NEUROLOGICAL ALLIANCE
of IRELAND

EXAMINING THE CONSEQUENCE OF THE COVID-19 PANDEMIC ON ACCESS TO CARE FOR PEOPLE WITH NEUROLOGICAL CONDITIONS

SEPTEMBER 2023

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FOREWORD

Professor Orla Hardiman: National Clinical Lead for Neurology

I welcome the opportunity to provide a foreword to this important piece of work examining the consequences of the pandemic on access to neurological care services.

Research worldwide has highlighted the disruptive effects of the COVID-19 pandemic on access to care for people with neurological conditions. A proportion of this population were highly vulnerable to the impact of the virus itself including neurological patients with high levels of disability such as those with progressive conditions or recovering from stroke/acquired brain injuries, patients requiring immunomodulatory therapies and patients with motor neurone disease and other related neurogenerative conditions.

The community of health professionals and not for profit organisations caring for people with neurological conditions mobilised an immediate response to ensure ongoing care and provide information and practical supports to patients and family carers. As National Clinical Lead for Neurology, I was concerned to protect neurological care services by preventing vital frontline staff from redeployment, developing clear clinical guidance and introducing telemedicine supports.

This report highlights vital lessons for the future of neurological care in Ireland. It clearly documents the post lockdown impact on neurological services envisaged in the consensus statement issued in June 2020 by myself and my consultant colleagues in the Clinical Advisory Group for Neurology. This paper highlighted the significant backlogs in areas such as diagnostics and increased demand post pandemic for neurorehabilitation services.

The COVID-19 pandemic exposed the underdevelopment and lack of capacity across neurology and neurorehabilitation services which were significantly overstretched pre pandemic. This is borne out by the findings of this report, highlighting the ongoing impact on patients and their families.

The findings from this report are a timely warning that investment in neurological care is critically needed at a time when demand for these services continues to grow. This includes investing in and protecting the vital services and supports provided by not for profit neurological organisations which form such an integral part of neurological care provision throughout Ireland.

KEY FINDINGS

Neurological Care Services Struggling to return to Pre Pandemic Levels because of underresourcing pre COVID-19

The most striking finding from the report was the lack of confidence amongst all respondents that there -would be capacity within neurological care services to address the backlog and pent-up demand post pandemic as a result of disruption to services. It was highlighted by all groups of respondents that services pre-COVID-19 were already under resourced, and this has under resourcing has been compounded by the disruption caused by COVID-19 as well as a potential new cohort of people with neurological symptoms who will require access to neurological services. Those with pre-existing neurological symptoms are fearful that investment in long COVID will detract from an already under-funded service.

Emerging Service Needs due to neurological consequences of long COVID

More than one in ten respondents to the NAI survey on the impact of the pandemic on access to neurological care services self-identified as having long term neurological symptoms as a consequence of contracting the COVID-19 virus. The vast majority were unable to access neurological services despite needing to and they expressed despair, anxiety and distress about their condition deteriorating further because they could not access services. These findings highlight the need to put in place specialist services to diagnose and treat the neurological consequences of long COVID.

Voluntary Providers Facing Significant Challenges Post Pandemic

Voluntary providers have demonstrated their agility and flexibility in responding needs of people with neurological conditions when the pandemic restrictions were in force, however they have also outlined the challenges they face with the additional demands that the pandemic has generated for their services, particularly the increase requirement for psychological support. They also require support to respond to new demands from those services users with neurological symptoms relating to long COVID.

Mental Health Consequences of the Pandemic for People with Neurological Conditions & Family Carers

This report has demonstrated that people with neurological conditions experienced increased isolation, uncertainty about their treatment options and anxiety and distress related to health deterioration due to delays in assessment and treatment. Families have also experienced undue stress and mental anguish resulting from difficulty in accessing treatment for their family member as well requiring support when they were bereaved. Prior to the pandemic, access to services to support mental health and wellbeing were difficult to access. Whilst the advent of virtual services has made some of these services more accessible, there is still a dearth of options, resulting in mental health needs of people with neurological conditions and their families being undetected, exacerbating the challenges they face and adding complexity to service providers as they seek to respond.

RECOMMENDATIONS

In May 2021, the HSE published a recovery plan for COVID-19[1] which outlined a wide range of impacts across the health system and a series of recommendations to address the immediate and longer-term consequences of the pandemic response.

A number of the recommendations are examined below in the context of the findings of this current NAI report

HSE COVID-19 RECOVERY PLAN: A clear plan is needed for the recovery of all services. This must acknowledge the significant gaps in services prior to the pandemic that have resulted in long waiting lists for acute and community services and address these with investment

NAI RECOMMENDATION

A specific assessment and recovery plan is needed for neurology and neurorehabilitation services to address the critical capacity issues in these services which predated the pandemic and continues to impact significantly on the ability of these services to respond post pandemic.

COVID-19 impact assessment reports produced during the pandemic by the Neurological Alliance of Ireland[2], and by both the National Clinical Programmes in Neurology[3] and Rehabilitation Medicine highlighted that neurological care services were at particular risk because of significant resource needs which predated the pandemic.

The findings of this current NAI report highlight that the disruption to neurology and neurorehabilitation services as a consequence of the pandemic has not resolved. Service providers highlight throughout that the historic underdevelopment and underinvestment in these services meant that they lacked the capacity to return quickly to pre pandemic levels. The impact on service users of longer waiting times and lack of access to essential supports is clear from survey findings and individual responses.

HSE COVID-19 RECOVERY PLAN: The partnerships developed with community organisations and voluntary groups should be deepened to broaden their role in partnering with the health services in tackling the impact of the pandemic.

NAI RECOMMENDATION

Engagement with voluntary providers is critical to addressing the impact of the pandemic on both existing and emerging groups of service users with neurological conditions

The focus groups with voluntary providers in this report highlighted the challenges they continue to face in addressing the impact of the pandemic on service users and their families: from the effects of delayed diagnosis to the range of psychological and psychosocial consequences due to isolation, anxiety and bereavement.

There is also a recognition in this report that people experiencing neurological consequences due to long COVID will seek supports from the voluntary sector as the main providers of long term supports for people with neurological conditions in the community.

