Long Covid Advocacy Ireland (LCAI) statement to the Oireachtas Committee on Health: Long Covid April 2024

Long Covid is defined as the continuation or development of new symptoms after a Covid infection. Thousands of research papers published over the last four years confirm that it is a complex multi-organ and multi-system disease characterised by widespread inflammation and immune system dysfunction.

While we would all like to talk about the pandemic in the past tense, the reality is that it is ongoing and that Long Covid is the outstanding crisis which we as a country have not dealt with. There are people in Ireland who developed Long Covid following infection during the very first wave and have had no recovery. Some continue to worsen. Their lives are utterly devastated. People continue to join our ranks, often in disbelief both that Long Covid could happen to them in the first place and at the paucity of support available to them.

We welcome the opportunity to update the Oireachtas Committee on Health on what we are currently facing in terms of available services, education, the financial situation, mitigations, and public awareness and ask for your support for our asks which are aimed at improving a truly dire situation.

Education & Services

In October 2022, the Oireachtas Committee on Health held a session on Long Covid. At that time, you were told that knowledge around Long Covid was still emerging and evolving and that the services provided to sufferers would develop and improve accordingly. For the most part, that has not happened.

As an Advocacy Group, we have played our part. We assisted in the HIQA reviews designed to inform the model of care. We assisted (albeit unfortunately only in the post-design stage) in the FADA study designed to estimate the burden of Long Covid. We have submitted requests to provide PPI to the existing clinics, and we have offered to work with the ICGP in providing education to their members. However, while we are advocating on behalf of those who have been left with no quality of life – bedridden, unable to eat, unable to communicate etc., we are also sick and each of us will suffer the consequences over the coming days and weeks of this exertion. We simply cannot and should not have to do this alone; we need your help.

At that same meeting, the deputies raised concerns and asked many questions of those with responsibility for delivering services. In response, assurances were given. However, many of these have still yet to materialise, some even to progress. Deputy Shorthall expressed concern that the interim model of care at that time was 13 months old. It is now 31 months old and has had zero updates. Many clinics remain understaffed and therefore not fully operational. The ‘centre of excellence, one-stop shop’ planned for Long Covid patients does not exist in any hospital, instead, it has become a potluck pick and mix of services with no apparent specialised training in understanding and treating Long Covid patients. While we have received positive reports from patients about individual doctors and some multidisciplinary supports including occupational therapy and psychology, these are unfortunately the exception rather than the rule.

At the same meeting in recognition of the rapid pace of emerging new evidence on Long Covid, the HSE committed to looking at establishing clinical guidelines. Reports from patients of vastly different approaches to diagnosis and treatment prompted HIQA in 2023 to also recommend the development of clinical guidelines to achieve some consistency for patients. These have not materialised.

The question of what education and training was being provided to GPs was raised both by members of the committee and again at the Westminster Long Covid forum which LCAI partook in last year. We were reassured that training around the diagnosis and management of Long Covid was being given to GPs. Further queries as to the format of that education and training revealed that the entirety of HSE training consisted of a two-page article in 'Forum' magazine issued to GPs with instructions on how to refer to Long Covid clinics.

In November 2023, our queries to the ICGP led us to understand that the entirety of their training consisted of an article in the same magazine. This limited training material might just have been understandable in 2020 when so little was known about Long Covid. But four years later, telling GPs that Long Covid management consists only of ruling out other conditions, assessing mental health effects of the lockdown, and referring patients to Living Well programmes and online CBT, alongside a reminder that there are no evidence-based treatments for Long Covid is unacceptable and insulting. Patients expect and deserve so much more than this. This is an illness that overnight has entirely disabled previously healthy people with busy professional and family lives. And yet many are still being refused medications that will not 'cure' their Long Covid but could help manage their symptoms and improve their quality of life.

At the last meeting the deputies were confidently, optimistically told that most people recover over time. We would question the empirical nature of this statement; it is as difficult to challenge as it is to prove given that no follow-up data (or any data) is collected through Long Covid clinics as to why patients stop attending. Perhaps they have recovered, but we have enough anecdotal evidence of patients who do not return because they see the services on offer are at best unhelpful and at worst actively harmful to their health to remain sceptical. Others recover but remain well below the quality of life they enjoyed before Long Covid while some relapse following reinfection. Of much more importance is that recovery over time should not be used to justify any failure to proactively provide treatments and ongoing support for those who are not as fortunate.

While things may have improved for some patients in terms of their symptoms being validated, the lack of recognition at government and HSE level coupled with the on-the-ground reluctance to be proactive and ambitious in treating Long Covid patients means we are being failed daily.

The lack of appropriate services and the quality of education being provided mean that patients are being harmed. We have spent hours on the phone with patients, listening to stories of disbelief, dismissal, minimisation, misunderstanding and gaslighting. This cannot be passed off as a few disgruntled patients, there is a widespread problem here.

