

# DÁIL ÉIREANN

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## AN COMHCHOISTE UM SHLÁINTE

## JOINT COMMITTEE ON HEALTH

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*Dé Céadaoin, 30 Márta 2022*

*Wednesday, 30 March 2022*

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Tháinig an Comhchoiste le chéile ag 9.30 a.m.

The Joint Committee met at 9.30 a.m.

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Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Colm Burke,	Frances Black,
Cathal Crowe,	Seán Kyne.
David Cullinane,	
Bernard J. Durkan,	
Gino Kenny,	
John Lahart,	
Róisín Shortall.	

I láthair / In attendance: Deputy Mark Ward.

Teachta / Deputy Seán Crowe sa Chathaoir / in the Chair.

## **Business of Joint Committee**

**Chairman:** No apologies have been received. Draft copies of the minutes of the meetings of 13, 18 and 25 January 2022, 1, 2, 15 and 22 February 2022, and 23 March 2022 have been circulated. Are these agreed? Agreed.

### **Impact of Covid-19 on Neurological Services, Care and Capacity: Neurological Alliance of Ireland**

**Chairman:** We are meeting today with representatives from the Neurological Alliance of Ireland to discuss the impact of Covid-19 on neurological services, care and capacity. I welcome Ms Magdalen Rogers, the alliance's executive director, and Professor Orla Hardiman, national clinical lead for neurology and professor of neurology at Trinity College Dublin.

All witnesses are reminded of the long-standing parliamentary practice to the effect that they should not criticise or make charges against any person or entity by name or in such a way as to make him, her or it identifiable or otherwise engage in speech that might be regarded as damaging to the good name of the person or entity. Therefore, if their statements are potentially defamatory in relation to an identifiable person or entity, they will be directed to discontinue their remarks. It is imperative that they comply with any such direction.

I invite Ms Magdalen Rogers to make her opening remarks.

**Ms Magdalen Rogers:** On behalf of the Neurological Alliance of Ireland, I thank the members of the committee for the opportunity to appear in front of them today. I commend the committee on providing our umbrella organisation, which represents more than 30 patient organisations, with the opportunity to highlight the impact of Covid-19 on access to services for people with neurological conditions and the effects of the pandemic on an already-under-resourced area within our health services. I will begin by paying tribute to all those who provided services and supports to people with neurological conditions and their families throughout the pandemic and continue to work to mitigate the impact on the care and treatment of people with neurological conditions. In particular, I want to acknowledge the often-taken-for-granted work of the voluntary sector in its response to the pandemic, as highlighted in the 2021 National Economic and Social Council, NESCC, report from the dialogue forum with voluntary organisations and in the words of the HSE's chief executive officer, Mr. Paul Reid. Mr. Reid referred to the importance of building a new relationship with section 38 and section 39 organisations grounded on mutual trust and respect. It is vital that the sustainability issues that threatened the sector before the pandemic and were considerably heightened by the collapse of public fundraising be addressed to ensure these organisations remain a vibrant and essential part of our healthcare system. There is a need to have effective mechanisms of funding, administration and governance that properly recognise and integrate the specialism and expertise of voluntary organisations in the management of chronic disease within the health system.

In Ireland, as in countries throughout the developed world, Covid-19 has had a serious impact on access to care and treatment for people with neurological conditions due to the closure and curtailment of services and the redeployment of staff. However, in Ireland, this impact was exacerbated because neurology and neuro-rehabilitation services were already significantly overstretched and under-resourced before the pandemic. The Neurological Alliance of Ireland

will shortly commence a project to examine in depth the hidden impact of Covid-19 on people with neurological conditions, including the impact of delayed or curtailed access to treatment and neuro-rehabilitation services. There is, however, a clear and immediate indication of the resourcing issues in neurology services evidenced through growing waiting lists and waiting times experienced by patients. The latest figures available from the National Treatment Purchase Fund, dating from February 2022, show there were 23,815 people on waiting lists for a neurology appointment. This is by contrast with 13,218 on the waiting list in 2015. The recently published waiting list action plan commits to a target of ensuring that no one is waiting more than 18 months for an initial outpatient department appointment. In January 2022, there were 7,587 patients waiting for more than 18 months. This is an increase from the 4,871 waiters in January 2019, which was before the pandemic. Reducing this number and actively managing the ever-increasing waiting lists for access to neurology services cannot be achieved without additional investment in resources, especially in the context of Covid-19 backlogs.

The Neurological Alliance of Ireland carried out a nationwide audit of neurology resourcing in November 2020. One of the stark findings that emerged from this audit was the critical shortage of nurse specialists across neurology services. According to the model of care for neurology services in Ireland, we have an overall shortfall of 100 nurse specialists across neurology services. What does this mean in practice for the more than 800,000 Irish people living with neurological conditions represented by the member organisations of the Neurological Alliance of Ireland? It means that four fifths of Irish people living with Parkinson's disease, for example, do not have access to a nurse specialist, while there is an absence of nurse specialists in adult neurology services for complex neurological conditions such as muscular dystrophy and Huntington's disease. This led the alliance to launch its Patients Deserve Better campaign to tackle the shortage of 100 nurse specialists within neurology services. I pay tribute to the committee members in that I recognise their support for this campaign in their local constituencies since it was launched in October last year. More than 90 parliamentary questions have been raised on this campaign, and it has been raised on almost 20 occasions in both the Dáil and Seanad, including in the form of topical issues and commencement matters.

Investing in nurse specialists in neurology services is critical to reducing waiting lists and improving patient care. We have clear evidence within our health system of the role of nurse specialists in waiting-list reduction and the prevention of hospital admission. The final evaluation report on the benefit of advanced nurse practitioners, launched by the Minister for Health, Deputy Donnelly, in May 2021, notes that an average of 4.3 patients per advanced nurse practitioner are avoiding hospital admission weekly and points to an average reduction of 3.9 patients per week from specialist waiting lists.

The neurology clinical programme will make proposals for the 2022 Estimates process that will recommend the recruitment of significant additional numbers of nurse specialists in neurology services, as well as other clinical staff, as part of a five-year plan to implement the model of care for neurology services. This will require year-on-year investment in what could be up to 20 specialist nurses each year to tackle the shortage of specialist nurses in neurology incrementally. We request that the committee make urgent representations to the Minister for Health in support of our key ask, which is to increase staffing numbers significantly within neurology services, particularly in specialist nursing, in line with the model of care for neurology and within the lifetime of this Administration.

I sincerely thank Professor Hardiman for supporting the Neurological Alliance of Ireland here today. We welcome any questions from the committee.

**Senator Seán Kyne:** I welcome Ms Rogers and Professor Hardiman. I acknowledge the campaigning work of the Neurological Alliance of Ireland. All Oireachtas Members received copious emails before Christmas and since from its members and other people advocating on behalf of family members and loved ones, with some success. That has to be acknowledged.

Ms Rogers mentioned that outpatient lists are now approaching a 50% increase since 2015. This might be an obvious question but, leaving Covid aside, why has that happened? Is it retiring staff who have not been replaced? Is it increased referrals or diagnoses? Is it increased patient life expectancy, repeat consultation visits or a loss of graduate nurses? Is it a combination of everything?

**Professor Orla Hardiman:** It is probably all of the above. The demographics in Ireland are changing, as members are aware. One reason is that we have an increasing and ageing population, and neurological conditions occur later in life. Another reason is that many neurological conditions that were previously essentially diagnosed but not really engaged with thereafter are now treatable conditions, so there is a need to continue to provide multidisciplinary care. The unmet need has increased because the benefits of attending neurological consultations with multidisciplinary services integrated by specialist nurses is now very much to the fore. The need and the population have increased and the population is ageing but there is actually a lot more we can do now to improve the outcomes for and quality of life of people with neurological conditions.

**Senator Seán Kyne:** Is Professor Hardiman referring to services immediately post diagnosis or ongoing care and rehabilitation for the rest of the person's life?

**Professor Orla Hardiman:** It depends on the condition. Some of the work we have been doing within the clinical leads programme is to think about how we might integrate the delivery of services for people with neurological conditions along the lines of the Sláintecare aspirations. Of course, that is about providing care at the lowest level of complexity and closest to where the person lives to the greatest extent possible. That means providing a really good regional service for people with neurological disabilities. Unfortunately, there is significant geographic inequity in the delivery of care for people with neurological disability. That is very much the case in the north west and, to some extent, in the south east and Dublin. The regional inequity is significant and that has very much impacted the waiting lists for people with neurological disabilities.

**Senator Seán Kyne:** To which hospital groups or CHO areas is Professor Hardiman referring?

**Professor Orla Hardiman:** The issue of how we might develop neurological care in Ireland is very much a work in progress within the group that I lead in the clinical design or clinical leads programme. We have identified ten hubs for neurological care. Five of these are in Dublin, at Beaumont Hospital, the Mater, St. James's, Tallaght and St. Vincent's. From a regional point of view, there is the South/South West Hospital group in the Cork and Kerry region, the Waterford-Kilkenny region, the Galway region, Sligo and the north west, and Limerick. There are different levels of maturity in terms of the delivery of services and the integration of multidisciplinary care within these regions. Probably the best developed are in the Dublin areas and the least well developed are in the north west and the south east. I refer to Galway and Sligo. There is very significant unmet need north of Sligo, in the Letterkenny-Donegal region. That whole western part of the country is very poorly served at the moment.

**Senator Seán Kyne:** As regards nurses specialising as neurology nurse specialists, what is

the process there as compared with a standard nursing graduate, if that is not a poor choice of words?

**Professor Orla Hardiman:** It is part of nursing professional development. It is wonderful that in the course of my professional career we have had a really good career structure for nurses. Talented clinical nurses no longer have to go into management to progress their careers. We have clinical nurse specialists, advanced nurse specialists and advanced nurse practitioners. The career trajectory for nurses when they come out of college is to undertake general training. Those who are interested then undergo specialist training at clinical nurse specialist level and can then extend out to advanced nurse practitioner. We do not have many advanced nurse practitioners in neurology. We have some clinical nurse specialists. The level of expertise or specialisation of the clinical nurse specialists depends a little bit on where they are located. There are parts of the country where it is appropriate, for example, to have a general neurology nurse specialist, but there are other parts of the country or areas where the service is sufficiently mature that there is far more scope for people to specialise. For example, we have four specialist nurses in motor neurone disease funded by the HSE. We need more of them. Many of our hospitals have multiple sclerosis nurses because that is a relatively mature service, although still under-developed. Some hospitals have Parkinson's disease nurses. Some of the underdeveloped regional areas to which I referred have scope to put in neurology nurses who we could then help to support, mentor and specialise as the service grows in the context of the development of this hub model where we have a hub of specialist care providing the whole range of neurological services with a full multidisciplinary team in one of the ten hospitals I mentioned and feeding out into a notional population of 500,000, for example. The hubs would provide the basic level of care required for people with common or less common neurological conditions, while care for those with rare neurological conditions would be centralised in one or two major hubs of tertiary or quaternary referral. The level of nursing expertise would be determined by the needs within the hub.