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[1] *The impact of the COVID19 pandemic and the societal restrictions on the health and wellbeing of the population, on our staff and on health service delivery and capacity: A plan for healthcare and population health recovery (May 2021) Health Services Executive*

[2] *Submission on Neurological Care Services in Ireland: a sector in crisis due to prepandemic underinvestment and the impact of COVID-19 (November 2021) Neurological Alliance of Ireland submission to the Oireachtas Committee on Health*

[3] *Consensus Statement on Neurological Care post COVID19 lockdown (June 2020) National Clinical Programme for Neurology*

There is a vital need to ensure that voluntary organisations are included as equal partners in the development of measures to address the impact of the pandemic on service users with neurological conditions and their families.

HSE COVID-19 RECOVERY PLAN: Adequate community rehabilitation services for patients with post-acute COVID-19 syndrome must be provided.

NAI RECOMMENDATION

Priority resourcing is needed for specialist supports for service users with neurological consequences from long COVID. Immediate investment should focus on the expansion of the only dedicated long COVID neurology service in Ireland to include a full multidisciplinary team. Action to address the critical lack of community neurorehabilitation services must be urgently addressed by fully staffing nine community neurorehabilitation teams around the country.

The findings of this report, including the survey findings from service users identifying as long COVID patients and the testimonies of clinicians point to the need for additional resourcing of specialist supports for this emerging cohort of patients.

The Interim Model of Care for Long COVID[4] puts forward a three pillar approach to a national post COVID-19 service which focuses on

a. Patient led rehabilitation and recovery

b. General assessment, support and rehabilitation

c. Specialist assessment support and rehabilitation

The model of care highlights the need to formalise pathways to the neurocognitive clinic (St James Hospital) as a priority for implementation. This clinic, the only dedicated neurocognitive clinic in Ireland for long COVID patients is currently staffed by one consultant neurologist without access to the dedicated multidisciplinary team required to meet the complex and challenging needs of this group.

Demand for community neurorehabilitation services, already high pre pandemic, has increased significantly due to the combined needs of those who needed to be discharged early and missed out on neurorehabilitation, those impacted by the curtailment or closure of services due to lockdown and those requiring rehabilitation after the virus. The Neurological Alliance of Ireland is calling for funding to fully staff a community neurorehabilitation team in each of the nine HSE CHO (community health organisation) areas nationwide as recommended in the 2019-2021 Implementation Framework for the National Neurorehabilitation Strategy[5].

HSE COVID-19 RECOVERY PLAN: Continued investment will be needed for mental health services and supports

NAI RECOMMENDATION

Need for targeted support to address the mental health impact of the pandemic on people with neurological conditions and their families

All contributors highlighted the need for targeted dedicated mental health supports to address the wide-ranging impact on the mental health of people with neurological conditions and their families as a consequence of the pandemic. Isolation, anxiety and dealing with bereavement were significant themes identified in the report. Research carried out in the UK has highlighted that people with neurological conditions struggle to have their mental health needs met within neurological care services, a nationwide survey of over 10,000 people[6] with neurological conditions found that 58% of people with a neurological condition have not been asked about their mental health by a health professional and 40% of patients with a neurological condition feel that their mental health needs are not being met.

It is vital that addressing the mental health consequences of the pandemic among service users and their families is prioritised at a time when there is increased pressure on existing services to deal with the backlog and disruption caused by COVID-19 restrictions.

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[4] *COVID19 Interim Model of Care for Long COVID-19 (September 2021) Health Services Executive*

[5] *National Strategy & Policy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Practice: Implementation Framework 2019-2021 (February 2019) Health Services Executive*

[6] *UK Neurological Alliance Report 2019 Still Waiting for Improvements in Care. Accessed May 2023 https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-patience-2019-1.pdf*

INTRODUCTION & CONTEXT

Introduction

Research worldwide has highlighted the disruptive effects of the COVID-19 pandemic on access to care for people with neurological conditions.

The purpose of this report is to examine the consequence of the pandemic on access to care from the perspective of neurological patients as well as service providers.

The main theme that will be examined will be the impact on the future of neurological care services in the wake of the pandemic. Within this theme, consideration will be given to explore changes in access to services for those who were accessing services prior to the pandemic, those who were awaiting diagnosis during the pandemic and people who have developed longer term neurological symptoms following COVID-19.

Particular consideration will be given to the following three areas:

- The extent to which services have returned to pre pandemic levels and challenges and future concerns of service users
- The responses from service providers in relation to the impact of the pandemic on service users and on their own service provision, including changes to how services were provided
- The needs of people who developed longer term neurological symptoms following COVID-19 and the implications for neurological care services in meeting their needs

The findings and recommendations from this report are considered in the context of a number of recommendations of the HSE COVID-19 Pandemic Impact Paper May 2021[7], referred to as the HSE COVID-19 Recovery Plan (2021)

Context

Over 800,000 Irish people are living with neurological conditions[8]. The lack of investment and successive cuts to Section 39 Organisations (Community, Voluntary & Not for Profit Agencies being funded under Section 39 of the Health Act, 2004) meant that services and supports for people living within neurological conditions were already at breaking point prior to COVID-19 (NAI 2020[9]). To compound this, COVID-19 disproportionally affects people with pre-existing neurological conditions and neurological manifestations have been recognised as an important component of the disease (WHO 2021[10]). In effect, the longstanding barriers to accessing services for people with neurological conditions have been exacerbated by the pandemic. (National Neuroscience Advisory Group 2021[11]).

From an international perspective, there have been several reports and articles published that have generated evidence on the impact of the pandemic on access to neurological services.

The WHO Scientific Briefing (WHO 2021) reported that COVID-19 disproportionally affects people with pre-existing neurological conditions, and this cohort have also been affected by interruptions to routine care, delayed care, and disruptions to the supply chains for medicine. These findings are consistent with[12] a global survey carried out on disruption of neurological services during the COVID-19 pandemic. The most impacted services were cross-sectoral neurological services and neurorehabilitation. The report from the European Federation of Neurological Associations (EFNA) in June 2021[13] summarises evidence gathered from organisations across the European Neurological Community and noted that the pandemic response saw a serious impact on access to care coupled with a real lack of patient engagement and involvement.