We have been permitted to share a patient's story here.

Ann is in her early forties and was hospitalised in April 2022 with COVID-associated respiratory distress. She remained in hospital for 6 months. She was soon diagnosed with POTS (Postural Orthostatic Tachycardia Syndrome) which is where a change in body position causes the heart rate to rapidly increase, resulting in many disabling symptoms.

POTS is commonly associated with Long Covid and Ann's case was extremely severe with multiple daily episodes ranging from experiencing dizziness, light-headedness, and visual disturbances which lasted hours to a full loss of consciousness.

A month later, her consultant decided that her POTS symptoms were due to deconditioning (note, POTS specialists and charities are clear that POTS is NOT caused by deconditioning).

Her consultant became adamant that movement was the cure. Ann had been using a commode, however, in a bid to force her to mobilise, and against her wishes, the staff removed her access.

For the next 5 days, Ann had a total of 47 POTS episodes, as she was forced to try to get to the bathroom. A few weeks previously Ann had lost consciousness and hit her head and required a CT scan. Despite the continued risk of falls, her care team persisted in their plan, requiring her to attempt to walk to the bathroom. Ann's body became covered in bruises from her many falls.

After expressing great distress at how ill the forced mobilisation was making her, she was permitted access to her commode but only at night. The staff regularly took 1-2 hrs to bring it, this resulted in many instances of bedwetting and soiling. As she had no access to a commode during the day and couldn't get to the toilet safely, her husband would try to remain with her, to move her himself.

A physio prescribed bed exercise. Ann reported that the day after her physio, she would find that all her symptoms were much worse. Ann has since learned that this is post-exertional malaise or PEM which has also been identified as a common feature of Long Covid. It was clear that neither the physio nor the consultant had any knowledge of PEM as they ignored these red flags.

The doctor insisted that each day she mobilise, gradually over the weeks, she became increasingly unwell until the 1st of August, the last day that Ann managed to leave her bed in her wheelchair. After that, her POTS was so severe she could not tolerate being upright at all, so was too unwell to even use the wheelchair. From that point on, Ann observed a clear deterioration in her tolerance for movement, to the point that even sitting propped up in bed began to trigger episodes leaving her forced to remain almost fully recumbent.

Ann left the hospital more unwell than when she arrived. She lost thirty-two pounds during her hospital stay.

During her stay, no clinician suggested the possibility of Long Covid, even though her symptoms were clearly consistent with that diagnosis.

The exercises and movement were clearly making Ann worse not better, but the team persisted. Despite the evidence in front of their eyes, the Drs couldn't accept that exercise was making her more ill.

In 2020, NICE issued a statement stating exercise was NOT a treatment for Long Covid. By 2022, it was well documented that for the PEM form of Long Covid, exercise could cause significant deterioration. It's extremely disappointing that Ann's medical team did not seem to be aware of this guidance.

Sadly, Ann is no better now. She can't move without triggering a POTS episode and has severe difficulties going to the bathroom and washing. She is stuck in bed, with no quality of life. Her POTS is just one part of the range of Long Covid symptoms from which she suffers.

Even attending medical appointments is very challenging as the movement triggers her symptoms, resulting in falls and fainting.

Ann was diagnosed with Long Covid just 2 weeks ago (March 2024).

It took two years, despite the severity of her illness and despite the fact that her illness began immediately following acute infection.

To date, she's received no public healthcare. Her illness has been a huge financial burden.

*How would Ann's health be today had the hospital team diagnosed her and appropriate care been given? Her case demonstrates what so many patients have experienced, that attempting to push through symptoms leads to deteriorati*on.

We wanted to share Ann's story because she suffers from severe Long Covid. Too often the voices of those with more severe forms of this illness are missing, as they are too sick to leave their beds, too sick to be seen at clinics, too sick to contact us. It is essential that there is an understanding of just how extremely debilitating Long Covid can be, despite the widespread misconception that it is merely a few bothersome lingering symptoms.

We are aware of one lady in the South West of the country, who had been dealing with severe Long Covid symptoms but was repeatedly told her symptoms were 'all in her head'. She advocated for herself repeatedly but felt extremely isolated and spiralled into depression when she was met with such disbelief about her symptoms.

This woman subsequently died by suicide.

Long Covid disproportionately effects women (one estimate suggests 70% female predominance).

Historically speaking, Ireland does not hold a strong track record in its approach to women's health. Medical conditions impacting women such as Hepatitis-C, cervical cancer, ME/CFS have often resulted in dismissal of early symptoms or diagnoses of anxiety or hysteria. The response to Long COVID from the government, HSE, and from society overall, has been yet another failed test of gender equality.

One patient's experience at a Long Covid clinic highlights this point.

