



NEUROLOGICAL ALLIANCE
of IRELAND

**RESOURCING
OF NEUROLOGY
SERVICES IN IRELAND
FIVE YEARS ON:
2015 -2020**

KEY FINDINGS FROM THE
NEUROLOGICAL ALLIANCE
OF IRELAND 2020 SURVEY
OF NEUROLOGY SERVICES

MARCH 2021

RECOMMENDATIONS FROM THIS REPORT

1. ADDRESS ONGOING CRITICAL UNDERSTAFFING ACROSS NEUROLOGY SERVICES THROUGH YEAR-ON-YEAR INVESTMENT

There has been recent investment to tackle geographical inequities within regional centres by funding five new Consultant Neurology posts. However, there is a need to address critical gaps in multidisciplinary staffing across neurology services through continued year on year investment in staffing to increase the numbers of clinical nurse specialists, neuropsychologists and other multidisciplinary staff which continues to fall far below what is required.

2. INVEST IN NEUROREHABILITATION SERVICES

Findings from the 2020 survey of neurology centres show that access to neurorehabilitation services has deteriorated even further since poor levels of access were reported in 2015. Section 2.5 of this report highlights the lack of progress in implementing the Three-Year Implementation Framework for the National Neurorehabilitation Strategy 2019-2021. The ongoing lack of commitment to address serious gaps in neurorehabilitation service provision, particularly in the community, continues to impact significantly on longer term outcomes for neurology patients.

3. ADDRESS CAPACITY ISSUES TO ENABLE NEUROLOGY SERVICES TO MEET CURRENT AND EMERGING NEEDS

A comparison of the 2015 and 2020 surveys highlighted many of the same issues for centres in accessing space for clinics, dedicated beds, access to diagnostic tests etc. There is a vital need for significant investment in neurology to enable the service to develop and expand to take advantage of new treatments and develop new services in response to the needs of specific groups.

4. TACKLE THE FUNDING CRISIS AMONG NOT-FOR-PROFIT PROVIDERS OF NEUROLOGICAL CARE

Neurology services are critically reliant on a network of not-for-profit patient organisations which provide specialist supports and services in the community. These services are under serious threat because of a legacy of funding cuts and the collapse of fundraising due to the COVID19 pandemic. NAI echoes the call across the disability sector for Section 39 organisations to be funded by the State to reflect the true cost of providing these services.

This Neurological Alliance of Ireland initiative is supported by the following partners and sponsors.



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NEUROLOGICAL CONDITIONS IN IRELAND

Neurological conditions affect the brain and spinal cord and include common conditions such as migraine, epilepsy, stroke, multiple sclerosis, acquired brain injury and Parkinson’s disease as well as rare and genetic conditions. According to the World Health Organisation: Neurological conditions are now the leading cause of disability and second leading cause of death worldwide. An estimated one in three people worldwide has a neurological disorder at some point in their lifetime¹.

Over 800,000 Irish people are estimated to be living with a neurological condition with 40,000 newly diagnosed each year².

Table 1: Estimated numbers of persons with neurological conditions in Ireland

(Applying the percentages presented in the UK neuro numbers report) Source: Strategic Review of Neurology and Neurophysiology Services in Ire-land (2007) National Hospitals Office, HSE

CSO POPULATION PROJECTIONS FOR IRELAND

	UK NEURO NUMBERS REPORT	2006 IRISH CENSUS 4,234,925	2011 YEAR 4,488,000	2016 YEAR 4,811,000	2021 YEAR 5,070,000
Persons living with a neurological condition	17%	725,987	762,960	824,743	869,143
Help with daily activities	0.6%	25,410	26,928	28,866	30,420
Disabled by neurological conditions	2%	84,699	89,760	96,220	101,400
Neurological condition but able to manage lives on a daily basis	14.5%	615,879	652,683	699,657	737,323
Each year number newly diagnosed with a neurological condition	1%	43,559	48,110	48,110	50,700
Number caring for a person with a neurological condition	1.5%	61,709	70,790	70,790	74,601

A definition of neurological conditions is not given in the Neuro-numbers report but the text indicates that stroke and brain injury are included in the statistics.