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[7] *The impact of the COVID19 pandemic and the societal restrictions on the health and wellbeing of the population, on our staff and on health service delivery and capacity: A plan for healthcare and population health recovery (May 2021) Health Services Executive*

[8] *Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) Report Commissioned by the National Hospitals Office Health Services Executive*

[9] *COVID-19: The Impact on People with Neurological Conditions and Family Carers June 2020*

[10] *Neurology and COVID-19 Scientific Brief 29 Sept 2021 WHO*

[11] *Lessons learnt from the COVID-19 pandemic Priorities in care for people with neurological conditions after the pandemic. A report by the National Neurosciences Advisory Group. April 2021. Hannah Verghese and Georgina Carr*

[12] *Chahnez Charfi Triki et al (2021) Global survey on disruption and mitigation of neurological services during COVID19: the perspective of global international neurological patients and scientific associations. Journal of Neurology (2021) June 11; 1-13*

[13] *Addressing the impact of COVID-19 on the lives of people living with neurological disorders EFNA June 2021. Accessed May 2023 https://www.efna.net/wp-content/uploads/2021/06/EFNA-Report_Final-.pdf*

Its recommendations stress that any future changes to service delivery are made in the interests of those living with neurological conditions.

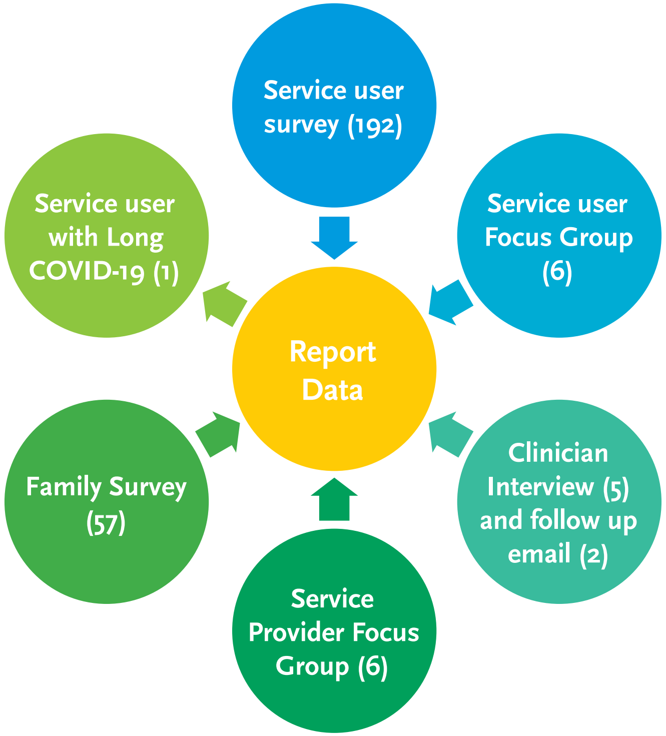
Specific data from Ireland is not yet available, however there have been clear warnings from the Neurological Alliance of Ireland and from papers produced by Clinical Programmes in Neurology and Rehabilitation Medicine of the lack of existing capacity to meet demand post pandemic.

The Consensus Statement on Neurological Care Post COVID-19 Lockdown prepared on behalf of the Clinical Advisory Group for Neurology in June 2020[14] anticipated that the neurological consequences of COVID-19 would require additional resourcing of neurology and neurorehabilitation services.

METHODOLOGY

Range of Neurological Conditions Among Respondents to Survey on Access to Services

Acquired Brain Injury
Brain Tumour
Dystonia
Chronic Pain
Epilepsy
Functional Neurological Disorder
Huntington's Disease
Long COVID
Motor Neurone Disease
Migraine
Multiple Sclerosis
Myasthenia Gravis
Parkinson's Disease
Post polio syndrome
Spinal injury
Stroke



A mixed methods approach was used to inform the findings of this report combining online surveys, focus groups and interviews. The themes for the surveys and interviews were informed by reports and research relating to this theme, and these were gathered via desktop research. The views of service users and family members were initially sought via online survey in August 2022. A series of in-depth focus groups and interviews were subsequently held with a group of service users and service providers, and individual interviews were held with a range of neurological clinicians (Consultant Neurologists, neuropsychologists, nurse specialists etc) . An interview was also held with a person with long COVID experiencing neurological symptoms. The data from the online surveys, focus groups and interviews were analysed using a thematic approach. There were some limitations on the data collected, including a small sample size of some of the cohorts, the reliance on self-reported information, and lack of previous research in this area.

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[14] *Consensus Statement on Neurological Care Post COVID-19 Lockdown On behalf of the Clinical Advisory Group for Neurology. 03 June 2020. Prof Orla Hardiman https://www.nai.ie/assets/9/1C509519-53D2-46C5-9003E4D2FA8E1229_document/Neurology_re-opening_post_COVID_3rd_June_2020__FINAL.pdf*

THEMES EMERGING FROM THE DATA

The following themes have been extracted from the data and each of these will be explored from the perspectives of the service users, families, service providers and clinician

1) Impact on access to services
2) Long COVID
3) Psychosocial impact
4) Value of hybrid services and what resourcing is required

THEME 1: Impact of the pandemic on access to services

As a result of COVID-19 lockdown, service users have experienced disruption in access to services. In particular: appointments with neurologist (26%), scans (23%), access to nurse specialists (20%), physiotherapy (19%), and neuro rehabilitation services (15%) have not returned to pre-COVID-19 levels. These challenges were also reported by family carers responding on behalf of their family member with a neurological condition (see Charts 1 and 2 below).