''He did not want me to speak.. He was visibly frustrated throughout and kept rubbing his hands and his face and sighing when I spoke and cutting me off. He kept repeating.. "You have psychological issues. I can clearly see you have psychological issues". My mother tried to speak up for me, but he silenced her by speaking over her'.''

Long Covid also affects children and young people. During the October 2022 meeting, Deputy Hourigan asked several questions concerning Long Covid services for children. At that time, it was stated that there were no plans for specific Long Covid clinics for children, that children recovered faster than adults and symptoms tended to resolve quickly. This sentiment was also echoed by Minister Donnelly at a later stage. However, this approach is failing our children. On that note, we would like to share another patient experience.

Kate contracted COVID at age 14 in February 2022, whilst attending her first disco. Before her infection, Kate was fit and healthy. She then developed Long Covid symptoms and for the first five months was entirely bedbound..

Kate spends 50% of her daytime hours in bed and struggles to get up and down the stairs. She attends school for one lesson here and there, but after just one hour of school must recover for the day. She has missed 80% of school.

EEGs have confirmed that COVID has impacted her neurologically and triggered subclinical seizures. Kate suffers from profound fatigue and is too weak to stand to brush her teeth. Amongst her other symptoms are migraine, dizziness, loss of vision, pain in joints and loss of appetite.

The presence of her siblings means that normal family continues around her and is a reminder of what she is missing every day.

Kate was unable to do her junior certificate and is unlikely to sit her leaving. She was an avid dancer but has had to leave this and her other activities behind. Kate wishes to study law but right now she and her parents have no idea what her future looks like.

For the first full year of her illness, Kate received no medical care.

Despite daily migraines, from which the pain was waking her 6/7 times a night, she was simply told by her GP to take paracetamol, eat fermented foods and not to worry. He advised her that she was taking school too seriously and suffering from anxiety.

Eventually, she attended a public consultant, who asked her if there was something in her life she was particularly anxious about. That consultant was unable to offer any help regarding her illness.

This was 2022, Long Covid had been reported since spring 2020, two years in and neither the GP nor the consultant were able to recognise clear and obvious signs and symptoms of Long Covid.

Kate's parents have spent a significant amount on private care and on alternative therapies.

The only effective medical care that Kate has received to date has been through private services, a neurologist, and a consultant with experience in Long Covid

Kate has missed every major milestone of this stage of young adulthood. Her life has been obliterated. She is surviving, not living.

Her parents have fought for her every step of the way, but they have faced a system which they feel is unable to provide adequate care for a child with Long Covid. We are here to ask the government to ensure that Kate's experience doesn't continue to be repeated.

Kate's case is unfortunately not unique. Although some children who developed LC more recently find a more informed GP, most report that their concerns are dismissed, minimised and frequently psychologised. In many cases, it may take 1-2 years for a child to be seen by a consultant, only then to find the consultant may also not know how to diagnose and manage Long Covid. Many parents have been given recommendations that contradict international best practices regarding Long Covid such as being encouraged to maintain their previous full routine and to exercise through symptoms.

We're aware of one HSE consultant who has experience of post-acute viral illness in children and is seeing those with Long Covid symptoms. The HSE have advised that a service for under 16s with fatigue-based conditions is being developed. Whilst we welcome news of

services, Long Covid is not being diagnosed there, and we are concerned that this clinic may be basing its approach on the UK ME/CFS children's clinic model which is now extremely outdated.

We have yet to speak to one parent who felt their child had received adequate medical care. The previous Taoiseach advised that no specialised services were provided for children because Long Covid in children is 'rare and of short duration' Parents of many children, now ill for up to 4 years, would disagree.

The lack of services consistently available across Ireland has resulted in many Long Covid patients paying thousands of euros out of pocket either for private services in Ireland or to travel overseas seeking treatment that is not available to them in their own country, a situation that seems akin to an Ireland of decades ago.

This financial burden borne by individuals is further impacted by the current situation regarding employment.

Financials and Employment

Greater provision of education and services is one piece of the jigsaw in enabling the recovery of Long Covid patients. Another is providing the safe space and security of time to recover by ensuring they have the support required to focus on that recovery. Those supports must include financial support to relieve some of the pressure of day-to-day life. However, here again, we are failing those with Long Covid both in terms of recognition and in access to support that that recognition can bring.

Ireland is an outlier across the EU. We are one of only two countries, alongside Greece, which does not currently recognise Covid as an occupational injury meaning that those who contract COVID encounter difficulty in accessing social welfare for illness benefit, invalidity pension, disability allowance and disablement benefit.

The SLWP scheme that has been in operation in the HSE since mid-2020 has ensured that frontline healthcare workers who contracted Covid while on duty at the height of the pandemic can continue to receive full pay and pension entitlements while unfit for work due to their debilitating Long Covid.

