobacco in a landmark evidence review by Public Health England. This has been echoed by a report by the Royal College of Physicians, London.
- The replacement of tobacco smoking for a lower risk alternative source of nicotine represents one of the ways which Ireland can reduce the cost and societal burden of smoking harms.
- Policies on sale, recommendation and use of these products by adult smokers must take into consideration that the relative risk is far lower compared to smoking, and any possible negative policy consequences should be carefully considered.
- There are a number of very low-cost policy initiatives that should be introduced, which would help individuals who still smoke, and overall improve public health in Ireland thus saving cost to the health system.

The Healthy Ireland Survey<sup>1</sup> of 2014 put the prevalence of smoking in Ireland at 19.5%, or 780,000 current smokers. Smoking remains one of the leading causes of death and disease in Ireland, with 19 people per day dying from smoking. It also represents one of the largest preventable cost burdens to our health system, with each hospital admission due to a smoking related illness estimated at €7,700<sup>2</sup>.

We concur with the emerging evidence based expert opinion that harm reduction – or the displacement of smoking by low risk nicotine containing alternatives – presents a breakthrough opportunity for society to reduce the disease and cost burden of smoking lit tobacco<sup>3</sup>. It has been known for many years, highlighted by one of the most forward thinking tobacco control specialists who first advanced the harm reduction theory, Dr Michael Russell, that "people smoke for the nicotine but die from the tar"<sup>4</sup>.

In a landmark evidence review, citing pieces of evidence, Public Health England put a figure on the relative risk of vaping versus smoking. The report<sup>5</sup>, led by two leading tobacco control researchers Professor Ann McNeill of King's College London and Professor Peter Hajek of Queen Mary University of London had some key findings:

- the current best estimate is that e-cigarettes are around 95% less harmful than smoking
- nearly half of the UK population at time of writing (44.8%) don't realise e-cigarettes are much less harmful than smoking

- there is no evidence so far that e-cigarettes are acting as a route into smoking for children or non-smokers
- e-cigarettes release negligible levels of nicotine and toxins into ambient air with no identified health risks to bystanders

This was followed by a paper published by the Royal College of Physicians, London, titled "Nicotine without smoke: Tobacco harm reduction <sup>6</sup>" which stated that:

- for all the potential risks involved, harm reduction has huge potential to prevent death and disability from tobacco use, and to hasten our progress to a tobacco-free society.
- provision of the nicotine that smokers are addicted to without the harmful components of tobacco smoke can prevent most of the harm from smoking.
- e-cigarettes are marketed as consumer products and are proving much more popular than NRT as a substitute and competitor for tobacco cigarettes
- hazard to health arising from long-term vapour inhalation from the e-cigarettes available today is unlikely to exceed 5% of the harm from smoking tobacco
- the available evidence to date indicates that e-cigarettes are being used almost exclusively as safer alternatives to smoked tobacco, by confirmed smokers who are trying to reduce harm to themselves or others from smoking, or to quit smoking completely
  - there is a need for regulation to reduce direct and indirect adverse effects of e-cigarette use, but this regulation should not be allowed significantly to inhibit the development and use of harm-reduction products by smokers
- in the interests of public health it is important to promote the use of e-cigarettes, NRT and other non-tobacco nicotine products as widely as possible as a substitute for smoking

Our association believes that outside of ensuring there is adequate data collection and monitoring, it should be within the Government's remit to ensure there is support and facilitation of harm reduction as a tool to reduce the burden of smoking on the state.

The following recommendations are what we consider low cost initiatives, which would improve public health and therefore represent a cost saving for the state:

- There is evidence to show that if smokers do not understand the benefits of vaping over continuing to smoke, they will not make the switch to vapour products. Some position statements by prominent health bodies are now outdated and do not take into consideration current available evidence. This needs to be rectified. A public health awareness initiative (shared among the Department of Health, Healthy Ireland, HSE, the Institute of Public Health or NGO's working in smoking cessation) should clearly communicate the relative risk of vaping and smoking so as to counter misperceptions in the public domain surrounding these products' relative safety.

- The Royal College of Physicians in London have correctly identified that physicians are key in relaying information about vaping to smoking patients. To date, none of the representative medical bodies here have publicly done so. This needs immediate rectification. The Department of Health should liaise with public health body stakeholders and urge that medical professionals provide accurate information about vaping to smokers.

- As there are no discernible risks to bystanders from vaping, policies on their use in public areas need to reflect this. In the UK a number of hospitals and medical facilities have rolled back bans on their use. We recommend that the HSE consult with hospital managers in the UK to learn how they consulted with relevant stakeholders, and perform a similar consultation with staff, HSE, users of e-cigarettes, and patients here.

- There is a framework for how vaping can be integrated into existing tobacco cessation initiatives already working well in the UK. Stop smoking services there liaise with experienced users and local specialised retailers (vape shops) for practical tips and mentoring of smokers who use their services and wish to use vaping as part of a quit attempt. The HSE should begin a similar consultation process here involving the managers of "vape friendly" UK service managers, local HSE stop smoking officers, Quit.ie, and local independent retailers.

- With regards to the recommendation above, stop smoking services in the UK have been issued with a set of guidelines that inform how best to talk smokers through switching to vaping, published by the UK National Centre for Smoking Cessation and Training (NCSCT). Given that, to the best of our understanding, the HSE outsource the provision of training materials in the area of smoking cessation to the NCSCT, we recommend that that the use of that document (or similar) be introduced here.

- Vaping represents a low risk, low cost alternative to smoking tobacco in populations where smoking prevalence is higher. This should be taken into consideration when policies that ban their use impact on vulnerable communities such as patients in mental health facilities. There are no grounds on which to ban vaping indoors, and in mental health facilities where service users and patients may be banned from smoking, forcing them outdoors, it may be preferable to allow them to vape instead. There is work being done in this area by the managers of the Leicester Stop Smoking Service in the UK, and the HSE should liaise with them as to how similar policies could be introduced here.

- An e-cigarette research forum has been set up in the UK by Public Health England in partnership with Cancer Research UK with the aim of "discussing new and emerging research, develop knowledge and understanding, enhance collaboration among researchers interested in this topic, and inform policy and practice". Those working in the area of tobacco control, public health, cancer and other related research areas (eg., cardiology, pulmonology, etc.) should be encouraged to collaborate with this forum so that Irish policy remains informed.

Gillian Golden , Administrator, IVVA Admin

<http://www.ivva.ie/homepage-2/>

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