**Senator Seán Kyne:** Budget 2022 provides for an additional 16 clinical nurse specialists and advanced nurse practitioners. I know the campaign is for 100 additional specialists. Three additional specialists have come to Galway, which is certainly welcome, but up to nine of them are needed in the general Galway area. Budget and funding aside, are there sufficient numbers of graduates who would be in a position to take up positions if those were available or is it a longer feed-in in terms of ensuring there are sufficient numbers of specialists coming through the system?

**Professor Orla Hardiman:** There is certainly an appetite among my nursing colleagues to develop. That can be seen in the Sláintecare implementation programme we undertook in respect of headaches. We identified three sites to develop a pilot project for headache management that focused specifically on the role or development of nursing. We had no difficulty recruiting nurses to those sites. Our expectation or hope in the context of the scheduled care transmission programme is to roll out that model to all ten sites for neurological care. We do not anticipate any difficulty in that instance in recruiting nurses who are interested in developing expertise within the headache or migraine fields. There is an appetite among our colleagues in nursing to engage. We need to be careful to ensure the programme is developed appropriately and that the resources and supports within the multidisciplinary team are there as we grow the nursing programme. Nurses' roles are best implemented when they are working as part of a larger multidisciplinary team, so there is significant investment required across the board for other members of the multidisciplinary team as well. Having a nurse who does not have the wherewithal to engage with other specialists and professionals limits the role and agency of the



nurse.

**Senator Seán Kyne:** Professor Hardiman expects that, realistically, the figure of 100 additional nurses will be reached in the course of several years. How many years would be realistic for training and for ensuring that a sufficient number of specialists are coming through?

**Professor Orla Hardiman:** At present, the training programme for these types of specialty services is through a mentorship system where the professional engages with an expert perhaps not of the same profession. For example, often it would be nurses engaging with doctors and learning on the ground. There is a role, of course, within the higher education sector to develop programmes of training and professional development, which is currently something that in my other job within the university is very clear. Certainly, the nursing services across the universities are alive to the need for that. It will be a combination of professional training with mentoring and educational programmes, which clearly will have to be resourced as well.

**Senator Seán Kyne:** I thank Professor Hardiman and Ms Rogers.

**Ms Magdalen Rogers:** I wish to respond briefly. The Senator spoke about the waiting lists for neurology and the impact of the pandemic and asked what the reasons were for them being so high. The Neurological Alliance of Ireland, in collaboration with the neurology clinical programme, carried out a national audit of neurology resourcing around the country in late 2020. We waited until late 2020 in order that it would not be impacted by the redeployment of staff. We were reassured that all staff were back in their normal posts by then. We compared that with a similar audit we had done in 2015. We found, very worryingly, that levels of staffing across neurology services had remained relatively static in those five years and had even decreased in some areas, particularly with regard to allied health professionals and the proportion of whole-time equivalents that were available to the neurology services.

Neurology staffing, as Professor Hardiman explained, has not kept pace with demand and especially in respect of nurse specialists. Even where there are nurse specialists in place around the country the case loads for those nurses are far in excess of what they should be. The recommended case load of patients for a multiple sclerosis nurse is 316 patients. We found that this is far exceeded, especially in the regional centres, so even if a nurse is in place and it appears on paper that there is a nurse providing a service, often those case loads are unmanageable and an additional post needs to be put in place there.

**Professor Orla Hardiman:** It is also important to note that as we develop new treatments - and multiple sclerosis is a very good example of that because there are many treatments for the disease now and it is very much more treatable compared with when I started out in my practice - continued surveillance and engagement with services are required. Those numbers change all the time. The ratio of nurses to patients will change because the need will change as well. These are evolving services and evolving treatments. It is also true with Parkinson's disease. We have some new and innovative treatments for Parkinson's disease, for example, deep brain stimulation. We also have a lot of evidence that engagement with multidisciplinary rehabilitation services can improve outcome and quality of life for people with Parkinson's disease and many of those services would be integrated by nursing specialist services. That is a real limitation at present in this country.

**Deputy David Cullinane:** Our witnesses are very welcome. I thank them for their presentation. My first question is more an observation with a question in it. It relates to waiting lists and the waiting list numbers for neurology. Often the focus is on the global number of 900,000

people on some form of acute hospital waiting list. I understand 630,000 are on an outpatient waiting list with 160,000 people waiting over 18 months. It is useful to go under the bonnet in respect of those figures and look at what impact they have in different specialties. Neurology is one where the wait times have increased dramatically since 2015. There are two things happening. The number of people who are on waiting lists and the number increasing is one thing, but the length of time people are waiting is the critical issue. If more people are waiting more than 18 months, and there is a threefold or fourfold increase in the numbers waiting over 18 months, that is critical and shows that there is a problem.

Separate from the acute waiting lists is the number of people waiting for a diagnosis or access to diagnostics. Is that a problem in neurology? There are 230,000 people on a waiting list for a diagnosis. Is that something the witnesses have encountered in neurology and is it an issue that arises in access to community diagnostics?

**Professor Orla Hardiman:** Yes, that is very much a live issue. I thank the Deputy for raising it. Looking at the waiting lists for neurology, and we have done some due diligence on this, approximately 25% to 30% of people on the waiting list are there for a headache or headache-type disorder. Clearly, that is of concern because when people get headaches people think that they might have a brain tumour. It has been the case up to quite recently that the process of investigating headache would require diagnostics. If people have health insurance they can buy a scan, but obviously that is not appropriate. We should be able to provide access to diagnostics for everybody in an equitable way.

In the past year or 18 months, the HSE has developed a programme whereby primary care practitioners, through the National Treatment Purchase Fund, can now access diagnostics within the community. That should start feeding into the need for diagnostic services and specialist opinion. In addition to that, the development of the Sláintecare implementation programme should help to reduce the level of the waiting list for that 25% to 30% of people who are waiting because of headache. Furthermore, when we look at the reason we have waiting lists, we look at things like the new-to-return ratio in clinics. That is quite variable as well, depending on the type of clinic. For some clinics' specialist services it is very appropriate that there would be many return patients, multiple sclerosis, motor neurone disease or Parkinson's disease being a case in point, but in other instances there might be other ways of managing the disability. Headache is a good example of that. Epilepsy is another good example. We could build a service whereby the other specialty services, particularly specialist nurses, working closely with the voluntary sector, can implement a programme of self care with professional support. We have been exploring that with the Sláintecare-funded migraine programme and have demonstrated that it can be very beneficial. There is also a programme for epilepsy that does that.

**Deputy David Cullinane:** I refer to the alliance's recommendations. We all accept that the waiting times are too long and that we need more capacity. The alliance has clearly set out its request in respect of increased staffing capacity, especially specialist nurses. I am assuming that is advanced nurse practitioners.

**Professor Orla Hardiman:** It is specialist nurses and advanced nurse practitioners. It is part of the career progression.

**Deputy David Cullinane:** The alliance says that 100 are needed. What is the time period for that? Obviously, the alliance wants as many as possible as quickly as possible. What is the request regarding those 100? How quickly are they needed in the system?

**Professor Orla Hardiman:** We are pragmatic in this regard. A five-year plan is an acceptable way of developing and growing this. As I said, we need to implement a learning mentorship training programme. We also must be very aware of the geographical inequity and the need for investment in the regional services because there is a greater unmet need regionally.

**Deputy David Cullinane:** With regard to the specialist nurses and the advanced nurse practitioners, one of the issues that has been highlighted is the very high wait times for acute hospital. However, many of the services are provided in the community, where they should be provided. When we talk about specialist nurses, is that a mix of nurses who would be in acute hospitals and in the community?

**Professor Orla Hardiman:** As we have been developing the scheduled care programme with the HSE team on the clinical scheduled care transformation programme, we have also been exploring the relationship between acute hospital care and community care. There is great scope for outreach services and, to some extent, services delivered in the community but in a type of spoke model with a hub.

**Deputy David Cullinane:** However, in terms of the alliance's request now, the main focus would be in acute hospitals as regards those specialist services.

**Professor Orla Hardiman:** For neurological services, a linkage with an acute neurology hub is essential.

**Deputy David Cullinane:** Obviously, we need as many neuro-rehabilitation teams as possible. Only a small number of additional teams have been funded in recent years so we definitely need more. In what areas are there shortages? First, are the teams that are up and running fully staffed? In the area of rehabilitation, there is a shortage of occupational therapists and physiotherapists across the board. Children with disabilities, for example, have difficulty accessing services, which is in the spotlight at the moment. What areas in the community side of things, including rehabilitation, are experiencing shortages and real difficulties?

**Ms Magdalen Rogers:** We are very much focusing on neurology and neurology nurses, but I am very glad Deputy Cullinane has raised the issue of the neuro-rehabilitation strategy because it is something we in the Neurological Alliance of Ireland are extremely concerned about. The three-year implementation plan for the neuro-rehabilitation strategy was published in February 2019. That committed to establishing the multidisciplinary community neuro-rehabilitation teams that the Deputy is talking about in every CHO in the country. As it stands at the moment, despite funding being provided for two additional teams in 2019 in CHO 6 and CHO 7, those teams have yet to be established and there are still no dedicated community neuro-rehabilitation teams in a majority of other areas of the country

**Deputy David Cullinane:** Can Ms Rogers give us a flavour of what those teams comprise?

**Ms Magdalen Rogers:** There is a well-functioning team in the mid-west. It is a multidisciplinary team that has psychology, speech and language therapy and occupation therapy. It provides a six- to eight-week intensive period of community neuro-rehabilitation for people with a range of neurological conditions, both sudden onset conditions like acquired brain injury and progressive neurological conditions like multiple sclerosis, Parkinson's disease and so on. The team provides an extremely effective service to maintain people's health in the community. These are people who have been discharged from hospital and also people who are living in the community.



In terms of indicators as to how well that is working, we asked in our neurology survey in 2020 about access to community neuro-rehabilitation. Neurology would be one of the main referrers to community neuro-rehabilitation services but the neurologists highlighted to us that access to community services had actually worsened since 2015. It was more difficult to get access to community neuro-rehabilitation.

**Deputy David Cullinane:** I have a related question on neuro-rehabilitation beds. Are they primarily in acute hospitals or are they also provided by some of the voluntary organisations? I imagine that some of those beds are in the community as well. Is there a capacity issue in terms of neuro-rehabilitation beds as well as staff?

**Ms Magdalen Rogers:** There certainly is a capacity issue with specialist neuro-rehabilitation beds for the type of neuro-rehabilitation provided by the National Rehabilitation Hospital, for example. We estimate that we only have half of the specialist neuro-rehabilitation beds that we need in the country. The majority of them are located in the National Rehabilitation Hospital in Dún Laoghaire. Again, as part of the implementation plan for the neuro-rehabilitation strategy, it was envisaged that there would be neuro-rehabilitation units with a minimum of 20 beds all around the country, especially in the west and south, which are areas of huge need. However, we have not seen progress on implementing that strategy. When we appeared before the Joint Committee on Disability Matters, we highlighted that the neuro-rehabilitation implementation group did not meet at all in 2021 to progress the strategy.