Chart 1

Person with neuro condition

Q4 To what extent has your access to services returned to pre COVID-19 levels following the restrictions (n133)

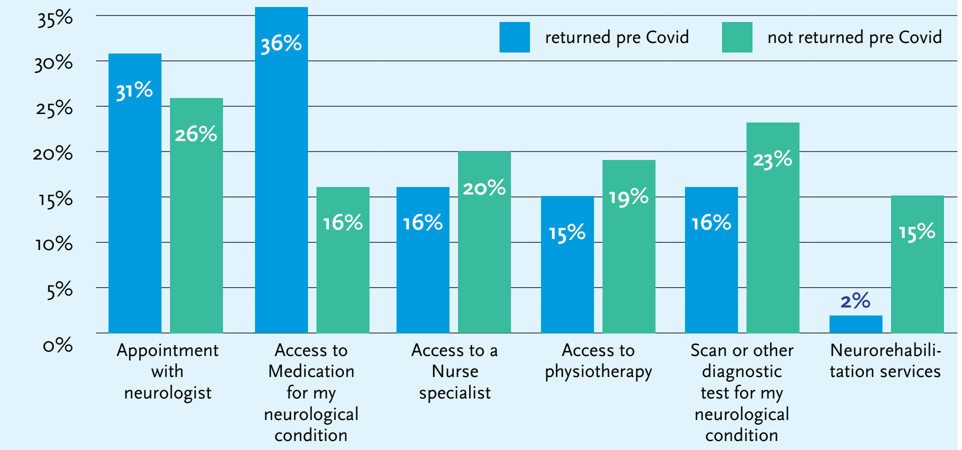
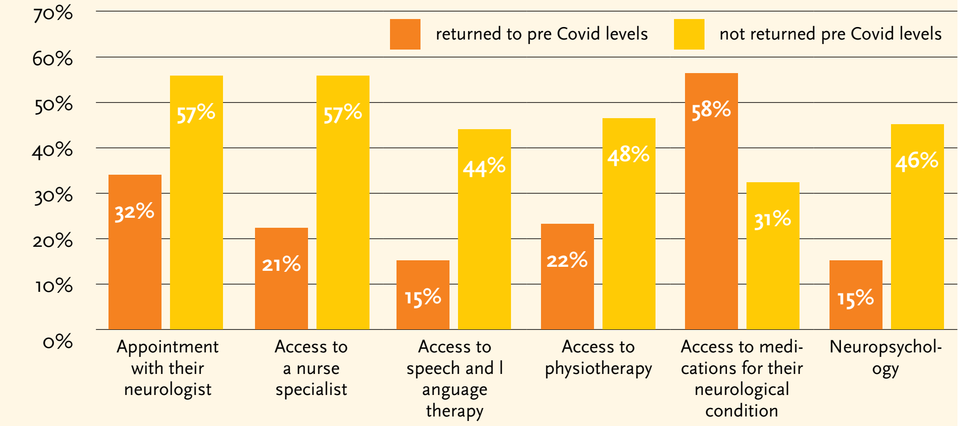


Chart 2

Family response

Q10 To what extent has your family member's access to services returned to pre COVID-19 levels following the restrictions (N28)



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5 *National Strategy & Policy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Practice: Implementation Framework 2019-2021 (February 2019) Health Services Executive*

6 *UK Neurological Alliance Report 2019 Still Waiting for Improvements in Care. Accessed May 2023 https://www.neural.org.uk/wp-content/uploads/2021/04/neuro-patience-2019-1.pdf*

In the focus group, the services users outlined that when they can access the service there has been, in some cases, interruption in the service flow and a reduction in the amount of service available due to service reconfigurations and virtual services replacing face-to-face consultations. These difficulties have resulted in delays in diagnosis, assessment and treatments which in turn have led to frustrations and a sense that potential recovery is not being maximised and the level of deterioration they have experienced could have been avoided. The clinicians concurred that the delay in tests and scans caused by the pandemic had negative consequences. These included delayed diagnosis, not accessing treatment options which resulted in worsening of their condition and patients presenting at more advanced stage with secondary complications. This was also observed by service providers, who also reported that they have noted that there has been an increase in number of people dying who avail of their service, compared with pre-COVID-19 years.

"We started to see evidence of people's condition worsening because of lack of access to certain services and being unable to come in for treatments." (Clinician Interview)

"That my condition is getting worse and there is no help available while I am waiting for consultant appointment." (Service User Survey)

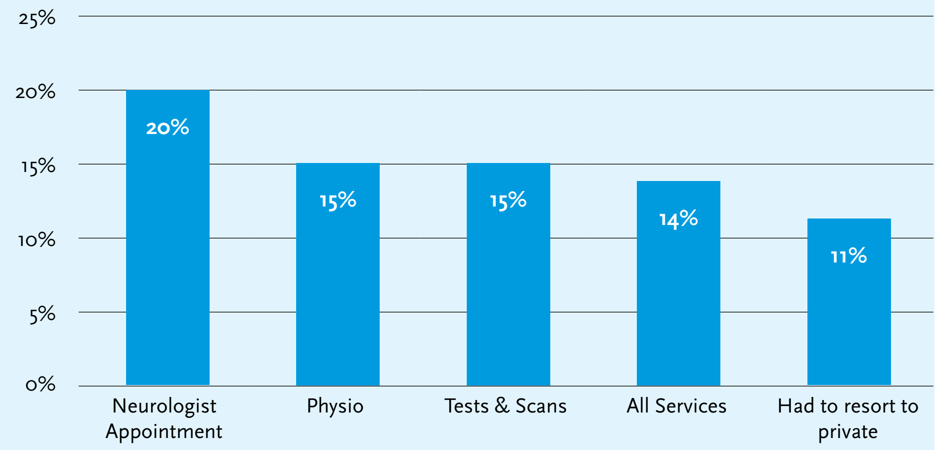
When asked to consider what services service users found most difficult to access, the most common were appointments with their neurologist (20%), access to physiotherapy (15%), tests and scans (15%). 14% of respondents noted that all services were hard to access, and 11% stated that they resorted to private healthcare, as represented in Chart 3 below.