The Central Statistics Office population projections (M1 F2) assumptions are likely to be conservative estimates. Ireland has an ageing population and the prevalence of neurological conditions increases with age.

¹ Consolidated Report by the Director General (May 2020) World Health Organisation pages 8-9 A73_5-en.pdf (who.int)

² Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) National Hospitals Office, Health Services Executive

NEUROLOGICAL ALLIANCE OF IRELAND

The Neurological Alliance of Ireland (NAI) brings together over thirty non-profit organisations to advocate for the rights of 800,000 people in Ireland living with a neurological condition. Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions and their families. Our campaigns are rooted in the experience of our members and the individuals and families with whom they work. We provide a united and expert voice on neurological care through research, advocacy, policy development and education. Further information is available at www.nai.ie and www.loveyourbrain.ie

FIRST NATIONAL SURVEY OF NEUROLOGY SERVICES 2015

Between January and March 2015, the Neurological Alliance of Ireland, in collaboration with the National Clinical Programme in Neurology, carried out the first nationwide survey of resourcing across neurology centres nationwide in order to provide baseline data to inform the Neurology Model of Care for Ireland³. Findings showed significant deficits in staffing across all centres, lack of dedicated beds, long waiting lists for MRI scans and a critical lack of neurorehabilitation services to support recovery and prevent disability among people diagnosed with a neurological condition.

KEY FINDINGS OF THE 2015 SURVEY

1. **DEFICITS IN STAFFING** across all neurology centres with little or no access to multidisciplinary teams in Sligo, Waterford and Limerick
2. **LACK OF DEDICATED BEDS** with only six of eleven centres having dedicated neurology beds. These are frequently required for other specialities within the hospital and not available to neurology
3. **UNACCEPTABLE WAITING LISTS FOR DIAGNOSTIC TESTS** Waiting lists for MRI scanning was a significant problem with 7 centres having waiting lists of a year or more
4. **CRITICAL LACK OF NEUROREHABILITATION SERVICES** Eight of the centres reported limited or very limited access to hospital-based neurorehabilitation services while ten of the eleven centres surveyed reported limited or very limited access to neurorehabilitation services in the community

RECOMMENDATIONS FROM THE 2015 NAI SURVEY REPORT

1. **ENSURE ACCESS TO MULTIDISCIPLINARY CARE** All neurological patients nationwide must be given equal access to multidisciplinary care by addressing critical staff shortages in neurology services
2. **RINGFENCED DEDICATED NEUROLOGY BEDS** must be made available to each neurology service, supported by multidisciplinary staff with appropriate training and expertise
3. **TACKLE LONG WAITING TIMES FOR MRI SCANNING** Immediate steps must be taken to address long waiting times for access to MRI nationwide
4. **INVEST IN NEUROREHABILITATION SERVICES** by implementing the National Neurorehabilitation Strategy⁴

³Summary Findings from the First National Audit of Neurology Services in Ireland (2016) Neurological Alliance of Ireland 2007 Strategic Review of Neurology and Neurophysiology Services in Ireland - Neurological Alliance of Ireland (nai.ie)

2020 SURVEY OF NEUROLOGY CENTRES

Between October and November 2020, the Neurological Alliance of Ireland, once again with the co-operation and support of the National Clinical Programme for Neurology, carried out a more comprehensive audit expanding on the initial survey and obtaining responses from twelve neurology centres nationwide⁵. This report represents the key findings of the 2020 survey which outlines progress on the key indices measured in the 2015 survey and reports on progress made in addressing the recommendations of the 2015 report.