An estimated 120 healthcare workers are remaining on the scheme. Over the past four years, they have faced repeated cliff-edges where the responsible government departments have arbitrarily announced that the scheme is due to end repeatedly referring queries from staff on the scheme to other departments – the DoH refers to DPENDR who then refer to the DSP and back again.

In November 2023, the scheme was extended until the end of March as the Labour Court recommended that union representatives meet with government departments to explore the matter of persons with Long Covid in the Health Services. Instead, the Department of Health supported by the Department of Public Expenditure, NDP Delivery and Reform has stated in communications that this recommendation supports the end of the scheme and has negotiated accordingly, repeatedly asserting that the standard health care sick leave scheme could be utilised. As of the 12th of April, these workers remain in limbo. This issue will be returning to the Workplace Relations Commission next Wednesday.

It is important to note that the standard sick leave scheme is not capable of adequately supporting these workers. In three months,' pay is reduced to 50%, and three months later again, and only if granted TRR provides 37% of pay for a limited period.

We would like to share the story of one of those affected.

Siobhan is a nurse and cared for Covid patients at the very beginning of the pandemic when Simon Harris was Minister for Health. She did not have adequate PPE and had no vaccination to protect her. She experienced Covid symptoms herself in early March 2020 and subsequently developed debilitating Long Covid.

She suffers from severe brain fog, word-finding difficulty, extreme fatigue, nausea, and vomiting. Her heart races wildly after minimal day-to-day activity such as showering. She cannot play with her young child who himself is afraid to leave the house for fear she will die.

In 2020, the Taoiseach was on TV promising 'we' would do everything we can to support healthcare workers of whom so much was being asked. Four years later, Siobhan is spending hundreds of euros monthly on medical care and will lose her home in a few months when her standard health sector sick leave runs out.

Everyone else was told to stay at home to protect themselves and now Siobhan will lose hers because she did what was asked of her. To use Siobhan's words, it has gone from a round of applause to a middle finger from the government.

This is perfectly encapsulated by the recent comment in the Dail from the former Taoiseach in response to a question specifically regarding SLWP who justified ending the scheme on the basis that: "Covid-19 is now being treated as any other respiratory virus would be treated and long Covid is being treated as any other chronic disease would be treated… We have moved beyond the idea that Covid-19 is a different category of disease from other viral or post-viral syndromes. The suggestion is that people acquired Long Covid at work, but that is not necessarily the case. Most people acquired Covid-19 in their homes where they spent most of their time. That may not have been the case for everyone, but it was generally the case."

At the time when this group of healthcare workers contracted Covid, it was not just another respiratory virus. It was considered so dangerous that their family members were working from home and schools were closed. This revisionism and misinformation is unacceptable. It should be emphasized that there is no clinical justification for terminating this scheme. Eligibility for the scheme was based on it being likely that Covid was acquired in the workplace. For these healthcare workers, nothing has changed. They are in the same position as they were in when they first fell ill.

If we are not willing to continue to support those frontline workers whose sacrifice you stood and applauded in the Dail just as we did around the country, whose bravery when asked to face the risk of continuing to serve our most vulnerable at the height of the pandemic while the rest of us remained at home we lauded daily in the media, and who we called 'our heroes' while promising to do "all that we can to support them"; what does that say about us as a society and how can such sacrifices be expected again in the face of any potential future pandemic if we abandon them now?

The HSE is not alone as an employer struggling to adapt and support employees with Long Covid. Employers have struggled to understand both the episodic nature and the severity of the illness or to provide the accommodations which would be needed for people to remain in work.

Reasonable Accommodations such as:

- Prolonged phased return.
- Remote working.
- Flexible work hours.
- Reduced physical and cognitive workload.
- Rest-time accommodations.
- Altered tasks, a longer time to complete tasks.
- Recognising the episodic and unpredictable nature of Long Covid; and
- Support from an occupational health professional to support pacing protocol and increases in workload and hours.

Just as the failure to recognise COVID as an occupational injury prevents access to associated supports so the failure to recognise Long Covid as a disability means that reasonable accommodations such as these are often not provided making return to work more challenging than it needs to be.

Public Awareness and Mitigations

Public Awareness

One of the most important findings that emerged from the HIQA review in 2023 was the confirmation that Long Covid can affect any person, of any age, and any prior health or vaccination status. This is important because it is at odds with much of the public perception and messaging that 'severe' Covid infections are attributable to circumstances specific to individuals or that only certain people are impacted when the reality is it can happen to anyone at any time.

We have a population that is being repeatedly infected - some people multiple times a year. Not only do re-infections further deteriorate the health of existing Long Covid patients, but research shows that each re-infection increases the risk of developing Long Covid. If the virus is allowed to re-infect the population time after time, the world can soon expect an avalanche of disability to follow. In the words of HIQA: *"the best way to prevent Long Covid is to prevent COVID-19."* Sadly, it seems for many of us the awareness of how to prevent COVID has been lost while the understanding of what Long Covid is and how it impacts people has never been communicated appropriately.