**Deputy David Cullinane:** I will just make one final observation. I thank the witnesses for their responses, and I fully support all of their requests. Obviously, we need to be practical in terms of how quickly we can respond to those requests but it must be done and the strategy must be properly resourced.

I want to comment on the section 39 organisations and their funding model. Unfortunately I did not have time to pose questions on that but I am fully aware of the sustainability needs of that area. There are issues in relation to staff and pay and conditions which need to be addressed if we are going to recruit and retain staff within section 39 organisations. When it comes to neurology, the voluntary sector and the section 39 organisations are significant providers of services and we need to make sure there is a sustainable funding model for that sector. I did not want to finish my contribution without recognising that. I thank all of our witnesses.

**Professor Orla Hardiman:** That is a really important comment about the relationship between the voluntary sector and the HSE-delivered services. There is a very close relationship there and we really need a better way of generating service-level agreements than what has been happening up to now. I completely agree with Deputy Cullinane on that.

I would also like to add a comment on rehabilitation. In order for a neurological service within the country to work effectively, we need neuro-rehabilitation teams within the community. We are very much committed to the Sláintecare model, but that does not take away from the fact that each of the centres for neurological care to which I referred earlier should also have a full complement of multidisciplinary services. Specialty services within the hospital sector are required in the acute interaction with patients and also in the chronic management of rare and complex diseases. There are some models of this working well between the hospital and the community, where there is an outreach service between the hospital rehabilitation service and the community service. That is a model we should be using. There is a massive need for community neuro-rehabilitation, but there is also an equal unmet need for hospital-based neuro-rehabilitation within the neurology hubs around the country. As the Neurological Alliance of

Ireland survey demonstrates, that is seriously under-resourced at the present time.

**Chairman:** Thanks very much. Deputy Lahart is next.

**Deputy John Lahart:** I thank our guests for their presentations. I attended a recent event on Huntington's disease. In my conversations with the Neurological Alliance of Ireland, the importance of advocacy was made clear. To have even one or two voices advocating for those suffering from what are termed rare neurologically debilitating conditions is vital.

I want to focus on the nurse specialists initially and share a personal experience. My late father passed away in 1995. He had motor neurone disease. At that time, the care of patients with motor neurone disease was probably at the stage that the care of Huntington's disease patients is at now. There was very little available. I remember one experience that I shared with Ms Rogers yesterday. My late father had to spend a period of time in St. James Hospital. We invest a huge amount of trust and faith, and rightly so in many cases, in nurses, but what struck me from his experience there was that the nurses really did not have a clue what the symptoms and manifestations of motor neurone disease were. That surprised me at the time but it should not have done. They were completely lost. That situation has changed considerably as a result of the work of Professor Hardiman. There is now a course and a pathway for patients with motor neurone disease, assisted I suspect in part by some very high profile individuals who have had personal experience of it. It has been highlighted a lot in the media but it is not always possible for people with rare neurological conditions to highlight their cases or to have people advocate for them.

What training, over and above general nurse training, do specialist nurses get? Why are they so vital to the continuing care of people with neurological diseases and how long does that training take? When they have done that training, how is it applied in hospital settings and community settings?

**Professor Orla Hardiman:** I thank Deputy Lahart for his comments on motor neurone disease. It is probably a very good exemplar of what can be done. I take the Deputy's point about the tragedy of some people who are in the public domain who developed this condition. I must also say that the voluntary organisation, the Irish Motor Neurone Disease Association, IMNDA, was very much instrumental in the development, through Beaumont Hospital, where I work, of a national service for motor neurone disease. Advocacy is important but commitment and an understanding of the disease is equally so and that was done in collaboration with the IMNDA.

In terms of the types of training we would require for specialist nurses for these rare conditions, the programme for training, as I mentioned to Senator Kyne earlier, is that nurses will train initially at staff level and then at clinical nurse specialist level. That training is undertaken, to some extent, like an apprenticeship by operating within the system and being mentored by more senior individuals. The role of the advanced nurse practitioner is one to train and teach as well. We have very few advanced nurse practitioners at the moment in Ireland but with those that we have, and also the candidate advanced nurse practitioners, much of their remit is to undertake training and the education of younger colleagues and colleagues in other disciplines in order that the experience the Deputy's father and his family had would not be replicated and that people would understand the disease.

There are conditions for which we have not really been able to initiate that type of training programme of which Huntington's disease is a very good example. Where the condition is complex, where the manifestation or presentation of the condition can be quite chaotic and

difficult. There is also a high risk of falling out of the system and of not being able to access service because of behavioural change. Understanding the factors that lead to this is really important. There is a need to train nurses and other healthcare practitioners to understand the chaotic nature of the condition, identify means by which we can continue to care for those people and provide a meaningful service that enhances and improves quality of life for people from the time of diagnosis through to end of life. Does that answer the question?

**Deputy John Lahart:** Yes. I acknowledge the IMNDA. Even 30 years ago, it was a huge resource. What resources are necessary to replicate the motor neurone pathway of care across other rare neurological debilitating diseases?

**Professor Orla Hardiman:** We have thought a lot about this in the context of the scheduled care transformation programme. In fact, we have been working with Dr. Siobhán Ní Bhriain, the clinical lead in integrated care, on identifying the pathways. We have set ourselves the task of mapping out pathways for rare neurological diseases. We have mapped out the motor neurone disease pathway because it is well established, although it still requires some resourcing.

The pathway for Huntington's disease and other rare conditions - and we are using Huntington's disease as an exemplar - is much more complicated for a number of reasons. The services that are required are cross-disciplinary and across a number of different funding structures within the HSE, which is very challenging. Huntington's disease also comes in under the young onset dementia programme, which is under the remit of the National Dementia Office. In our consideration of what this might look like, one of the things has been to really determine the need to establish a working group with all of the stakeholders. That would include the National Dementia Office, the neurology clinical lead, me, representatives from psychiatric services that are hospital-based and community-based, genomics, representatives from the national genetics programme, representatives from palliative care and, finally, representatives from the national physical and sensory disability programme, because with Huntington's disease and similar conditions, where there is a progressive degeneration there is also a need for long-term care. Many of these people are under the age of 65. The resourcing that is required comes out of the national physical and sensory disability pot of money, which is under the control of the local regional disability managers and which means that there is a limit to that money.

In order for us to develop a programme that is meaningful and impactful, we need to look at the overall cost to manage somebody with a condition like Huntington's disease from the time that he or she is pre-symptomatic and has a gene variant that we know is going to cause the disease, right the way through to end of life. That is a very big programme that requires many different stakeholders. It is possible. We could certainly map it out and we could definitely put a price tag on it. However, the challenge is going to be how to resource that in the current iteration of resourcing within the health sector, which is, unfortunately, not yet that the money follows the patient, it is being able to dip in and out of the various different funding pots that are available, and that leads to many tragic situations. In conversation with the Deputy, we elucidated one very tragic story of a young man who has fallen out of the system and has nowhere to go. There is no funding for him to go into long-term care in an appropriate setting.

I suggest that we ask this committee to think about these types of overarching strategic developments that would require multiple stakeholders. We have the support of my colleague, the lead in integrated care, Dr. Siobhán Ní Bhriain, in this regard to set up a working group with very clear terms of reference, timelines and deliverables to come out with a plan and a price in terms of what it would look like to provide an integrated service for people with Huntington's disease.

in the context of Huntington's disease, there is a charitable entity, Bloomfield Health Services, which is located in Deputy Lahart's constituency. Bloomfield has expertise in dealing with the later stages of Huntington's disease. We need a system within neurology to allow us to develop high-level service level agreements at national level. I know from my conversation with representatives from the IMNDA that there is a service level agreement which the IMNDA has with the authorities in Dublin north, but the service and reach are national. If we are going to do this effectively, we should have a HSE system whereby we can generate an overarching service level agreement with the expert entities that are outside the HSE system but within the voluntary sector, yet are proven to have an expertise and a skill set that is beneficial to patients. That is very difficult to establish at the moment with the structures we have.

There are two things. One is to develop a system where we commit to the money following the patient, where we can map out what needs to happen and identify a funding source that does not involve seven or eight different funding structures. The second is where the expertise is available but not within the public sector but within the charitable sector that we can access that expertise with an overarching service level agreement. Those are the two take-homes from this meeting that I would like to leave with the committee, in addition to the messaging around nurse specialists. It is the integration of delivery of care between the service that I provide, as a public HSE-funded practitioner, and the integration that I have in my practice as a representative with the voluntary sector.

**Ms Magdalen Rogers:** The Neurological Alliance of Ireland is working on a project with the Disability Federation of Ireland supported by the HSE. We are mapping the type of services and supports that are provided by the voluntary sector to people with neurological conditions who live in the community. One of the issues that we want to consider is exactly what Professor Hardiman described. I refer to instances where a small charity is located in one region or has one or two branches around the country yet provides national support to patients. The entity might have one office in Dublin or the south of the country yet provide a much wider service. That situation is among the things that we seek to capture in our mapping project. Professor Hardiman made the very good point that there needs to be more of a complexity and nuance around the service level agreements that are in place with voluntary organisations to capture the support that is provided by small charities that have a national reach.

**Deputy John Lahart:** This is the first time that a comprehensive and easy-to-follow road-map has been given to the committee in respect of what needs to be done. I ask our guests to give us a ballpark figure for the annual cost of the motor neurone disease pathway that has been created. If they cannot do so, that is okay.

**Professor Orla Hardiman:** I cannot give a figure for that off the top of my head.

**Ms Magdalen Rogers:** We can certainly follow up on that. We will send on the information to the Deputy.

**Professor Orla Hardiman:** We have done some costings in respect of the management of motor neurone disease through the years. However, rather than give the Deputy that figure without having recourse to the work we have done, I will follow up in writing. It will be easy to provide that way. That said, we would need to include the cost of the four IMNDA nurses who work closely with the four HSE-funded nurses who work out of Beaumont Hospital. Effectively, we would be costing eight nurses, of whom four are currently funded by the State and four by charitable philanthropic engagement which is very much at the mercy of the generosity of the Irish people. Clearly, that is a concern. In order for us to give the Deputy a real cost,

we would have to include the cost of the nurses and the equipment bank the IMNDA provides which, in my opinion, should be supported through the public purse rather than through church gate collections and coffee mornings.

**Deputy John Lahart:** I ask our guests to give us an insight into the impact and the differences these interventions make.