SECTION 1: SUMMARY OF FINDINGS FROM THE 2020 SURVEY

FIVE YEARS ON: TO WHAT EXTENT HAVE THE RECOMMENDATIONS OF THE 2015 REPORT BEEN IMPLEMENTED

1. **DEFICITS IN STAFFING:** While there has been some progress in addressing regional gaps in consultant staffing, Clinical Nurse Specialist staffing across neurology services represents only 44% of what is required and multidisciplinary teams continue to be understaffed in all centres and entirely unavailable in some regional centres
2. **DEDICATED NEUROLOGY BEDS:** Findings from the 2020 survey indicate that this remains a critical issue for neurology services. A majority of the twelve centres surveyed reported insufficient numbers of inpatient beds or lack of ring-fenced beds for the neurology service
3. **WAITING TIMES MRI SCANS:** Waiting times for non-emergency MRI exceeded 12 months across a majority of centres surveyed, with an increase in the proportion of centres reporting longer waiting times in 2020 compared with 2015
4. **ACCESS TO NEUROREHABILITATION SERVICES:** Access to neurorehabilitation services appears to have deteriorated even further over the past five years: centres responding to this item in 2020 were more likely to report limited or no access to both community and inpatient neurorehabilitation than in 2015. Five centres reported lower levels of access to community neurorehabilitation services and lower access to inpatient neurorehabilitation services for their patients.

⁴ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health

⁵ Note that responses from Connolly Hospital and Kilkenny Hospital were obtained in the 2020 survey but these centres were not captured in the 2015 survey. The configuration of services in the South of the country has changed and therefore while the Mercy hospital was included in 2015 it was not included in the 2020 survey. A total of 12 centres were surveyed in 2020, 11 centres in 2015. As no comparative figures are available for 2020: the Mercy hospital responses for 2015 are not included in Section 2 of this report.

NEUROLOGY SERVICES 2015-2020: THE CONTEXT

A number of factors are outlined below in the context of increasing demands and pressures impacting on neurology services over the five years 2015-2020 and going forward.

RISING DEMAND, RISING ACTIVITY

In the period 2015-2020 demand for neurology services has increased significantly with the number of people on OPD waiting lists for a first-time appointment to see a neurologist almost doubling from November 2015 to November 2020⁶.

Table 2: OPD waiting lists and times for Neurology November 2015 and November 2020

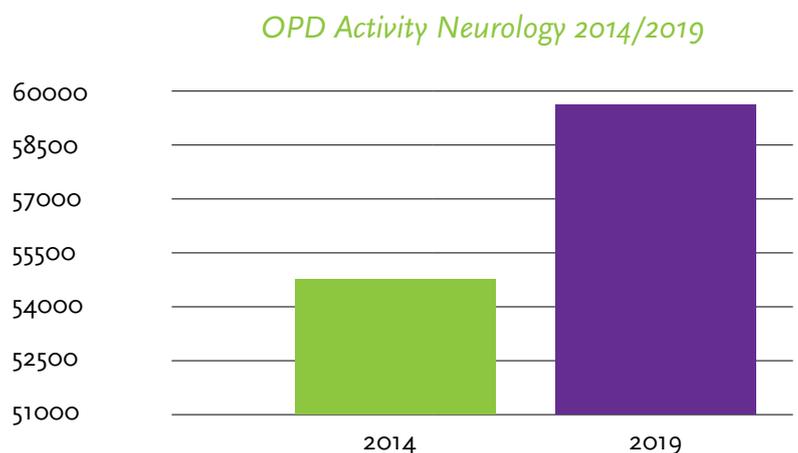
	2015	2020
Total (months)	13,529	22,649
0-3	4810	4960
3-6	3104	3104
6-9	2203	2203
9-12	1300	1300
12-15	893	893
15-18	565	565
18+	654	654

“There are 1,600 patients on the OPD waiting list for our centre alone (and growing). Routine time for an appointment is now 16 months”

“Outpatient waiting times currently 4+ years for many people”

Over a similar five-year period from 2014 to 2019, activity levels in neurology services have increased significantly.