This has led to many negative consequences. There is a trickle-down effect that many patients' own family and friends do not believe them while some GPs and clinicians refuse to take Long Covid seriously repeatedly attributing symptoms to anxiety of various forms. This leads to patients starting to doubt themselves convincing them to 'push through' their symptoms instead of convalescing often resulting in causing further damage as a result. Time and again we hear parents of children with Long Covid telling us that they had no idea that children could develop it, patients believing that 'severe' COVID only affected the elderly or those with pre-existing conditions, and that its 'just like a cold now' and there is no need to stay out of work/school or avoid social gatherings with suspected or confirmed COVID.

For some time now, the Minister for Health has stressed that in terms of COVID, we are now in a phase of personal risk assessment, for example, an elderly person may choose to wear a mask due to their own personal risk being higher. However, to be able to assess their

personal risk people must be fully informed of what those risks are while certain mitigations cannot be implemented at the individual level and for which government intervention is required.

Clean Air

Still, in 2024, many people are misinformed on how the virus spreads. SARS-CoV-2 is airborne. Handwashing, while important for other pathogens, does little to reduce Covid transmission. A helpful analogy to understand what this means is to think of it like cigarette smoke. If you are close enough to someone where if they were smoking a cigarette you could smell it, you are close enough to catch COVID if they are infected. In poorly ventilated indoor spaces, the virus can linger in the air for hours, even after an infected person has left.

We have the tools to mitigate airborne transmission. The key is that we need to use them. The Health and Safety Authority published a new Code of Practice for Indoor Air Quality last year, outlining minimum standards for ventilation and air filtration in indoor workplaces - both of which play a crucial role in reducing indoor transmission of viruses like COVID, influenza, RSV, and measles. These codes apply to schools, which we know are a driving force of transmission. It is recognised that after healthcare workers, teachers are the most likely occupation to develop Long Covid. Despite this, there is no awareness, monitoring, or enforcement of these guidelines. Parents have reported Carbon Dioxide levels - an indicator for ventilation - nearly three times the legal limit in their children's classrooms. Others have told us that CO_2 monitors were not being used at all, HEPA filters were not being turned on, or filters have not been changed in two years. This is even though a UK-based study presented at the European Air Conference in 2023 showed a 20% reduction in school absences in classrooms that used air filters. Why aren't we using the tools we have to keep our children, teachers and communities safe?

Masking in Healthcare Settings

Airborne mitigations also include the use of masks - specifically FFP2 & FFP3 respirators - especially in high-risk settings. Since the dropping of the mask mandates in healthcare, Long Covid patients have been forced to risk re-infections to access critical medical appointments in often poorly ventilated rooms with unmasked patients and staff. This puts both staff and patients at greater risk at a time when the health service continues to be under severe pressure and staff numbers are limited.

Antigen Testing

Last year the HSE began advising against home antigen testing, even for individuals with symptoms. This advice, and the overall messaging from the Government that the pandemic is in the past - is recklessly putting the population's health at risk. Not only are people potentially unaware of their infection and passing it to others, but many who will subsequently go on to develop Long Covid symptoms or new onset health conditions in the weeks and months following will not connect their deteriorating health to a recent COVID infection. Many healthcare providers have already been failing to diagnose Long Covid for four years - this problem is now further magnified in the absence of testing. Without diagnosis or even suspected diagnoses, many patients will not be provided with the information or medications to help manage symptoms and give themselves the best chance of recovery - or at the very least - prevent further deterioration.

Vaccination

The Covid vaccines saved millions of lives and provided hope to us all that life could return to normal without the fear that we all experienced at the height of the pandemic. Research shows that COVID remains not just prevalent but continues to evolve. Updated boosters have become widely inaccessible to most of the population, and this winter's rollout of the Novavax vaccine can only be described as shambolic. The HSE must continue to ensure that updated boosters, including Novavax, are available to those who wish to avail of them to maximise their protection from contracting Covid in the first place.

However, historically Long Covid patients have had major difficulties in getting access to additional boosters as they were not considered officially immunocompromised. In continuing to provide vaccination we must recognise that while critical for reducing hospitalisations and death, vaccines provide little protection against infection or development of Long Covid.

It is also important to recognise that while the vaccine programme has had an overwhelmingly positive impact, it is widely acknowledged that vaccines, as with all medications, carry risks of adverse reactions, most of which are mild and transient. A minority of people suffer serious reactions. In this respect, the Covid 19 vaccine is no different. While it is important to stress that the vast majority of Long Covid occurs post infection, one form of adverse effect related to the Covid vaccine has been the triggering of symptoms consistent with Long Covid. The potential for the vaccine to also induce Long Covid like symptoms was recognised by world experts such as Dr. David Putrino based in Mount Sinai in late 2021. We therefore ask that the government also acknowledge Vaccine induced Long Covid.