**Professor Orla Hardiman:** I can certainly give the Deputy scientific evidence from our work in motor neurone disease - this has been recapitulated in other areas as well - that the life expectancy of those who attend a specialist multidisciplinary clinic service is enhanced by one third for motor neurone disease. We have done this twice. We looked at people who attend a national clinic compared with those who do not in the South, and we also did a comparative analysis between people attending a clinic with devolved care in Northern Ireland. Those demonstrated the same thing. Many of my colleagues across Europe have recapitulated that. Not only do we improve outcome in terms of people's life expectancy, we also improve quality of life and it is cheaper in the longer term. There is a very strong health economic evidence base in support of what I am saying and I have no doubt that would also be the case in all of the other conditions we have discussed. Speciality nurses are good value for money because they reduce unnecessary interventions, investigations and engagement. There is a one-stop shop and a go-to person. That go-to person is the nurse. Ms Rogers gave figures in respect of engagement with a nurse and the number of consultations it reduces. I do not know if she wants to reiterate that point.

**Ms Magdalen Rogers:** I thank Professor Hardiman. Data from the UK that we presented as part of our Patients Deserve Better campaign, for example, indicate that the appointment of a Parkinson's disease nurse can reduce consultant neurology outpatient times by 40% through assuming responsibility for monitoring and adjusting medication and reducing readmission rates by 50%. There is clear evidence from other jurisdictions on the value of nurse specialists in neurology. Professor Hardiman has done work in respect of the value of nurse specialists in the management of motor neurone disease. There is a study from the school of nursing and midwifery in Trinity College Dublin, in association with Epilepsy Ireland, on the role of clinical nurse specialists and advance nurse practitioners in epilepsy services in improving the management of epilepsy in patients, improving patient satisfaction, adherence to medication and the effective running of outpatient epilepsy services.

**Professor Orla Hardiman:** We also have data that we have presented in part from the Sláintecare pilot implementation programme in respect of the evolving engagement with the nurses we have trained in migraine care. Those data show an increase in engagement with nurses and a reduction in engagement with physicians within the headache and migraine clinics, as well as a transformation from patients returning to the clinic to patients engaging in self-care with support from the nurses. There is a significant amount of evidence to support the fact that it is very good value for money.

**Deputy Róisín Shortall:** I welcome our guests. I thank them for their presentation and all the work they are doing. I want to go back to the neuro-rehabilitation strategy. Most groups that appear before the committee call for a strategy. In this case, the strategy dates from 2019. For one reason or another, it has not been implemented. I ask our guests to expand on that. Ms Rogers stated that there was to be a community neuro-rehabilitation team in each of the nine CHOs but the majority of the CHOs do not yet have such a team. Two of them were funded in 2019 but the staff were never recruited. Why is that the case? What happened to the funding that was provided in 2019? Why is this really important area getting so little attention in the



context of decisions that are being taken in respect of funding and recruitment and so on?

**Ms Magdalen Rogers:** I thank the Deputy for raising this issue. I am very conscious of the demands on the committee but I strongly recommend that it hold specific hearings or consultations on the issue of the national neuro-rehabilitation strategy, to include, if possible, access to neuro-rehabilitation services for children, which is not included in the national neuro-rehabilitation strategy but is also a critical issue. I highlight the serious concerns of the Neurological Alliance of Ireland in respect of the fact that, as the Deputy stated, a strategy is in place. The implementation plan for the strategy was published in 2019. It was a three-year implementation framework that ended in December 2021. There has been a dismal lack of progress in terms of putting in place hospital-based inpatient beds and also in developing community neuro-rehabilitation teams. Deputy Cullinane raised this issue earlier.

We have an added concern in respect of the neuro-rehabilitation strategy following on from the Covid-19 pandemic because we believe there is a hidden impact of Covid on access to neuro-rehabilitation services. Because teams are not in place, there are no waiting lists for those teams. No one is reporting waiting lists for those community neuro-rehabilitation teams. We are aware there was a significant amount of closure and curtailment due to staff redeployment in the community for access to the neuro-rehabilitation that there is in place. That has increased since the pandemic. There are people who are cocooning or deconditioning, as well as those who were discharged early from acute hospitals for their own safety. There were no community neuro-rehabilitation services in place to discharge them to, so they effectively missed out on a period of rehabilitation. There is an entire backlog of care through the past two years. On top of that, members of the Neurological Alliance of Ireland have reported that there are people with symptoms of long Covid trying to access their services. There is a perfect storm in the context of neuro-rehabilitation services and, matched with that, a strategy that is not working. It is not being implemented on the ground.

**Deputy Róisín Shortall:** How many of the nine CHOs have community teams?

**Ms Magdalen Rogers:** It is very hard to tell without an effectively running implementation group for the strategy but, to our knowledge, there are three teams in place and up and running. That is not much different from the situation a decade ago when the strategy was first published.

**Deputy Róisín Shortall:** What about beds? How many beds were to be provided under the strategy?

**Ms Magdalen Rogers:** As I stated in response to Deputy Cullinane, it is estimated that we have half the specialist rehabilitation beds that are needed.

**Deputy Róisín Shortall:** What is that in terms of numbers?

**Ms Magdalen Rogers:** For a population of our size, 230 beds are needed. We have half that number. The majority of those beds, with a few exceptions, are concentrated in the National Rehabilitation Hospital in Dún Laoghaire. Under the three-year implementation plan and the national neuro-rehabilitation strategy, there was a commitment to have units of up to 20 inpatients and more than 20 inpatients throughout the country. This has not happened, however.

**Deputy Róisín Shortall:** It is just the global figures I want. Was there a commitment to create additional consultant posts? What is the situation with vacant posts? Are there vacant posts in this area?

**Ms Magdalen Rogers:** I will need to come back specifically on these figures, if it is possible. To our knowledge, similar to the situation in neurology we have the lowest numbers in Europe for consultant staffing in rehabilitation medicine. This is something that has not radically changed over the decades since the neuro-rehabilitation strategy was published. The implementation of the strategy and the three-year framework envisaged an increase in consultant numbers to staff the rehabilitation units throughout the country and staff the mini-national rehabilitative centres envisaged in the south and west of Ireland. Because the strategy has not been implemented the staffing numbers have not been increased significantly.

**Deputy Róisín Shortall:** What is the view of the witnesses as to why the strategy has stalled? Where is the logjam? Is there an issue with access to the Minister, the Department or the HSE? Why is nothing happening on it?

**Ms Magdalen Rogers:** Professor Hardiman can speak on this. The Neurological Alliance of Ireland is a member of the neuro-rehabilitation strategy implementation group, which recently recommenced meetings. The implementation group did not meet throughout 2021. As I explained earlier, there was a three-year framework from 2019 to 2021 to implement the strategy. I view the fact the implementation group did not meet from more than a year and a half as a failure of commitment and implementation. I would definitely call for action from the committee on this.

**Deputy Róisín Shortall:** Whose responsibility was it to call the meetings and to lead on the strategy?

**Ms Magdalen Rogers:** It is a joint strategy of the HSE and the Department of Health. The ultimate responsibility needs to be for momentum to implement the strategy and call the meetings. There are all sorts of internal and systemic reasons, such as staffing changes, but they should not take away from the need or momentum to implement a three-year strategy. The Neurological Alliance of Ireland has stated over and over again that it is simply not good enough to use the excuse of staffing changes and changing senior clinical staff as a reason not to keep momentum.

**Deputy Róisín Shortall:** Who is it in the HSE or the Department that should be leading out on this? Who does Ms Rogers call about any of these issues?

**Ms Magdalen Rogers:** We have made many requests of the committee today but I have another one, which is that the committee holds a specific hearing on the very issue of the neuro-rehabilitation strategy. The lid needs to be lifted on the complexities involved in all of the false dawns and false starts in its implementation. We need to get a greater understanding of the impact of the Covid-19 pandemic on neuro-rehabilitation services. It is without the effective structure of ongoing meetings. We have situations where the group has not met and meetings have not been held. I encourage the committee to hold to account the HSE and the Minister responsible for the implementation of the strategy.

**Deputy Róisín Shortall:** I note the points Professor Hardiman has made on the various funding cuts. In this day and age we should not be operating key services on the basis of having various funding cuts and trying to put together funding packages. It is indicative of the dysfunction in the HSE. Does Professor Hardiman wish to make a comment on the proposal on the major trauma centre and separating it from the national neurosurgical centre? What is her view on the implications of this?

**Professor Orla Hardiman:** I do not think it is appropriate, with respect, for me to comment on it. My role is clinical lead for neurology.

**Deputy Róisín Shortall:** Okay.

**Professor Orla Hardiman:** I have personal views but I do not think it is appropriate for me to comment on it.

**Deputy Róisín Shortall:** I accept that. I know it is a sensitive issue and the committee might look at it at some point. I also want to ask about the decision in 2018 when the HSE agreed to recruit six epilepsy nurse specialists under the valproate response project. Does Professor Hardiman know what happened to this commitment?

**Ms Magdalen Rogers:** It is an issue for clarification as to where responsibility for it lies. Our understanding is that it comes under the women's health initiative. A strategy document was published on it recently by the Department of Health. What we need is clarity. Epilepsy Ireland as a member of the Neurological Alliance of Ireland has requested there be clarity on why only two of the six recommended valproate nurses have been appointed. The epilepsy association has requested clarity on who is directly responsible in the HSE and what is the latest update on it.

**Deputy Róisín Shortall:** I have questions on the governance of neurological services. We have spoken about various elements of neurological services. I have mentioned epilepsy. There is also Huntington's disease, motor neurone disease and many others. Is it possible to provide services to all of these categories of patients through a single model in terms of the strategy and the community neuro-rehabilitation teams? Can these teams provide services to all elements of neurological services?

**Professor Orla Hardiman:** It is an excellent question and comment. The HSE has recognised this in the appointment of my colleague Dr. Siobhán Ní Bhriain as clinic lead in integrated care. The Deputy is absolutely right that much of what we do in neurology interfaces with many other disciplines. The patient journey, which is what we should focus on, interacts with many different services in the hospital and community. We have a commitment to the Sláintecare aspiration to maximise engagement at community level and minimise, while retaining quality, engagement in centres where people may have to make long trips with long waiting times.

In trying to map out the patient journey in broad brush strokes with the various disabilities we take care of in the clinical lead programme for neurology, my colleagues in the clinically advisory group and I have divided neurological conditions into three major categories. One is relatively common conditions such as migraine and epilepsy where engagement at community level with good support through specialist nurses is appropriate. A small proportion of people may need to move to specialist care. This is primarily in the neurological domain but there are very close interactions with the community. Epilepsy is a very good example of this. My colleague, Professor Colin Doherty, with funding from the Sláintecare pilot programme, also looked at engagement with homeless services. He worked very closely with general practitioners to try to improve access for vulnerable groups that might otherwise not be able to access services. This is within a community setting.