Fig 1: OPD Activity in Irish Hospitals (Neurology excluding Paediatric Neurology) 2014/2019: Source Business Intelligence Unit HSE



⁶OPD waiting lists by speciality : National Treatment Purchase Fund website www.ntpf.ie

COVID19 AND NEUROLOGY

“With so many patients infected the overall number of neurological patients and their associated health burden and social and economic costs might be large.”

(Lancet 2020)

A recent Oireachtas Committee hearing heard reference to the huge unmet need facing the health system in the wake of the COVID19 pandemic⁷. Neurology is no exception, with the requirement to delay or cancel appointments creating a serious backlog for the service.

While many neurology services quickly and effectively embraced online solutions, there will be a resulting pent-up demand for care for neurology services already struggling to meet ongoing needs within current resources. Increasing evidence of a potential emerging new cohort of neurological patients due to COVID19⁸ is likely to create further demand on neurology services which will have to be resourced effectively to meet this need in the context of a service that was already struggling with serious resource deficits pre-COVID19.

It should be noted in the context of this report that while some of the indices measured in the survey: including access to MRI, access to neurorehabilitation services, have been negatively impacted by the COVID19 pandemic, the responses of the centres reflect longer-term ongoing issues in accessing these services and are not significantly attributable to COVID19. However as outlined in Section (2.5) of this report there is no doubt that access to neurorehabilitation services in particular will be further impacted in the future (beyond 2020) as a consequence of the curtailment of services due to COVID19.

⁷ Statements to the Oireachtas Committee on Health: Tuesday 9th February 2021

Documents – Committee on Health – 33rd Dáil, 26th Seanad – Houses of the Oireachtas

⁸ Neurological Associations of COVID19 (2020) The Lancet: Sept (1) Volume 19, Issue 9 p.767-783

“The vital importance of not-for-profit organisations in the delivery of everyday care for neurological illness in this country cannot be overstated. They contribute millions each year from fundraised income without which neurological care in this country could not be sustained”

(Professor Orla Hardiman:
National Clinical Lead for
Neurology)

THREATS TO THE SUSTAINABILITY OF NOT-FOR-PROFIT PROVIDERS

It is important that this review of neurology resourcing draws special attention to the serious challenges facing patient organisations which represent the bedrock of long-term services in the community for people with neurological conditions.

There is an overwhelming reliance on patient organisations to provide a range of vital services for the long-term management of neurological conditions in the community. These are extremely wide ranging but include services such as information and helplines, self-management programmes, key worker and case manager roles, vocational, respite and residential care services as well as clinical services, research and health professional training.

Successive funding cuts and an ongoing shortfall in statutory funding in order to fund the true cost of providing services mean that the not-for-profit neurological sector is struggling to survive year on year.

Four NAI member organisations represent a significant proportion of the patients accessing the publicly funded adult neurology services examined in this survey. Three of these organisations (Epilepsy Ireland, MS Ireland and the Migraine Association of Ireland) faced a cumulative cut in HSE funding of up to 20% in the years between 2008-2014. This funding was never restored. The fourth organisation, the Parkinson’s Disease Association of Ireland receives no statutory funding from the HSE despite providing a nationwide network of supports to the 12,000 Irish people living with Parkinson’s disease.

Demand for the services provided by patient organisations has grown significantly year on year but the cost of providing these services has increased: including because of increased insurance costs, increased costs involved in complying with regulations/standards etc. In 2020, not for profit organisations faced a further increase in demand for their supports with the onset of COVID19 and the closure/curtailment of other services. (A survey of 680 Irish people living with neurological conditions carried out by NAI in April 2020 found that 40% of respondents listed patient organisations as their most important source of information on COVID19 as it relates to their specific neurological condition).