Those affected continue to live with near identical symptoms to those who developed Long Covid after infection. Yet they are often subject to more disbelief and while there has been progress since 2021 with some services now accepting these patients in Ireland, many still do not have the same (albeit limited) medical and financial supports available to them.

Economics

Mitigation actions and public awareness campaigns come at a financial cost. We understand this and appreciate that there is a finite number of resources available and an infinite number of competing priorities for those resources. However, this cost must be seen as an investment and a means by which a far greater cost can be avoided.

While there is no Irish data available and international reports vary in their approach and their conclusion the overriding consensus is that the economic burden of Long Covid will be substantial if we do not act now. A report by the Kennedy School in Harvard '***The Economic Cost of Long Covid: An Update***' identified three economic costs arising from a Long Covid population of an estimated 9.6 million people: 1. Loss of quality of life due to Long Covid 2. Loss of earnings 3. Higher spending on medical care. The report concluded that the cost to the American economy could be as high as €3.7 trillion.

A recent report looking at Long Covid in the UK estimates the economic burden of Long Covid as 1. Loss of earnings 2. Higher spending on medical care 3. Loss of employment to cost the UK up to £1.5 billion annually based on the current prevalence of 1.9 million people coupled with an ongoing loss of 138,000 jobs by 2030. These projections are considered the best-case scenario. Should the prevalence of Long Covid double by 2030 - a very realistic possibility in the absence of mitigations like clean air and masking in healthcare - the economic burden would rocket to £4 billion and more than 300,000 jobs lost.

As the Harvard report concludes:

'The enormity of these costs implies that policy to address Long Covid are urgently needed. With costs this high, virtually any amount spent on Long Covid detection, treatment, and control would result in benefits far above what it costs.'

Conclusion

Thank you for taking the time to read our submission. Our asks of the Committee are below.

Our Asks

We are asking for an ambitious and comprehensive response to Long Covid. Our asks are grouped into five key headings.

Education and Services

- Specialised training in Long Covid-related service provision should be a requirement for all professionals treating patients with Long Covid directly, incorporating patient experiences in the curriculum to ensure a consistent approach across Ireland.
- Basic training should be provided for GPs to ensure that all GPs have a basic understanding of the signs of Long Covid and how to appropriately respond including treatment of symptoms, ensuring a consistent approach across Ireland.
- Additional training should be provided for those interested (e.g. specialist interest GPs) to supplement the work of the Long Covid clinics and address the geographical access issue in terms of the Long Covid clinic locations.
- Update the HSE website page on Long Covid to provide an official source where citizens can obtain up-to-date and useful information, incorporating input from patients.
- Acknowledge the existence of vaccine-induced Long Covid and include the existence of such in the training of clinicians regarding Long Covid.
- Urgently review the interim model of care for Long Covid with patient input.
- Implement HIQA's recommendations regarding establishing guidelines for the management of Long Covid, to ensure a standardised approach to Long COVID services.
- Review the performance of the Long Covid clinics to date with input from patients, recommend changes to address any issues and implement those changes.
- Establish specialised Long Covid services for children.
- Dedicate resources to the study of Long COVID and the aggregation of patient data relating to patient numbers, experience, outcomes etc. to inform future healthcare strategies.

Financials and Employment

- Recognise Covid as an occupational illness to align Ireland with the rest of Europe.
- Recognise Long Covid as a disability to ensure patients have recourse to social welfare supports.
- Reinstate the SLWP scheme for frontline healthcare workers until a sustainable long-term agreement can be reached between union representatives and government departments

that adequately reflects the sacrifice made by those workers. That agreement should incorporate healthcare workers that were excluded from the original scheme due to arbitrary cut-off.

Public Awareness and Mitigations

- Launch a patient-inclusive campaign to educate the public on the continuing risk of Covid and how to reduce that risk, to adequately inform them, thereby ensuring they can conduct an accurate personal risk assessment.
- Launch a patient-inclusive campaign to educate both the public and healthcare providers on Long Covid, emphasising how individuals can recognise the signs and obtain help.
- Implement the recommendations of the Health and Safety Authority's Code of Practice for Indoor Air Quality and invest in 'clean air' solutions for schools and public buildings.
- Reintroduce mask-wearing in healthcare settings to protect staff and patients.
- Include the issue of Long Covid in the Terms of Reference of the upcoming Covid-19 inquiry.
- Conduct a comprehensive Long Covid risk assessment to estimate the current and future scale and size of the Long Covid threat and to identify a proportionate response and action plan as per the New Zealand example attached below.