"I have had to engage a private neurologist – too long waiting list for hospital" (Service User Survey)

Chart 3

PW Neuro Condition

Q5 What services have you found difficult to access over the last 12 months (August 2021 to August 2022) (n114)

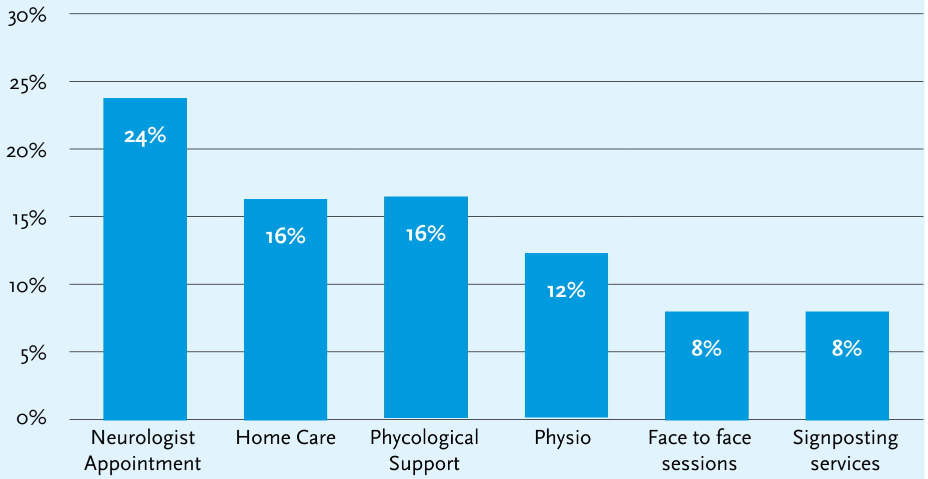


From the perspective of family members (Chart 4), in addition to neurologist and physiotherapy, they also reported difficulty in accessing psychological support (16%) and home care services (16%). The clinicians noted that that the adjustment to virtual services was particularly difficult for those with more advanced disease and those who were older. In addition, service providers noted that services were under-resourced prior to COVID-19 with a lack of Clinical Nurse Specialists, Physiotherapy, Occupational Therapy, Neuro Psychology, Speech and Language Therapy and Social Work in both acute and community settings.

Chart 4

Family response

Q11 What services has your family member found it difficult to access over the last 12 months (August 2021 to August 2022) (n25)



When, as part of the survey in August 2022, service users and family members were asked to consider what concerns they would have about accessing services in the next 12 months (September 2022 to September 2023), the biggest concern amongst both groups that there would be no access to services (35%) and (32%) respectively (Charts 5 and 6). Not surprisingly, these charts indicate another big concern would be a deterioration in their health (service users 15%) and (family members 18%). Just under 10% of service users noted that they had no concerns. In the focus group service users noted that those who are new to services were at most disadvantage, as it was hard to establish relationships with key personnel using virtual methods, and that the outcome of the assessment process was unsatisfactory.

"I worry my condition is deteriorating and I will fall between the cracks. I am only newly diagnosed with MS and the supports are very sparce. It makes me very sad." (Service User survey)

"Those new to services are at most disadvantage, relationships with key personnel not yet established and assessment process resulted in delays or referrals that were not appropriate." (Service Provider Focus Group)

"It has taken people two years or longer to get their diagnosis, yet they had symptoms before covid. They are very, very upset. Some people are very angry". (Service Provider Focus Group)

Chart 5

PW Neuro Condition

Describe your concerns about getting access to services Sept 22-Sept 23 (n95)

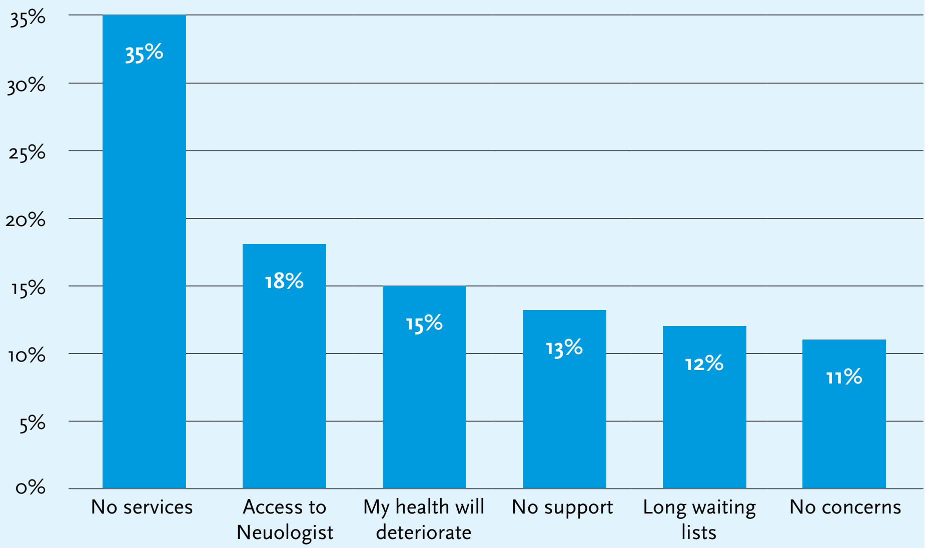
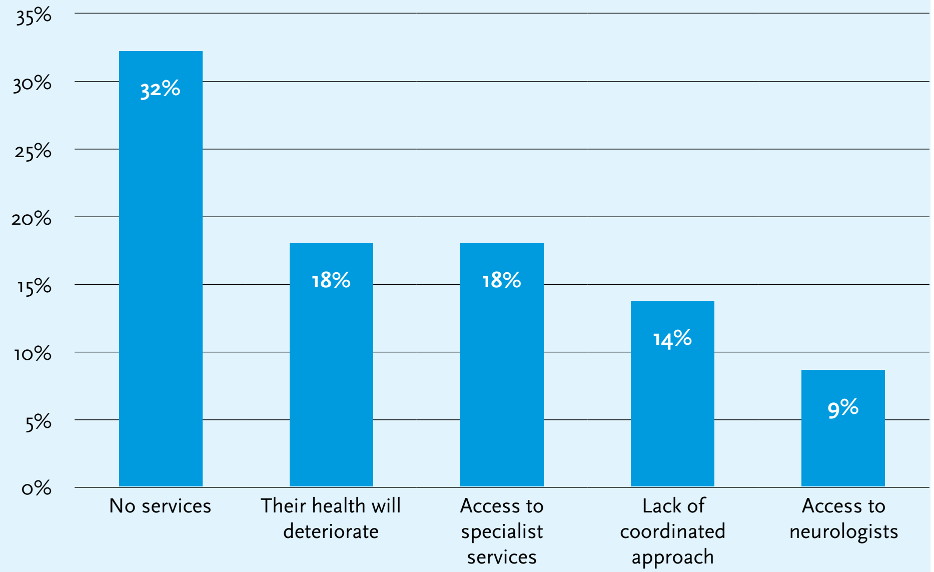


Chart 6

Family response

Q12 Describe your concerns about access to services for your family member Sept 22- Sept 23 (n22)



THEME 2: Neurological Consequences of Long COVID and emerging service needs

In the interviews with clinicians, respondents noted that there is an increased prevalence of neurological symptoms with Long COVID, and a critical need to recognise the need for specialist neurological and neurorehabilitative supports for this group in the development of the long COVID model of care and its implementation.