SECTION 2: DETAILED FINDINGS FROM THE 2020 SURVEY AND CONSIDERATIONS

“Untenably long and unsafe OPD waiting lists due to chronic understaffing particularly at consultant level”

“We need more Consultant Neurologists, Neurophysiologists, Specialist Nurses, Neuropsychology and dedicated allied health professionals plus the administrative support for same”

“Each hospital with a neurology service should have a minimum of 3 neurologists delivering that service”

Model of Care for Neurology in Ireland (2016)

2.1: STAFFING

Note on the 2020 survey and staffing numbers: The 2020 survey was deferred to late Autumn 2020 in order to ensure that the staffing numbers provided represented a true reflection of staff currently working in the neurology service. Staff across neurology services, in common with many staff across the health system, had been redeployed in the management of COVID19.

Table 3 shows a comparison of dedicated staffing levels reported across neurology centres in 2015 and in 2020.

- Every centre reported critical understaffing across all specialties
- The number of WTE Consultant Neurologists reported continues to fall far short of the 64.3WTE recommended by the Model of Care for Neurology Services in Ireland⁹
- Physiotherapy, Occupational Therapy and Speech & Language Therapy dedicated to the neurology service stayed the same or declined across most centres despite increased demand and activity within neurology centres
- Levels of Neuropsychology staffing remain largely unchanged overall since 2015
- While funding for additional consultant neurologists in Limerick, Sligo, Waterford and Kilkenny coming on stream in 2021 is a much needed improvement: critically these centres continue to lack dedicated multidisciplinary staffing to provide a full neurology service.
- A majority of neurology centres do not have access to a specialist dietician as part of the multidisciplinary team.

⁹ Model of Care for Neurology Services in Ireland (2016) National Clinical Programme for Neurology: Clinical Strategy and Programmes Division HSE/RCPI

Table 3: Staffing (WTE) Dedicated to the Neurology Service 2015/2020

	Consultant Neurologist	NCHD	Physiotherapy	Occupational Therapy	Speech & Language Therapy	Neuropsychology	Medical Social Worker	Clinical Nurse Specialist	Advanced Nurse Practitioner (includes candidate ANPs)	Dietician
Cork University Hospital										
2020	5	10	1	.5	.5	0	.2	2	2	.4
2015	5	9	.5	1	.5	0	0	3	0	.3
	NC	+1	+5	-5	NC	NC	+2	-1	+2	+1
Galway University Hospital										
2020	4.2	6	0	.2	.2	0	0	2	2	0
2015	4.4	5.4	0	.4	1	0	.5	2.4	2 (E)	0
	-.2	+6	NC	+2	-.8	NC	-.5	-.4	NC	NC
Mater										
2020	5	14	x	x	x	.2	x	5	1	0
2015	3	8	1	.5	.5	0	.5	2	1 (E)	.3
	+2	+6	x	x	x	+2	x	+3	NC	-.3
*Sligo										
2020	2	3	0	0	0	0	0	1	2	0
2015	1	2	0	0	0	0	0	1	2 (E)	0
	+1	+1	NC	NC	NC	NC	NC	NC	NC	NC
St James										
2020	3	6	1	1	0	0	.6	2	2	0
2015	3	4	1	1	0	0	.8	3.25	1.75	0
	NC	+2	NC	NC	NC	NC	-.2	-1.25	+2.25	NC
Tallaght										
2020	5	7	2	1	1	1	1	3	.5	.5
2015	4	5	2.1	1.5	1	1	1	2.5 (1E)	0	.4
	+1	+2	-.1	-.5	NC	NC	NC	+5	+5	+1
Vincent's University Hospital										
2020	4	8	1	1	1	1	1	1	3	1
2015	3	2	1	.2	.5	0	.8	3	0	0
	+1	+6	NC	+8	+5	+1	+2	-2	+3	+1
*Waterford										
2020	1.2	1	0	.5	0	0	0	0	0	0
2015	2	1	0	1	0	0	0	0	0	0
	-.8	NC	NC	-.5	NC	NC	NC	NC	NC	NC
*Limerick										
2020	2	6	IP	IP	IP	1	.8 IP	3	x	0
2015	2	3	.4	0	0	0	0	1	1 (E)	0
	NC	+3	+6	+1	+1	+1	+8	+2	x	NC
Beaumont										
2020	3.2	9	3	1	.2	2	.2	5	5	.2
2015	4.4	14	3	1	.8	3	1	5 (2E)	4	.5
	-1.2	-5	NC	NC	-.6	-1	-.8	NC	+1	-.3