  https://www.phcc.org.nz/briefing/long-Covid-aotearoa-nz-risk-assessment-and-preventive-action-urgently-needed

Appendix A - Examples of patients' experiences

The problem	Example
Children with Long Covid left untreated	One boy in his early teens left for 2 years in severe pain daily after developing sudden onset migraine. No investigations done. No medications prescribed.
Lack of awareness of the potential danger of exercise for those with PEM and its effect on prognosis	One individual in their 20s left entirely bedbound and on a liquid only diet, requiring around the clock care after participating in a graded exercise programme prescribed by GP
Psychologising Long Covid symptoms Lack of awareness of the potential danger of exercise for those with PEM and its effect on prognosis	16-year-old patient was told she had school refusal and anxiety and she'd be grand if she got out into the fresh air and exercised
Insufficient time given to take medical history and explore symptoms. Insufficient testing, relying on old bloodwork to assess current health status	A woman described a 9 month wait to be seen for a public clinic visit. After she left feeling devastated having had just a 15-minute consultation, where no exam or tests were done, and bloods taken over 6 months previously were considered recent enough to rely on.
Pre-existing prejudices against other post-acute viral illnesses influencing the attitude of clinicians. Inappropriate, unprofessional, dismissive remarks in reference to a serious disease	One man being assessed by Occupational Health mentioned he was being investigated for a possible diagnosis of ME, the Dr scoffed and said that ME was ' in vogue a few years ago'
Mask wearing is an appropriate action to take to ensure one's personal safety during a pandemic but patients taking precautions are assumed to have psychological problems.	An Occ Health Dr remarked to a patient that she must have a problem with anxiety as she was wearing a mask to the appointment
Lack of awareness of the potential danger of exercise for those with PEM and its effect on prognosis. Implying that a complex physical condition can be cured by positive thinking	A woman was told by her Occupational health Dr that she just had to have a positive attitude and that it was normal to feel sore after exercise.

The inequity between those using private vs public LC services. Patients accessing private services consistently report greater progress in regaining functionality and quality of life	One woman in her 30s who used to work full time and spend weekends volunteering is only able to work 8 hours a week and is only well enough to do that because of symptom management provided by a private consultant.
Lack of training on cognitive dysfunction in Long Covid patients, these symptoms mean that a nurse performing her daily duties could make a mistake resulting in patient injury, or fatality. Lack of awareness of the potential danger of over-exertion/exceeding available energy for those with PEM and its effect on prognosis	A 26-year-old nurse was told that she should return to work as it would act as rehabilitation and that it would give her a great feeling of satisfaction after each shift.
Consultants at Public Long Covid Clinic over-riding prescriptions/advice of other consultants despite it being outside their specialist area	Patient told at an LC clinic, to immediately stop her cardiac medications, that she didn't need them despite them having been prescribed by a cardiologist who was still overseeing her care.
Lack of awareness of the potential danger of exercise for those with PEM and its effect on prognosis Patients/Parents left to do their own research to find the correct and appropriate management strategies regarding PEM	GP advised mother and daughter that it was essential that the girl keep pushing through her symptoms and keep attending school and her sports activities regardless of how she felt. This led to severe deterioration, and she became entirely bedbound. After learning about pacing and staying without available energy, the child has made some improvement
Tendency to make premature assumptions about the cause of symptoms	One woman was told by her Dr that her weight was likely the cause of her symptoms , even though she had only gained the weight AFTER her illness onset.
Tendency to make premature assumptions about the cause of symptoms	In one case a GP insisted to a young woman that her symptoms were being caused by her depression medications despite the fact that no changes had been made to those medications for a year
Minimizing symptoms and their impact on daily life. Lack of training on Long Covid and how to recognise signs.	Young girl told by her GP that she needed to drink more water and get out in the fresh air and the symptoms would resolve
Clinicians giving out incorrect information to patients regarding potential risks of a medication which has been licensed for many decades and which has a good safety profile in all age groups. Clinicians frightening patients and steering them away from a treatment which has been used for some time in this country and internationally to treat many conditions and to which many Long Covid patients are responding well.	Patient told they should not take Low Dose Naltrexone, a medication which had been prescribed to them by another clinician experienced with Long Covid. The Doctor who urged against its use told the patient that it would be dangerous to take it.
Lack of training in Long Covid and the fact that it is well recognised that individuals may have a genetic predisposition to post-acute viral illness. It is common to see multiple cases of Long Covid within one family. Tendency of Drs to look for psychosocial cause of symptoms when no evidence to suggest it is the case	One mother was told that her two children who both had Long Covid symptoms were simply copying one another.
Dire financial consequences for patients including risk of homelessness. Lack of public awareness about Long Covid and of	Single mother at risk of losing home due to 12k mortgage arrears. Bank encouraged her to sell but tried to work on a