The middle conditions are not rare but not overly common and require neurological engagement. Multiple sclerosis and Parkinson's disease are examples. Much of Parkinson's occurs over the age of 65 and it is co-managed by colleagues in medicine for the elderly. Some

people with Parkinson's develop neuropsychiatric symptoms and need the engagement of old age psychiatry. Multiple sclerosis and Parkinson's need rehabilitation, which is in community rehabilitative services. Parkinson's with cognitive impairment falls under the national dementia strategy. They may engage with the National Dementia Office services. This is completely separate to the clinical design programme. Rare diseases include Huntington's disease and motor neurone disease as well as many others such as muscular dystrophy. In fact, about 40% of neurology concerns rare diseases. These require tertiary and quaternary services and many of these people require integration with other disciplines as well, such as psychiatry in the case of Huntington's disease, neuropsychiatry for some forms of motor neurone disease, or palliative care, which is really important, along with community services and implementation of the rehabilitation programme.

The Deputy is absolutely correct, therefore, that the focus on quality care is probably better mediated through the patient journey than through the sub-specialty or discipline. That is a significant challenge in Ireland because we are very siloed such that a neurologist might work in neurology in a hospital, for example, and therefore not in the community, and someone with a palliative care problem is not really considered to be that neurologist's problem. In order for us to enhance how we deliver care, we need to consider the journey and the issue of the money following the patient. The work we are doing with the scheduled care transformation programme involves mapping that out. Deputy Cullinane asked about community diagnostics, and that is part of the solution. If a general practitioner can access diagnostics rapidly, that can significantly reduce the wait time in the case of somebody who may have an early diagnosis of multiple sclerosis, for example, or somebody who just has a headache and who may not need to come to a specialist service any more.

Examining the programme in the context of the money following the patient is what we are trying to do with respect to the scheduled care programme. It involves mapping out these four exemplars, namely, rare, ultra-rare, relatively common and common and capable of being managed in the community, and putting a price tag on them in order that we can work out the cost and work out where the resourcing should go in order that, ultimately, the money will follow the patient. That is the ultimate objective, in my opinion.

**Ms Magdalen Rogers:** If I could come in there briefly, I re-emphasise the need for the neuro-rehabilitation strategy to be implemented. Many issues are arising throughout the patient experience. For example, the Ombudsman report of last year, *Wasted Lives*, was an indication of the neuro-rehabilitation strategy not functioning in its implementation. People are ending up in nursing homes because there are not appropriate long-term rehabilitation facilities in the community.

**Deputy Gino Kenny:** Many of the questions I had intended to ask have already been answered, so I will ask some supplementary ones. How does the number of neurological consultants in Ireland compare with that of other countries in Europe?

**Professor Orla Hardiman:** The number is still much lower than that in mainland Europe and even lower than that in the UK, which is also much lower than that in mainland Europe. We often compare ourselves to the UK but, in fact, the UK does not do very well in the delivery of neurological services or in respect of the ratio between consultants and patients. Our number is much lower than it should be. Again, there is inequity in that regard given parts of the country are really poorly served with respect to neurology, as I elucidated earlier. We really need to build the regional support services.

There are good stories here as well. In Limerick, for example, which is a hub in development, there are now four neurologists, whereas last year there were only two. Limerick as a region is a case in point of a really good development of a hub for neurological care, but other parts of the country remain very poorly served. We have to think not only about the ratio but also about the geographic terrain. The north-west is an example of that, whereby Donegal in its entirety is managed by my colleagues in Sligo, where there are two neurologists, although a third has been advertised and interviews for that have begun. The need in that part of the country and the waiting lists north of Letterkenny suggest that region is much more poorly served than anywhere else in western Europe, with very significant waiting lists.

**Deputy Gino Kenny:** How many neurological consultants are there in Ireland?

**Professor Orla Hardiman:** That is a slightly difficult question to answer because a number of people are in locum posts, while others are funded through the National Treatment Purchase Fund. The total number is 44, as far as I know, or in that order. The number of approved posts is about 34, but some people are in part-time posts, some are locums and others are in the National Treatment Purchase Fund. Under the consultant approval process, there are 34 full substantive posts but some are in the offing and coming forward. In any event, there are not enough.

**Ms Magdalen Rogers:** There are about half as many as there should be.

**Professor Orla Hardiman:** Yes, given the size of the population.

**Deputy Gino Kenny:** There is shortfall also in respect of neurological nurses. I understand there are 42 in the State, which needs to be at least tripled. As Professor Hardiman said, this should all be done over a five-year period.

My final question probably does not relate specifically to this subject matter but I will ask it nonetheless. It concerns the medical cannabis access programme. Two of the three conditions stipulated under the programme are neurological conditions, namely, drug-resistant epilepsy and multiple sclerosis. The programme has been up and running since November and only a small number of people have got access to medical cannabis. It is very frustrating for those who are trying to get access to medical cannabis via the programme. In Professor Hardiman's professional opinion, is there a role for medical cannabis, not least in respect of drug-resistant epilepsy, multiple sclerosis and other neurological conditions for which good evidence has shown efficacy in respect of medical cannabis intervention?

**Professor Orla Hardiman:** There is undoubtedly a role for it. My colleagues who look after epilepsy, both paediatric and adult, have researched the evidence base for this and, clearly, there is a very strong evidence base in support of medical cannabinoid products in the management of particular forms, or subtypes, of epilepsy. There is definitely a role for managing spasticity, and while the licensing relates to multiple sclerosis, there may be a role for some of the cannabinoid products to treat other types of spasticity. My understanding is that the difficulty in regard to access relates to the companies that make the most efficacious products and the process of reimbursement through the health technology assessment services and Professor Michael Barry's unit in the pharmacoeconomics sector. I understand there have been some delays in the negotiations regarding reimbursement. As far as I am aware, the issue relates not to a reluctance of colleagues to prescribe these products or of the HSE to permit them but rather to ensuring the best price will be available to the Exchequer, and the process for establishing that is under way.



**Deputy Colm Burke:** I thank our guests for their presentation. I will first discuss the availability of rehabilitation beds. In Cork planning permission has gone in for a private unit. If that project is built will there be a role for such a facility in view of the fact that there is a shortage of rehabilitative beds and there does not appear to be any proposal coming from the Department of Health or the HSE to build additional facilities?

**Ms Magdalen Rogers:** I thank the Deputy for raising the issue. It comes back to my earlier points on the lack of momentum in implementing the neuro-rehabilitation strategy. Nature abhors a vacuum and the development in Cork is a clear response albeit from the private sector to a very clear need.

For the past 20 years or more elected representatives have voiced the need to create neuro-rehabilitation services to serve the population of the south. The strategy is not up and running, and it is not being implemented. For over a year there were no meetings on strategy. Work to see how the proposed development fits in is not happening or else we have not been involved in it. There is always a space to fill a need. Our concern is that even if the facility is made available to public patients, and beds are made available to public patients within the facility, there is still a huge dearth of community neuro-rehabilitation services in the south. Even if the private unit that has been mentioned could be made available as part of the landscape of neuro-rehabilitation services in Ireland there is still a huge gap in community neuro-rehabilitation services. That points to a need for a joined-up and effective neuro-rehabilitation strategy.

**Deputy Colm Burke:** Ms Rogers must accept that it would be extremely expensive for someone to pay for a period of rehabilitation. I mean that rehabilitation is not something one can undertake today and come out tomorrow. It takes a period of time. Therefore, its role in just providing care for people who qualify under, say, private health insurance might cause difficulties so the only way that it can be fully utilised is to have buy-in by the HSE and the Department of Health. We must look at it from the outside on the basis of the period people must stay or require these facilities.

**Ms Magdalen Rogers:** Exactly, Deputy. What we do not want to see is a further disenfranchisement of people with neurological conditions where only those who can pay can access specialist rehabilitation in the south. I am cognisant of the workload and number of issues that come before this committee but, once again, I ask the committee to do a special hearing on neuro-rehabilitation services to examine these issues.

**Deputy Colm Burke:** I ask the delegation to compare the current rehabilitation facilities with what they feel we should have. What additional beds would we now require in real terms? If we decided in the morning to provide additional facilities then the delegation would have to accept that it would take us at least three years and maybe up to eight years to build a new facility. However, I understand that we do not even have plans to build additional facilities.

**Ms Magdalen Rogers:** I agree with the Deputy that everything needs to be on the table and I will outline the concerns of the Neurological Alliance of Ireland. There is a strategy and how it gets implemented needs to be decided plus the implementation process needs to be effective. The strategy group needs to meet on a regular basis - we cannot have the situation again where it did not meet for over a year and a half - to provide a forum in which to raise the kinds of issues that the Deputy has addressed. Given the systemic failure to implement the strategy I ask the committee to intervene and arrange a special hearing on neuro-rehabilitation services to highlight the issues.

**Deputy Colm Burke:** Who has the job to call a meeting of the strategy group?

**Ms Magdalen Rogers:** Deputy Shortall raised the same issue earlier. The ultimate responsibility lies with the HSE, the Department, and directly with the Minister for Health who is responsible for delivering the strategy.

**Deputy Colm Burke:** I wish to mention an issue that concerns consultants and specialists in this area. It is a question that I constantly raise with the HSE. We have a certain number of consultants who work in this area so let us consider the care that needs to be provided and long-term planning. Has the number of consultants who will retire over the next few years been analysed? Has the number of people who are training in this area and will be available to come onstream over the next five years been analysed?

**Professor Orla Hardiman:** Yes, an analysis has been undertaken under the national manpower programme and we were involved in contributing to that. There are neurologists in training. We would argue that there should be more. There is attrition across trainees in neurology. We lose some people; they move overseas. Unfortunately, the Irish health sector at the moment may not be the most attractive to young doctors who are in training and being able to attract people back can be challenging.

**Deputy Colm Burke:** How many people are training? How many posts will become available if people finish training within the next five years?

**Professor Orla Hardiman:** I will have to get back to the Deputy on those precise figures as I do not have them immediately to hand.

**Deputy Colm Burke:** What numbers do we need to increase the training posts by?

**Professor Orla Hardiman:** We will have to get back to the Deputy on those specific questions.

One of the issues that arises is the attractiveness of certain positions. That goes back to our comments around the need to really develop, and support, hubs for neurology around the country. It may not be very attractive to somebody who has done training in a national centre in the UK, US or Australia to come back and work in a centre that is poorly resourced and underdeveloped with respect to the complement of services that are required to provide a quality service. It is not just a question of the number of people that we have in training nor is it a question of the recruitment to positions. It is a question of making those positions sufficiently attractive and that is a big challenge in some parts of this country. We really need to pay attention to that because there have been situations where posts have been advertised and the uptake or the attractiveness of the posts has been such that there have been very few applicants. That situation is a big concern given the unmet need in this area. So not only is it a question of the training of people, it is a question of making the posts that are available sufficiently attractive to attract the best and the brightest back. That is an issue. There are parts of the country that we really need to pay attention to and invest in to make sure that no matter where one lives one gets the same level and quality of care, and that is not the case at the moment, unfortunately.

**Deputy Colm Burke:** Posts have been advertised over the last number of years. What number applied for the posts? How long did it take to fill the posts?