Explanatory Notes

Only centres for which comparative 2015 is available are included in this table

*Funding for 5 additional Consultant Posts in 2021 has been secured by the Neurology Clinical Programme for Limerick. Sligo, Waterford

*Staffing Figures for the Dublin Neurological Institute are reflected in the Mater hospital figures

x: Staffing information not available

NC: No change reported in staffing figures 2015-2020

E: Dedicated to Epilepsy

Note: Staffing identified by centres as specific to Stroke is not included in the above table

2.2: DEDICATED NEUROLOGY (EXCLUDING STROKE) BEDS

“We do not have ringfenced/dedicated neurology beds. Little or no opportunity to develop neurology nursing expertise as a result”

A majority of the twelve centres surveyed reported insufficient numbers of inpatient beds or lack of ring-fenced beds for the neurology service.

The Association of British Neurologists recommends 10-15 dedicated neurology (excluding stroke) beds per 500,000 population¹⁰. Extrapolated to an Irish context that equates to a MINIMUM of approximately one hundred dedicated neurology beds for our population. The 2020 survey findings indicate less than half of this number is in place with a lack of dedicated ringfenced beds reported as a significant problem across centres

“Access to day case beds for infusion therapies is the number one problem for our neurology centre”

2.3: CLINICAL NURSE SPECIALISTS

The number of Clinical Nurse Specialists in Multiple Sclerosis, Epilepsy, Parkinson’s Disease and Migraine are significantly below recommended levels for the Irish population^{11,12}.

Table 4: Current (2020) and recommended CNS Staffing for Parkinson’s Disease, Multiple Sclerosis, Epilepsy and Migraine. (Source Multiple Sclerosis Society of Ireland, Parkinson’s Disease Association of Ireland, Epilepsy Ireland and the Migraine Association of Ireland)

	Recommended	Actual
Multiple Sclerosis	30	13.75WTE
Parkinson’s Disease	30	6
Epilepsy	35	22
Migraine	32	4

This table reflects the number of permanent posts currently in place

“Poor investment in developing clinical nurse specialist roles for AHPs with expertise in neurology”

“Insufficient supports/ staffing to provide effective outreach to other hospitals”

¹⁰ Local Adult Neurology Services for the Next Decade: Report of a Working Party (June 2011) Association of British Neurologists & Royal College of Physicians UK

¹¹ (as above and also Model of Care for Neurology (2016) National Clinical Programme for Neurology: Clinical Strategy and Programmes Division HSE/RCPI)

¹² Model of Care for Epilepsy (2016) National Clinical Programme for Epilepsy: Clinical Strategy and Programmes Division HSE/RCPI

2.4: WAITING TIMES FOR MRI SCANS

While a number of centres had reported waiting times of 3-6 months or 6-12 months in 2015, in 2020 all centres which responded to this question reported a longer waiting time of over 12 months for non-emergency access to MRI.

Access to magnetic resonance imaging is increasingly important for neurology services both as a diagnostic tool and a critical aspect of ongoing monitoring and treatment programmes for neurological conditions.