They also outlined that the milder impact may not be fully recognised yet among individuals with long COVID, e.g. fatigue, brain fog and memory issues, and that this is likely to generate additional demand for neurology and neurorehabilitation services in the mid to longer term future. In addition, the clinicians noted that there is a need to examine how COVID-19 diagnosis impacted those who already had a neurological diagnosis, and the consequences of restrictions imposed by the impact and what their rehabilitation needs are to restore function to pre COVID-19 levels.

The clinical resources invested to date (December 2022) in long COVID neurology have been limited, with one full time temporary consultant appointed in Oct 2022, supported by a very limited dedicated multi-disciplinary team (Note: The consultant neurologist post was made permanent in January 2023). The clinicians stressed that any investment in addressing the neurological needs of long COVID patients should be in addition to and not instead of resources that are required to address the service deficit that existed prior to the pandemic.

"Many other individuals in this country have been waiting in excess of 12 months, sometimes up to or beyond 3 years for an Neurology appointment and the equal provision of services for everyone should not be forgotten moving forward." (Clinician interview).

Services users also expressed a concern that the necessary focus and investment going to long COVID could distract attention and divert funding from neurological services which are already under resourced. It has not been evident to the service providers or service users that any additional resources have been made available to respond to the impact of delayed treatment or additional mental health needs that are presenting as a result of COVID-19.

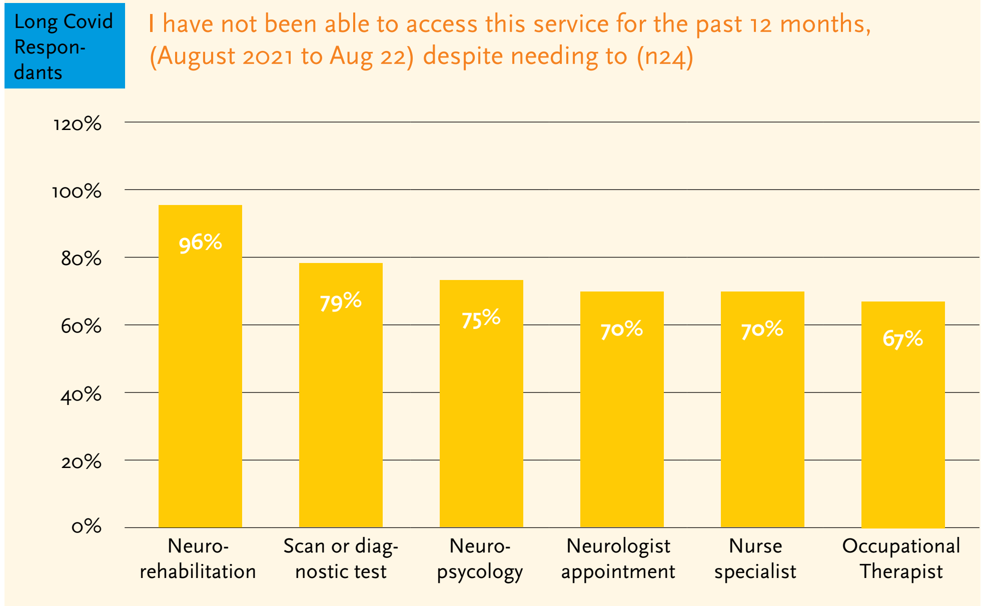
"All this talk about the need for services with long COVID. There are 12,000 people out there with Parkinson's who experience very similar symptoms and they are not getting access to services. And now it's all about long COVID." (Service User Focus Group).

Insights into Needs of long COVID patients from Access Survey

Twenty-four (12.5%) of the 192 respondents to the survey of people living with a neurological condition/family carers carried out in August 2022, self- identified as having neurological symptoms as a result of long COVID.

Their experiences are outlined below and this is followed by an interview with a person living with long COVID who has neurological symptoms. As evident in Chart 7, most respondents identifying with long COVID indicated that they were not able to access neuro-rehabilitation (96%), scans or diagnostic tests (79%), neuropsychologist (75%), neurologist (70%), nurse specialist (70%) and occupational therapist (67%) despite needing these services.

Chart 7



When asked what services they found most difficult to access, people reported difficulty in accessing all services and noted that the waiting lists were far too long. Particular difficulty was reported in accessing neurologist, scans and neurorehabilitation services. A small number of respondents reported that they have resorted to accessing services privately because of the lack of access.

"I have not been able to access a neurologist. I am on a 12 month plus waiting list. I have no access to any services for neurological condition." (Service User Survey)

"I need neuro rehabilitation after contracting covid. I have long COVID since January 2021, and have had zero neuro rehabilitation help from a professional despite being in two long COVID clinics." (Service User Survey)

"I have had to go private for all my needs, my neurological consultations and scans." (Service User Survey)

When asked to reflect on concerns about getting access to services for the next 12 months, people were mostly worried that their condition would deteriorate further as a result of not receiving any support. The emotional toll was also predominant, as respondents expressed how they felt alone and terrified as a result of their condition, with difficulty in carrying out their parenting role. Finally, a number of people expressed concern about losing their job and the financial toll of not being able to work anymore.

"I have been unable to work for 2.5 years. I cannot take care of my children, there is no support to help me." (Service User Survey)

"I need neurological support badly. I am afraid that permanent damage is being done to my brain while I wait to referred for an appointment. (Service User Survey)."