**Professor Orla Hardiman:** It depends on what part of the country we are talking about. In Dublin, we get a reasonable field of people with maybe five to seven people applying to the

Dublin hospitals and it is a similar situation for Cork. If we move outside of those areas, the numbers of people who apply for posts in the hubs for neurology that are under development is much lower than that. The length of time between a funding stream becoming available, approval by the consultant applications advisory committee approval and an advertised appointment depends on the structure of the hospital. As the committee knows, different hospitals have different governing structures. The signing off process varies across hospitals and there are some regional tensions that we should probably mention. Some centres may feel that they are being undermined or disenfranchised and, in some instances, they may attempt to slow down the appointments. We have certainly seen that in parts of the country.

To answer the question, it really depends on where we are talking about. In local geographic areas there are local politics as well. However, that should not stop our mission to ensure we provide the best care as close to the community as possible, and that involves building up ten regional hubs for neurology, resourcing them properly, ensuring they operate within a geographic region within which everybody can access high-quality care at minimum discomfort to them. We are not quite there yet and there is quite a bit of work to do.

**Deputy Colm Burke:** Does Professor Hardiman not agree that, with the demands from patients who require care, the reason for delaying appointments is not acceptable-----

**Professor Orla Hardiman:** I completely agree.

**Deputy Colm Burke:** -----and that there should be a mechanism put in place in order that those delays are not used by others? I am aware of the issue of medical politics; it is the same as any other politics. It can become difficult. However, we need to have a structure in place to make sure no one person or group of people can delay an appointment being made.

**Professor Orla Hardiman:** I am not specifically alluding to medical politics; I am alluding more to hospital politics actually.

**Deputy Colm Burke:** My apologies.

**Professor Orla Hardiman:** They are not the same thing. The Deputy is completely right. I totally agree. It is one thing identifying the problems, however, and quite another thing fixing them. That requires investment, particularly at regional level, such as in the west, the north west, the south east and, actually, the south west as well. This model we are developing - the hub-and-spoke model - will attempt to address that geographic inequity. It will come with a price tag. It will require us to have an adequate number of neurologists serving a notional population of about 500,000, with a full multidisciplinary neuro-rehabilitation team within the hospital reaching out reaching out to the community neuro-rehabilitation services and supported by appropriately trained specialist nurses. There will need to be an obvious well-developed pathway where the money follows the patient to secondary, tertiary, and quaternary engagement with expertise if needs be for rare or complex conditions. That is the aspiration model. There are many road blocks and bumps on the road to that but it is what our intention is, and it is in the best interests of the people we serve.

**Deputy Cathal Crowe:** I thank Ms Rogers and Professor Hardiman for being here. I have been following the meeting remotely. There is still not a normal working environment here, so I was tuning into this in my office. I apologise for just arriving now. I read the opening statement and I listened to the witnesses' interactions with the members. I am not medically trained. I do not think there are many of us who are, but we have a deep interest in advancing public

healthcare capacity in this country.

I wish to ask a few questions at the outset to elicit a better understanding of everything. I have received many emails, as I am sure other members have, from people lobbying for more neurological nurses. They kept telling me that there is a delay in diagnosis. What I am trying to understand is from the time a family GP makes a referral, how long does the pathway to diagnosis take? I know it is not a catch-all but, typically, how long can it take? How is the lack of neurological services in public healthcare delaying the typical diagnosis pathway?

**Professor Orla Hardiman:** We need to be careful because it depends. If somebody has a neurological disability that is of concern, there are mechanisms and facilities for general practitioners to access neurological consultations pretty quickly. The waiting list is triaged. When a letter comes into a hospital, the letter is reviewed. If the referral suggests that this is a problem that needs to be investigated urgently, my colleagues and I will triage that to an urgent emergency consultation. It is not the case that somebody with a potentially very serious or life-threatening condition would wait for the four years for a consultation. Our general practitioner colleagues are very good at identifying such cases and would make the referral through the appropriate channels and patients will be seen more rapidly. It is important to say that. There are situations where it may not be an acute or life-threatening condition where a neurological opinion would be valuable and develop a care plan. In those instances, from the time of first symptom, depending on the symptom, the general practitioner will make a referral.

As I mentioned earlier, when we audited the types of referrals coming in, across the board in all the hubs we looked at, between 25% and 30% of those referrals were related to some kind of headache syndrome. In order to address that, we put together a pilot programme to try to reduce the waiting time for those people and maximise the benefit of the consultation. The headache and migraine programme funded through the Sláintecare pilot implementation programme was very successful and it will hopefully be rolled out. In the process of doing that, we used three hospitals. We undertook work in each hospital to understand the waiting lists better. Some hospitals, including in Galway, did a waiting list audit and were able to reduce a significant proportion of people on the waiting list by engaging with patients by telephone. The waiting lists are a useful measurement but they are not an ideal measurement.

**Deputy Cathal Crowe:** The written submission indicates that approximately 13,000 people were waiting for neurological appointments in 2015. That has risen to 24,000. How much of that increase can be attribute to the disruption of public healthcare during Covid and how much was caused by a lack of capacity in our public health system?

**Professor Orla Hardiman:** It is both. Covid has had a very severe impact on our delivery of services. The number of people we can see is much reduced because of social distancing. At the beginning of the pandemic, it was necessary for many months to revert to virtual consultations, which are not ideal. The people involved had to be seen afterwards as well. That significantly impacted on services.

**Deputy Cathal Crowe:** It is a case of a bit of both.

**Professor Orla Hardiman:** There is also a capacity issue in the hospitals. For the purpose of social distancing, there is a requirement to reduce the number of people in the waiting rooms. Therefore, that has an impact on the number of people being seen. For example, in Cork University Hospital, the entire neurology services had to be moved to a different part of the hospital with much reduce capacity. Most of the hospitals have a capacity problem within outpatient

services. Even if we wanted to see more patients, many of the hospitals do not have the capacity to enable that. Some hospitals are looking at renting space elsewhere. For example, Beaumont Hospital has rented space in Northside Shopping Centre. The hospitals are attempting to improve that situation. It has been a big issue. The Covid pandemic and the requirements for social distancing has significantly exacerbated that. It is also the case, if we start looking at the high volume referrals, for example migraine, and build a pathway, which we have done for the scheduled care programme, that this identifies what we might call the pain points or the points where there are blockages in access. These include community diagnostics, which is now triaged through telephone consultations with a specialist nurse, and then reducing the number of returns by engaging with the Migraine Association of Ireland and developing self-care groups with psychology. They can all significantly impact on the waiting list because we reduce the number of people returning and increase the scope for new patients. We are making inroads on that and we are using migraine as an exemplar to build that pathway.

**Deputy Cathal Crowe:** I listened to the submission from Ms Rogers and we have been getting lobbying emails. I am particularly interested in the mid-west as I am a Clare Deputy. I do not know if the emails are geography-specific. My take-home point from this is that the mid-west is particularly pressured when it comes to neurological services. I know there has been recruitment and we have gone from two to four neurological nurses but best practice suggests we should have 11 and, somewhere in the middle, there seems to be a settlement that eight are required.

When somebody enters undergraduate nursing training, what additional training is required to go from that into the whole realm of neurological nursing? Without having pay grades in front of us, I presume that as it is an add-on skill, people are paid better. I have an additional question with regard to neurological consultants, which we have not discussed much today. Usually, when somebody is in private consultancy, they have a team around them. Are nurses who are qualified in neurological nursing more attracted to working in the private sphere, where conditions might be better, and is that also a factor that is driving them out of our public hospital system? Is the mid-west specifically more pressurised than other areas?

**Professor Orla Hardiman:** I would take issue with the Deputy. For neurological care, the public sector is better. There is not necessarily a multidisciplinary team within private hospitals. The private hospitals are within the private sector and they serve a very important purpose in Ireland because of the difficulties we have with capacity. However, multidisciplinary teams, which is what most people with neurological conditions benefit from, are in the public sector. People with neurological disability are much better off within the public sector, warts and all.

With respect to the training of specialist nurses, as mentioned earlier, it is an attractive career path for nurses. They come from the staff nurse grade usually to clinical nurse manager, CNM. There are a number of grades for CNM and then they move on to clinical nurse specialist and then to advanced nurse practitioner. There is a very clear career path for people in nursing and it is very attractive. When we recruit for nurse specialists in neurology, we get a good field and there is a lot of interest.

Specifically relating to the mid-west, it is a success story and there are a number of reasons why that is. When I took up the position of clinical lead for neurology, Ms Rogers and I did a tour of the country and visited all of the neurology hubs and chatted with our colleagues about the needs. One of the things that was very impressive to both of us was the quality of the neurological service in Limerick and the commitment of our colleagues in Limerick to the development of services and the expansion of services. There is also the commitment of the



University of Limerick to the delivery of neurological care and the facilities that are available within University of Limerick in that regard. Clearly, there is a lot of work to be done with my colleagues, of whom there will soon be four, with the third recently appointed and a fourth coming. It still needs a lot of investment but it is an area we should look to in order to learn how best to develop original services.

The Limerick services are advantaged by a very good neuro-rehabilitation team, with whom they engage closely. They also benefit from people like Professor Susan Coote, who is linked with the University of Limerick but is also an expert in multiple sclerosis physiotherapy. Professor Coote was awarded a Sláintecare pilot project demonstrating the benefits of virtual rehabilitation for people with multiple sclerosis, and that is being mainstreamed now. Nonetheless, it goes back to our issue around service level agreements and the need to be able to generate a good service level agreement with the voluntary sector.

**Deputy Cathal Crowe:** There is another issue with nursing in general and it was a topic we discussed here a couple of weeks ago. The Irish Nurses and Midwives Organisation, INMO, has a concern that in the last two years, whether it has been pay and conditions or the Covid pandemic, its members have been absolutely at the front face of all of this. Many fifth and sixth year secondary students who are looking at their career pathways are probably put off going into nursing or the medical sciences because of what they have seen and because of all the negativity that has surrounded pay and conditions in the past two years.

Deputy Gino Kenny was pursuing an interesting line of questioning at the end of his slot and I wish to follow up on that. I too am very interested in the whole debate about medicinal cannabis, which has two sides to it, but particularly its relevance to the sphere of neurology. In the HSE service plan 2021, the Minister, Deputy Stephen Donnelly, approved medicinal cannabis with certain criteria which were quite stringent. Will the witnesses comment? Is that over-restrictive or is it working okay from a neurological point of view, from where both of the witnesses are sitting today?

**Professor Orla Hardiman:** I think the criteria for the use of medicinal cannabis were appropriate and some of my colleagues are involved in the decision-making there. There is definitely a role for medicinal cannabis. As I mentioned earlier, the delays in accessing that are more procedural and relate to the reimbursement systems which, to some extent, has to do with the companies that are involved in the manufacture of medicinal cannabis. It is not within the reach at the present time of myself or the clinical lead programme to resolve that and I think that is going through a process at the moment. However, we would all agree there is definitely a benefit to medicinal cannabis and that the requirements at present are not inappropriate.