Appendix B – Mitigations: Further Information

Why are mitigations needed?	Wastewater indicates the virus continues to circulate at high levels in the community, even in the absence of testing. Current vaccines, while effective for reducing severe disease and death, are not enough to prevent infection or Long COVID Immunocompromised and disabled continue to be disproportionately impacted. HIQA review confirms that Long COVID can affect anyone, of any age, any background, and any prior health or vaccine status. WHO estimates 1 in 10 *infections* results in Long COVID? Re-infections increase risk of developing Long COVID and other health conditions. Allowing the virus to mass re-infect the population will increase pressure on the already strained health system, and have dire economic consequences: UK report estimates with growing prevalence, Long COVID is projected to cost UK economy 4 billion pounds annually and more than 310,000 jobs each year by 2030 HIQA review states "The best way to prevent Long COVID is to prevent COVID-19"
How must Government and HSE mitigate transmission and impact of the pandemic?	Publicly raise awareness that SARS-CoV-2 is airborne - meaning that it can be transmitted both at short range and long-range by an infected person by simply breathing, speaking, singing, etc.[1] Useful analogy being cigarette smoke. HSE website acknowledges airborne transmission of virus - states "Getting COVID-19 is probably much less common than getting it through the air from someone who has the virus." Yet majority of the population still believe that handwashing & keeping 2 metres away is enough to protect them - a public awareness campaign to reflect updated transmission information is urgently needed. Raise awareness of and ensure implementation of airborne mitigations to reduce transmission. This includes clean indoor air and FFP2/3 respirator use in healthcare (detailed below). Encourage the use of testing to identify positive cases and provide updated guidance on isolation time (detailed below)
Legal obligations to ensure clean indoor air	The Health and Safety Authority (HSA) Code of Practice for Indoor Air Quality outlines minimum legal standards for ventilation and air filtration in all workplaces Because carbon dioxide (CO2) is exhaled by humans, CO2 levels, measured in parts per million (PPM) are an indicator of ventilation. Poor ventilation can lead to a build-up of CO2 indoors (levels 1000 ppm or above are considered high and indicate an increased risk of transmission of airborne viruses if an infected person is present) All workplaces must consistently keep carbon dioxide (CO2) under 1000 PPM under

[1] WHO, 2024: Indoor airborne risk assessment in the context of SARS-CoV-2: description of airborne transmission mechanism and method to develop a new standardized model for risk assessment, https://iris.who.int/handle/10665/376346

	HSA minimum legal standards. If levels cannot be kept under 1000 PPM through natural (e.g. windows) or mechanical ventilation, air filters should be used to remove harmful particles, including those carrying viruses, from the air, with a minimum of 4 to 6 air changes per hour. HSA standards apply to schools - which evidence demonstrates are a driver of transmission. The vast majority of classrooms are not compliant - Many classrooms do not have CO2 monitors or air filters. Even those that do, parents have reported are not being used. Parents have reported CO2 levels up to nearly 3000 PPM, HEPA filters not turned on, or filters that haven't been replaced for 2 years. A UK study showed a 20% reduction in school absences in classrooms that used air filters.[2] Dept of Health and Dept of Education have a responsibility to raise awareness of and invest in the tools to keep our children - and communities - safe.
FFP2 & FFP3 respirators	Well-fitting FFP2 and FFP3 respirators provide effective protection against transmission of SARS-CoV-2 and other airborne viruses. Long COVID and other immunocompromised & disabled persons have been forced to risk re-infections to access critical medical appointments in often poorly ventilated rooms with unmasked patients and staff. Reinstating mask mandates in healthcare settings is critical to ensuring all patients can access healthcare safely. "First, Do No Harm."
Importance of increased testing & improved guidance on isolation	HSE guidance on testing currently discourages home antigen testing even for those with symptoms - meaning more people will be unaware of their infections. Not only does reduced awareness of infections increase the risk of transmission to others (as people are less likely to self-isolate), but those who will go on to develop Long COVID or other new-onset health conditions in the weeks and months following will not connect it to a recent SARS-CoV-2 infection. Without diagnosis or even suspected diagnoses of Long COVID, many patients will not be provided with guidance on how to manage symptoms and give themselves the best chance of improvement recovery - or at the very least prevent further deterioration. Current HSE guidance for positive cases is isolation for 5 days. This is not sufficient - as the HSE website also says that a person can be infectious for up to 10 days and therefore avoid vulnerable people. There is no way to know who is "vulnerable" in public spaces, and everyone is vulnerable to Long COVID. Guidance must be updated to encourage 10 day isolation and FFP2/3 masking where isolation is not possible.

[2] https://www.newscientist.com/article/2398713-schools-cut-Covid-19-sick-days-by-20-per-cent-using-hepa-air-filters/