"I am terrified that I won get any access to services and will be just left. Its having a huge impact on my ability to work and undertake daily tasks." (Service User Survey)

"I am alone with my illness. My GP cannot help me. I can't get access to a neurologist. I have been like this since getting COVID-19in March 2020." (Service User Survey)

This case history documents the experience of a university lecturer in her mid-50's who contracted COVID-19 in Jan 2021. She was interviewed by phone in November 2022, and has given permission for this synopsis to be included in the report.

COVID-19 has impacted her with both emotionally, physically and has required her to adapt many aspects of her life, which are described in detail. This is followed by her suggestions as to what would help in the future.

She explained that brain fog is by far the most taxing symptom, and that she requires prompts for single, simple words and has great difficulty spelling. The physical symptoms she endures such as breathlessness, cramps and pain are more bearable. She describes the emotional burden of dealing with the unpredictable nature of the condition as extremely frustrating, as she is unable to plan has had to renege on parts of her job that she loved. She describes how she takes her frustration out on her family, and they have to observe her when she is upset and having meltdowns. She is of the view, that her strong coping skills have actually meant that she is getting less treatment, and that this is unfair, and expresses how she is tired of being 'understanding' of a system that cannot respond to her needs.

In terms of adaptations, she has had to make, as well as curtailing elements of her teaching role, she has had to change the way she prepares for classes as she cannot rely on her memory. She finds these curtailments depressing, and not being able to rely on her memory or and the lack of spontaneity has affected her confidence. She describes how she has to rely on external prompts to remind her to carry out daily tasks, and that the effort of concentrating on priority tasks minimises her ability to recall casual conversations, and often leaves her too exhausted to socialise with friends, which she misses.

When considering the value of supports available from the health service, the most beneficial was access to the clinical psychologist as part of the long COVID clinic. However, this service was limited to 4 sessions, and she was informed that she would have to take the private route for future sessions, which she could not afford. In her experience, the GP and long COVID clinic did not seek to understand or address her neurological symptoms, but instead focus on physical symptoms like breathing and pain. She finds this approach frustrating and undermining, especially as she is often more informed than the clinicians, and it would be better if they admitted they were not fully informed on the topic. 'They don't want to listen about my memory or brain fog'.

In terms of what would help, she recommends that clinicians who are supporting people with long COVID provide more opportunities to listen to patients, provide more understanding of the situations they are facing and not to be dismissed. She also suggests that there are more opportunities for peer support, scheduled to support people who are working outside of the home, and that these support groups could be informative to staff. She would also like to see more flexibility in the workplace.

THEME 3: Psychosocial impact of Pandemic Restrictions

The toll of the pandemic on the mental health of people living with neurological conditions and their families was expressed by all participants. Service providers outlined how restrictions, both service limitations and the requirement to isolate, imposed by the pandemic have had a psychological and emotional burden both the person with the neurological condition and for family members. They have seen an increase in demand for counselling services as people experience increasing level of paranoia and anxiety as a result of the pandemic, and noted the additional challenge for people with acquired brain injury to deal with issues relating to their mental health. Clinicians observed that there may have been mental health impacts on those people with neurological conditions waiting to be seen for the first time, and it was evident that they missed the peer support when services went on line.

On a poignant note, the service providers observed the trauma for families who died during COVID-19, perhaps prematurely. The were not aware of any additional supports made available to address the painful consequences for families who have been traumatically bereaved as a result of their family member acquiring covid.

There are a lot of people who have lost members of their family and they are in a very bad emotional state. (Service Provider Focus Group)

They feel if they had got the services they needed earlier, they might not have died prematurely. (Service Provider Focus Group)

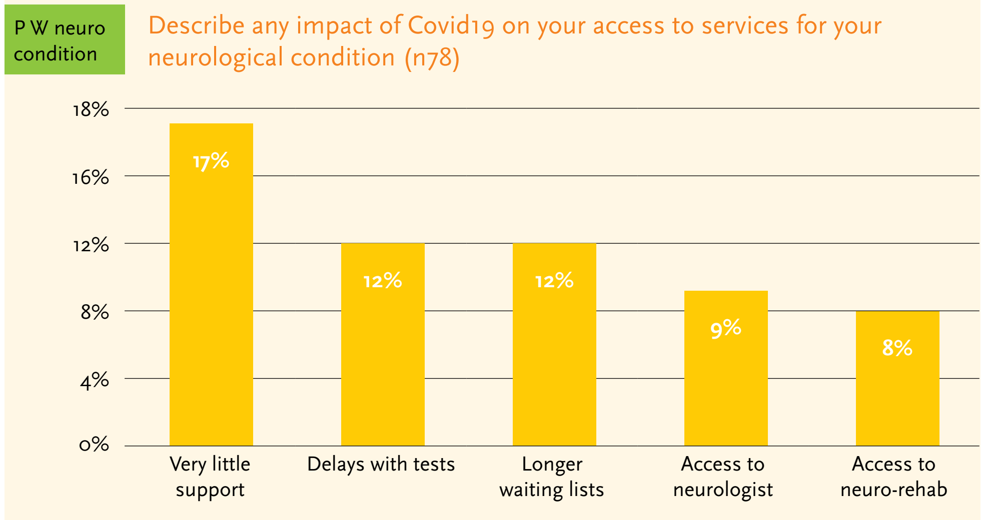
As well as concerns on physical symptoms, the service users who participated in the focus groups outlined how the delays and disruptions have caused greater uncertainty, adding further to the anxiety burden and emotional toll to what would normally be expected for people with neurological conditions.

I have ability to email in that because I know how to work the system. But others struggling, they don't have the energy to keep pushing and pushing. (Service User Focus Group)

According to my neuropsychological assessment, I am moderately depressed and highly anxious. And I am saying well what no wonder and all these things that I have to fight for and constantly put myself out there for and it's not my personality. This takes away from your physical recovery. The emotional toll. (Service User Focus Group)

In the survey, (Chart 8) the highest concern from service users related to 'very little support' (17%) when asked to consider the impact of COVID-19 on access to services, whilst family members noted that not being able to be present as their family member was in hospital or attending clinical appointments (20%) caused them greatest impact, with a small number of families stating that they felt abandoned (10%) (Chart 9). It is important also to reflect that 17% of service users noted that they experienced no impact on access to services.