**Deputy Cathal Crowe:** I am in the Minister's party, Fianna Fáil, and I will do what I can to support the alliance's request. It is far more prevalent in my county than I would have known and many families engage with the service. I will do what I can, along with others on this committee, to advance the cause of the alliance. I thank the witnesses for being here today.

**Deputy Mark Ward:** I thank the witnesses for the opening statements and for being here today. I have to agree with them. Neurological services were in crisis pre-pandemic but listening to the figure of 24,000 people waiting for neurological appointments now, it is fair to say that we are approaching an emergency situation, if we are not in an emergency already.

I am not a member of the committee and I thank the Chair for allowing me to come in to address the witnesses. As they know, I have met both of them before. I have a personal interest

in neurological conditions, having been diagnosed with multiple sclerosis 15 years ago. Listening to Deputy Cathal Crowe, I am reminded of the years prior to being diagnosed and not being treated. From the point of contact when I went to my GP to when I got my diagnosis, there was a seven-year gap, which is a frightening place for any young man to be - I was 25 years old at the time. I am in the public system and while I can only speak for my own experience, it is that the services available to me have been scant. I have had four appointments with my neurologist in the 15 years since I have been diagnosed. I have had two MRI scans, the first in 2007 and the next in 2018, and I was on a waiting list for all of that time. I would have been getting letters from the HSE to ask whether I still wish to have the appointment and I was sending every letter back to say that, yes, I still wish to have the appointment. When I got my appointment in 2018 for my second MRI scan, they could not find the records of my first one because the HSE had changed its administration. They could not tell in a neurological sense whether the multiple sclerosis had progressed. I have been on a waiting list to get my next follow-up MRI scan to see if it has progressed since 2018. That is my experience. I do not know if it has deteriorated in a neurological sense. I can only say in a physical sense for myself that I have not felt physically or mentally better in a long time. I have to say that.

My situation within the public service is not unique, however. It is an indication of the systemic failures in the system through years of underinvestment in neurology services. When we see figures showing that 24,000 patients are waiting for an appointment, it is really quite stark and frightening.

I wish to put on the record a word of thanks to MS Ireland for the support I got at the very start when I was first diagnosed. As a young person, being diagnosed with a neurological condition can be a really frightening place, especially for the young man I was then. I did not have the ability to articulate how I was feeling. I did not know how to express that I was frightened for my own and my family's future. I kind of started to isolate. I was suffering with depression because of the diagnosis but I did not know I was, which is a really frightening place to be.

The support I received from MS Ireland, which does not get talked about too much, was with regard to counselling. I gained an acceptance that I have multiple sclerosis. That was my first step forward to a way of dealing with this. It does not define me. At the time, it did, but it does not define me anymore. It has given me the ability to look at things in a different way. I kind of take life on life's terms now. I do not think, for example, that I would be here unless I got that diagnosis of multiple sclerosis, believe it or not. I was already involved with community activism but I probably would not have taken the chances I took by going to college and other stuff I have done over the years because of the diagnosis of multiple sclerosis and because I changed my thinking around it.

I always say to anybody who has been recently diagnosed and who might be listening today that it is not the end of the world. It is absolutely not the end of the world. Some of the advice I have given people and talked about a few times is to not do what I did at the start. Do not ask Dr. Google because Dr. Google will lead you down a bad path to a very dark place where you cannot see any light at the end of the tunnel. That is where I was. People should take a chance and talk about their feelings because feelings never hurt anybody. They should just talk about them and if they have the opportunity to get a bit of professional help with regard to talking about their feelings, they should do that as well. Those are two bits of practical advice that I found really helped me.

That is enough about me; I will ask some questions. I have an interest in long Covid especially. I had Covid and had symptoms for approximately five months afterwards. Thank God

they have cleared now. We know Covid is a new virus and we are still finding out what it is about. What early indications have the witnesses seen on the effect long Covid has on neurological conditions but also, as they mentioned already, on neurological services? Is there a plan for us to address that at the moment?

**Professor Orla Hardiman:** I thank the Deputy very much for his comments on multiple sclerosis. I am really sorry that he had such a circuitous journey in terms of both his diagnosis and accessing services. It is not really acceptable that he has been waiting such a long time for a scan. That should not be happening and probably needs to be investigated as to what the delay is.

With respect to long Covid, certainly, we know there is both a very significant neurological and psychiatric impact of Covid-19. Some work has been done on psychiatry that was published in one of the big journals, namely, *The Lancet*, showing that something like 20% or 30% of people, or even more, suffer either neurological or psychiatric sequelae from the first round of Covid.

There is a move to develop a set of long Covid clinics. Many of the symptoms of long Covid include the need for engagement with infectious disease. Cardiology and neurology are also parts of it. We have put the need to develop a number of national long Covid clinics into the Estimates, which would include neurological engagement. That is currently in progress through the Estimates. My colleague, Dr. Siobhán Ní Bhriain, who is clinical lead in integrated care, is committed to this and to the development of long Covid clinics. A number are up and running already but there is a need to expand that out.

It is also important in the context of long Covid to describe another set of neurological conditions because the neurological symptoms of long Covid are not unlike other neurological symptoms we see. They account for approximately 50% of referrals that we see in neurology, which are people who have a neurological disability for which we cannot identify an anatomical reason. That is the case in long Covid as well, actually. There is a need for-----

**Deputy Mark Ward:** I am sorry for cutting across Professor Hardiman.

**Professor Orla Hardiman:** In other words, the scan looks normal.

**Deputy Mark Ward:** In layman's terms, I know it is very early with Covid and I am not trying to speculate. Would Covid itself be a new neurological condition, however? Could it be classified as a new? For some people who have the effects of long Covid, could that be deemed a new neurological condition?

**Professor Orla Hardiman:** I do not think we know enough yet to be able to answer that. Quite a lot of work is being done to try to understand whether the virus gets into the brain. It probably does not but we do not really know. It certainly gets into the part of the brain that is responsible for smell. The longer-term disability associated with that is very real. It needs, again, much disciplinary care, which includes colleagues in the areas of physiotherapy, occupational therapy, neurology, respiratory illness, cardiology and infectious disease.

From a neurology point of view, that sort of multidisciplinary engagement is very close to what we need in these other conditions where the scan might be normal but the person has a very bad disability. That is called functional neurology. Part of the development we see in the context of long Covid is to at the same time actually develop services for functional neurology and functional neurological disorders. In our submission to the Estimates, we reference the

need for, again, multidisciplinary integrated care for people with long-term functional neurological disorders. These people can do very well and get back into living. We expect that is the case with long Covid as well. It just takes time and multidisciplinary engagement, including physiotherapy, graded psychological support, psychiatric support, sometimes, and other specialty services in an integrated care setting. That plan is currently being implemented and we have also put it into the Estimates for this year.

**Ms Magdalen Rogers:** If I could come in there, our colleagues in the Neurological Alliance in the UK are much better resourced in this regard. They are not as well-resourced as some areas in Europe but they are certainly better resourced than Ireland in terms of neurology and neuro-rehabilitation services. The Neurological Alliance issued a report highlighting Covid as the perfect storm for neurology and neuro-rehabilitation resourcing because not only did we have the backlog and lack of service available during the pandemic but now, potentially, as the Deputy asked, is it a new neurological disorder? It is certainly a new neurological need presenting on a service already at breaking point in terms of capacity. Again, in terms of the issues we are highlighting to the committee today, it is an additional need. It is already presenting to services and must be taken into account in terms of the overall resourcing of those services.

**Professor Orla Hardiman:** The management is multidisciplinary, however. The management is engagement in diagnostics by people like me but it is actually management through multidisciplinary rehabilitation services in both hospital and community settings

**Deputy Mark Ward:** I will ask a question on the multidisciplinary teams. We could have any group before the committee, as we did with the Sub-Committee on Mental Health. Child and adolescent mental health services, CAMHS, are looking for multidisciplinary teams. We had a debate last night in the Dáil on disability services that are calling for multidisciplinary teams. We have it with today's witnesses in neurology. We also had it with primary care. The biggest issue we seem to be getting is with regard to recruitment and retention of staff. Are there any practical ways the witnesses think we could be able to address that?

**Ms Magdalen Rogers:** With regard to the neuro-rehabilitation strategy, we have not even got there yet. We have not even seen an attempt to recruit those multidisciplinary teams. As I explained earlier, there was a commitment in that three-year neuro-rehabilitation framework to have one community neuro-rehabilitation team in each CHO. That has not been progressed. As I said, the funding was made available for teams in CHOs 6 and 7, so the Deputy's own constituency is involved, but despite that those teams have not been put in place. It is not even a recruitment issue; it is a momentum issue. The posts have not even been advertised at this stage.

**Professor Orla Hardiman:** If you are talking about recruitment, and this came up earlier with regard to the regions, if you make a job attractive, people will go for it.

**Deputy Mark Ward:** Yes.

**Professor Orla Hardiman:** If you do not make the job attractive, people will not go. If you are working in a situation where you are not adequately resourced and you do not have the services around you, people will not apply for them. By contrast, if the job is part of an integrated service where you are supported and valued then people will go for those jobs. It is a question of value. It is a question of recognising the value and putting in the resources that allow the team to grow and develop. Then people will apply for those jobs and the team will work really well.

**Deputy Mark Ward:** Okay.

**Professor Orla Hardiman:** It is a question of value.

**Deputy Mark Ward:** I thank the Neurological Alliance of Ireland. I echo the call for a special sitting of this committee on the neuro-rehabilitation strategy. It is something that should happen. I am probably being a bit cheeky by saying that because I am not a member of this committee but I am sure it will consider that. I hope it happens soon. I thank the Chairman. Did I just drop him in it there?

**Chairman:** Not at all. It is certainly something the members will discuss in the next private session. It is a reasonable request. The biggest challenge the Neurological Alliance of Ireland and the Deputy is facing is that there are so many challenges within the overall health service that every week we are jumping from one crisis to another, unfortunately. There is the pressure we are putting on staff. We are meeting three and four times per week. It reflects the challenges that exist.

I have a couple of questions. I might follow on from what Deputy Ward was saying with regard to the multidisciplinary teams. Ms Rogers stated earlier that there were three full teams up and running. Where are they based?

**Ms Magdalen Rogers:** There is a very well-functioning team in the mid-west neuro-rehabilitation team. That has been functioning for over ten or 15 years now. As Professor Hardiman said, that is a critical part of the overall success of neurological care in the mid-west. It is critical to the neurology services and community services for people with neurological conditions. That is one team. There is also a team in the north west of the country. Again, once they are working well these community neuro-rehabilitation teams make an enormous difference. They are a point of contact for hospitals discharging patients but they also provide that maintenance of people with neurological conditions in the community without them deteriorating or needing a succession of hospital admissions. The teams are a hub for so many services referring into them and for keeping people with neurological conditions in the community. The other team is based in the wider Dublin region. There were two teams funded in CHOs 6 and 7. The funding was made available. It was made available through a specific initiative of Sláintecare called the care redesign fund but we have not seen those teams put in place on the ground in CHOs 6 and 7.