Chart 8

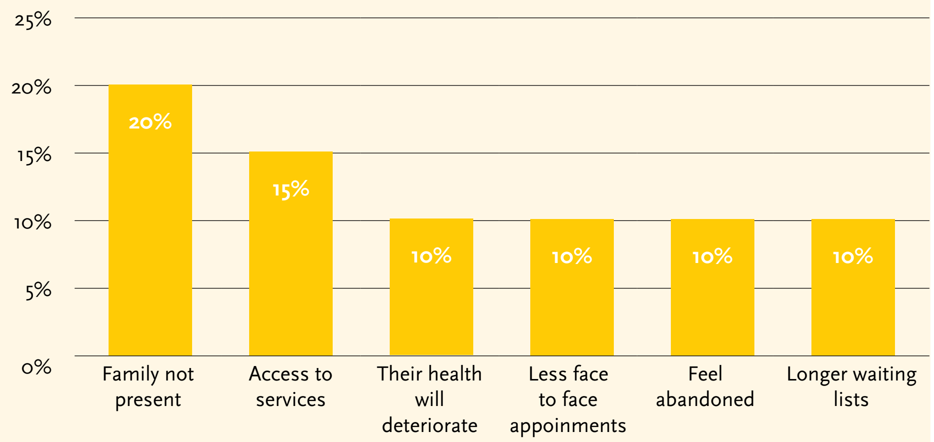


Describe any impact of Covid19 on your access to services for your neurological condition (n78)

Chart 9

Family response

Describe any impact of COVID-19 on access to services for your family member with a neurological condition (n20)



THEME 4: Investing in hybrid services

The adaptations, such as virtual or hybrid access, that have been introduced by both statutory and voluntary providers have yielded some benefits for people with neurological conditions, though it is still a work in progress to get the balance right. The learnings need to inform the development of neurological services in the future from both community and acute perspectives.

For some people, the introduction of virtual clinics removing the travel burden has made access to services easier, however it is not always feasible to replicate the experience of face-to-face assessment and interventions. This concern was also raised by family members. Those who were new to services during covid, were at most disadvantage, as relationships with key personnel had not been established, and the assessment process resulting in delays or referrals that did not respond to their needs.

"With COVID-19 some of the appointments are just over the phone, so the last time I got into see my neurologist I was in there [hospital] for 6 hours and you are leaving absolutely exhausted, and you the next time I will definitely take a call as I don't want to be sitting in a hospital for six hours. But it means that when you are in having a chat with them, they are giving you the info. Because you are not in front of them online you can't put up your hand or let them know you have a rebuttal to make." (Service User Focus Group)

"COVID-19 did help bring some of the online services – not all ideal – there is some that are very beneficial. Not either or – you need a bit of both." (Service User Focus Group)

Several service users commented on how the virtual communications have enabled them to stay in touch with their peers, and participate in maintenance rehabilitation programmes, that would not have been otherwise possible.

"We adapted our face-to-face set dancing classes since pandemic. Got everyone onto zoom, over a 6-month period. We now have double the amount of people attending. Quite positive. This wouldn't have happened only for COVID-19. Little bit of silver lining." (Service User Focus Group)

The service providers acknowledged the positives and negatives attached to service reconfiguration and accessing services virtually, and a welcome shift to provision of services in the community services, which they hope will continue, though additional training is required to respond to the more complex cases.

It was noted that those with cognitive issues can have additional challenges as they navigate and communicate with clinicians and service providers using online methods, and extra accommodations were not always available to maximise their participation. For many the introduction of online services and clinics was more convenient, obviating the need for travel or assistance from carers. It was noted, however, that accessing services online further perpetuated the isolation some people were experiencing. While many people welcomed the return of face-to-face services or introduction of hybrid options, there are some people who are still reluctant to go back to face-to-face appointments, either due to the convenience or for some fear of infection. The service providers noted that the pandemic required a welcome shift to provision of services in the community services, which they hope will continue, though additional training is required to respond to the more complex cases.

"We tried to switch some of our short-term neuro programmes remotely, but they didn't all work. Cognition may have interrupted. We are bringing people back, but there is a huge nervousness." (Service Provider Focus Group)

The service providers welcomed many of the service adaptations and reconfigurations that have come about due to covid, particularly the increasing focus on community services, staff skills being more fully utilised, services reaching people who were previously isolated and more choices available for clients.

"COVID-19 showed the value of MND (motor neurone disease) nurses, we changed around our practice, and provide a service for patients nearer to home or at home, reducing their need to travel to tertiary hospital." (Service Provider Focus Group)

"The pandemic forced us to do things online. We turned our services on our head, and we are now more efficient." (Service Provider Focus Group)

However, some of these changes have resulted in placing added expectation on staff as they deal with a more complex caseload, which may require additional training, resourcing and orientation, and this is not always available. Additional structures and resources are required to ensure these 'pandemic pivots' remain.

The clinicians who were interviewed agreed that telehealth doesn't replace in person services, especially for new patients. However, they noted that it is a very efficient way of delivering services: virtual and remote services are good option for a sub set of patients, with many patients opting to continue with online treatment when face to face clinics returned.

In planning for the future, it is important to learn what has worked from the online and virtual clinics, and invest in standardised infrastructure, software tools and protocols to maximise the experience for everyone.

FURTHER INFORMATION

The Neurological Alliance of Ireland has been proactive throughout the pandemic and its aftermath in researching and reporting on the impact of COVID-19 and the disruption to services on people with neurological conditions and their families. Here is a list of NAI reports/submissions in this area.

Submission to Oireachtas Committee on COVID-19 July 2020

Embracing Digital Solutions to Neurological Care July 2021

Submission to Joint Oireachtas Committee on Health on impact of the COVID-19 pandemic on access to neurological care services November 2021

Submission to Joint Oireachtas Committee on Health March 2022 on impact of the COVID-19 pandemic on access to neurological care services.

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