**Chairman:** Again, why that has not happened is a practical thing we will try to follow up on. It comes as news to me and I am a Teachta Dála who represents one of the CHO 7 areas.

**Ms Magdalen Rogers:** I should say to the Chairman that we do not call for a special hearing by the committee on neuro-rehabilitation services lightly. To us, the failure of implementation of the strategy is so systemic at this stage we feel we need the time to explore that with members in more detail. It is impacting on all sorts of other initiatives within the health services. For example, we have an excellent trauma strategy in place that will fail unless neuro-rehabilitation services are put in place to carry on the interventions from a very successful trauma network. Again, we are not calling for this lightly. We are very aware of the demands on the committee's time but we just feel it has got to such an endemic stage of not progressing that the committee needs to lift the lid, point out why and ask some serious questions.

**Chairman:** It was news to this committee, and seems extraordinary, that the implementation committee did not meet for a long period. The Neurological Alliance of Ireland wants us



to go into that in detail at some later stage.

Professor Hardiman mentioned Donegal. I think of Donegal as the north west. Ms Rogers was saying there is a team there. What is the problem there? Is it that sufficient staff cannot be got or is it that if services were realigned around the Derry-Donegal region it would work better? What makes it possibly the worst in Europe, as she said?

**Professor Orla Hardiman:** Donegal is served by Sligo. There are two colleagues, soon to be three, in Sligo who work hard and provide an outreach service to Letterkenny. The plan there would be to cover the people who live in Donegal appropriately through the service in Sligo as a hub with a high-quality outreach spoke into Letterkenny. The difficulty is Sligo is a really well-run, well-functioning hospital. My colleagues there work really hard and are top-quality neurologists. However, it does not have an academic link and it is not that well-served with respect to the overall multidisciplinary resourcing. It does not have a neurophysiologist, who is someone who does electrical studies on people. It needs a significant investment to make it a proper, well-functioning hub people want to go and work in and then provide that outreach to the north west and a really high-quality service in Letterkenny, which is a very busy hospital as well. It is really a question of recognising the geographic inequity and the need for substantial investment in neurological services. I do not just mean neurologists but the whole neurological team and the team of nurses required to make that service fully-functional. If we do that it will become an attractive place to work and that will significantly improve the reach and services for people in the Donegal area. That is what the problem really is. It is about having a critical mass within that hub.

**Chairman:** The submission states that neurological services are short around 100 nursing staff. Is that number still increasing or is decreasing?

**Professor Orla Hardiman:** The number is based on a calculation from the best-fit model from the UK. If we work it out on the ratio of people with neurological disabilities, we expect and the ratio we should have with nurses then that is what that number is. However, if the population increases then obviously we are going to need more. Many neurological conditions get worse as people get older so as the population ages the number will probably increase as well. We must recognise the geographic terrain as well. If you are going up to Bloody Foreland and going back to the base in Sligo, that is a very long trip. It may well be, therefore, that in certain parts of the country the appointment of nurses will be as much a function of the geographic reach they have. There is a similar issue in Scotland with the Highlands. The number of people managed by specialist nurses is much smaller because the geographic distance is much greater so you must allow travel time for these people. That is important.

**Chairman:** What has the reaction to the Patients Deserve Better campaign been from the HSE and the Department?

**Ms Magdalen Rogers:** We have had the appointment of migraine nurses.

**Professor Orla Hardiman:** There are two things. We met the risk management part of the HSE and did a submission. There is a recognition in the HSE of the need for developing neurological services. We have put in a submission to build on the success of the Sláintecare headache programme which looks like it is going to happen. I understand it is in train now. There is a recognition now. If we can generate a good body of evidence and can demonstrate value for money and benefit then the reaction of the HSE is positive. Demonstrating the need, the roadmap and the evidence of benefit is what is required in the scheduled care programme.

We have been working very closely with them in building those requirements, and we have been getting quite good traction with them in this regard. As we said at the beginning, we do not expect all of this to get fixed in a year. This is a work in progress. A roadmap to where we should be, which includes the development of the neurology hubs and the recognition of the unmet need and the evidence base to support that, is really where we are at the moment.

With respect to this committee and the take-home from this engagement, I go back to the comment that was made earlier and was alluded to by Ms Rogers earlier, it is about recognising the role of the voluntary sector. We do that at a practical level in that we work very closely. Deputy Ward also referred to the work of MS Ireland. We do not integrate the voluntary sector adequately within the delivery of care, but we rely heavily on their resources to deliver services. I have been in my job for a very long time. To my mind, it is not acceptable that the essential services we provide for people are funded through fundraising and philanthropic support. We should really be recognising those services for what they are, which is an essential part of care. As I said at the beginning, the process of generating a service level agreement is very complex and done at a regional level. There is no overall overarching mechanism for a national service to develop a service level agreement with the voluntary organisation. That is a thing we could fix quite easily within the HSE in order to have a system whereby a voluntary organisation that has proven to deliver a high-quality service should be able to have a service level agreement, to support the service they are providing, through the Exchequer. That is very difficult to do at the moment, as Ms Rogers said. They are done through very local and regional services within the disability sector. For example, the IMNDA's service level agreement is with north Dublin but they have four nurses that provide an national outreach who are an integral and integral part of the motor neurone disease service. That is something we could fix quite quickly by exploring how we could do a national service level agreement, obviously with the important due diligence, evidence of appropriate use of the services, and appropriate governance structures. That is very doable and we have been exploring that also. That is a take-home message that I would like to put the committee: that we should be able to do that by way of integrating the voluntary section 38 sector organisations.

**Chairman:** Reference was also made to Paul Reid's comments about the importance of building new relationships with section 38 and section 39 organisations.

**Ms Magdalen Rogers:** There is a mechanism for that through the ongoing dialogue fora with the voluntary sector on foot of the independent review group on the role of voluntary providers in health and social care services. There is a forum and the committee could be mindful and watchful of that space so there is a full implementation of the recommendations of the report arising from that dialogue and forum.

On the support we have got from the HSE and the Department of Health to date in respect of the Patients Deserve Better campaign and the Estimates process this year coming into the development of the next service plan and successive service plans, as Professor Hardiman said, we are being realistic. We know we are not going to get 100 nurses in one year, but we will certainly be watching this space in terms of the commitment in successive service plans, through the lifetime of this Administration, to tackle the shortage in nurse specialists.

**Professor Orla Hardiman:** I will raise one final point apropos of a comment by Deputy Shortall, which is to recognise that people with complex neurological disabilities often need services that are in addition to neurology, and to develop a pathway that is important in that regard is essential. Referencing Deputy Lahart, if we were to use Huntington's disease as an exemplar for that, Huntington's comes under the national prevention strategy, under neurology,

under palliative care, under national disability services, under psychiatric services, and under genetic services. If we were to put together a working group with all of the appropriate stakeholders to develop what that would look like, this would be a first. It would be a demonstrator for how we show that we care about these conditions and it would also show how the money would follow the patient. It would be relatively straightforward to calculate the overall budget for what would be required there. The question is, however, where would the budget come from? Who is going to give the budget for that? Nobody is going to give the whole budget. It is going to come from seven or eight different sectors, but nobody wants to give up their budget. How do we make a system for a complex disease like Huntington's disease? We would need to ring-fence that and would need to have some kind of overarching mechanism to ring-fence the budget for those patients. At present, there is no mechanism to do that. Possibly it could be through the national prevention strategy but the best way to do that would be set up a working group to explore how best to establish that. That could be used as an exemplar for many of these complex conditions that are spread across many different siloed parts of the HSE where the critical care falls down because one part of that silo no longer has the resources and may have spent all of its money by March. That put that person falls out of the system there. That happens a lot in neurological conditions. That would be a good way to really explore that, by setting up a working group with all of the stakeholders for a complex condition with a massive unmet need such as Huntington's disease. I commend that to the committee, if the committee would be willing to consider that and make some recommendations in that regard.

**Chairman:** To go back to the earlier discussion on long Covid, it is the same argument whereby people who have long Covid are saying that it is an infectious disease and also pulmonary and all of the those services. The ideal approach would be not be under the infectious disease, and going from one hospital to another hospital, and that one would have the group of services there that would look at the whole body and the individual in relation to that.

**Professor Orla Hardiman:** With ring-fenced funding that could come from the various different funding pots. The difficulty is that one would have to establish that the money is coming from those funding pots. This has happened in the delivery of medications through hospitals for multiple sclerosis. We do have a ring-fenced budget that is administered through the primary care reimbursement service. It is possible to do that where the hospitals contribute a small amount of money and there is no rationing any more of the multiple sclerosis drugs, which there used to be ten or 15 years ago. There is a wherewithal to do it if we have the will to do it. It is really important because these are complex conditions and if we rely on the individual budgets within the local sectors, there is a very high likelihood of failure for the delivery of care for these people, unfortunately.

**Chairman:** Reference was made to the upcoming examination of the hidden impact of the pandemic on services. When is it expected o publish this?

**Ms Magdalen Rogers:** That is a small-scale piece. We are a very small organisation and this is a piece of work we are undertaking. It is more of a qualitative piece of work. We want to talk to patients and we want to talk to clinicians on the front line. We can all read waiting lists and neurology waiting lists, which we can access very easily, but we want to get a sense of whether there is a hidden impact, which we are hearing about directly from patients themselves and also from the organisations we represent. How does one measure someone who has deconditioned due to not being able to have their physiotherapy and their speech and language therapy during the pandemic? How do we measure the effects of isolation, loneliness and anxiety? It is more of a qualitative project, but we are certainly very willing to share the findings

with the committee when they are available. We hope it will be later on this year when we have the findings.

For us, the ongoing implementation of the neuro-rehabilitation strategy is really of significant concern for us at the moment. We are concerned that there has been an impact from Covid and it is not being examined or looked at effectively because the strategy is not up and running as it should be.

**Professor Orla Hardiman:** What we will find in that, from my experience as a practitioner as well, is the need for a massive expansion of psychological and counselling services. Psychiatrists will say there is an epidemic of anxiety and stress disorders. We see that in the neurological community so we will be demonstrating the need for a significant expansion of psychological and counselling services. That is an important part of the multidisciplinary team for immunology as well.

**Chairman:** We have listened to the witnesses' asks and will hopefully respond positively to them. The contributions were really useful and it was a comprehensive discussion. Different members' questions came from different angles but we share the concern about location affecting whether someone gets or does not get services. That is in other elements of healthcare as well. We will try to follow up as a committee on many of the issues raised and try to get answers on them. I appreciate the witnesses coming in and giving their time.

**Ms Magdalen Rogers:** I thank the committee for giving us so much time.

**Chairman:** I thank the witnesses.

The joint committee adjourned at 11.51 a.m. until 10.30 a.m. on Wednesday, 6 April 2022.