“MRI access is very poor with waiting times in years for non-emergency cases not uncommon”

“No dedicated Neurophysiology has ever been provided”

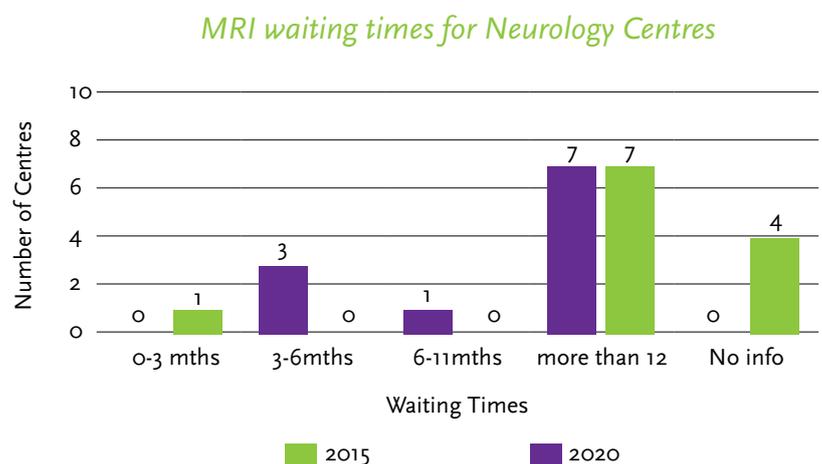
“Excessive waits for diagnostics - particularly outpatient”

Table 5: Waiting Times for MRI by Neurology Centre 2015/2020. Centres that experienced an increase in waiting times are marked with an ^x

	Waiting Times 2015	Waiting Times 2020
Mater	More than 12 months	Info not available
Sligo	2-6 months	0-5 days
St James ^x	2-6 months	More than 12 months
Waterford	More than 12 months	Info not available
Tallaght	More than 12 months	More than 12 months
Limerick	More than 12 months	Info not available
Cork	More than 12 months	More than 12 months
Galway ^x	6-12 months	More than 12 months
Beaumont	More than 12 months	More than 12 months
Vincent's	More than 12 months	More than 12 months

Note that not all centres responded to this question

Fig 2: Waiting Times for MRI scans 2015/2020 comparison across neurology centres



2.5: ACCESS TO NEUROREHABILITATION SERVICES

2020 findings show an increase in the number of centres reporting no access to community neurorehabilitation services. In contrast to 2015, no centre reported very good or moderately good access to neurorehabilitation in the community. In terms of access to inpatient neurorehabilitation services, centres reporting in 2020 were more likely to report no or limited access to inpatient neurorehabilitation than in 2015.

“We really need a dedicated rehabilitation facility for patients with severe brain and spinal injuries in Munster. Only a very small percentage gain access to the National Rehabilitation Hospital for rehabilitation”

Tables 3 and 4 compare self-reports from the same centres between 2015 and 2020: five centres reported lower levels of access to community neurorehabilitation services while five reported lower levels of access to inpatient neurorehabilitation services for their patients.

The 2020 survey included an additional question on access to Rehabilitation Medicine Consultant Opinion, half of the centres which responded to this question reported very limited or no access.

The findings show that, overall, access to neurorehabilitation supports continues to be a critical issue for neurology services: access to hospital and community-based neurorehabilitation services has not improved and has in fact worsened over the past five years.

(Note that the terms “limited” and “very limited” etc used in the context of these survey questions represent the subjective opinion of clinicians/neurology service managers completing the survey and are not based on an objective index e.g., access within a certain time period, percentage of referrals who can subsequently access a service etc).

Table 6: Self Report from Centres: Access to Community Neurorehabilitation Services 2015/2020

Centres which reported a deteriorated level of access between 2015 and 2020 responses are marked with a ^x

	2015	2020
Sligo ^x	Limited Access	No Access
Tallaght ^x	Very Good Access	Very Limited Access
St Vincent's ^x	Limited Access	No Access
St James ^x	Limited Access	Very Limited Access
Limerick ^x	Limited	Very Limited
Galway	Very Limited Access	Limited Access
Beaumont	Very Limited Access	Very Limited Access
Mater	Limited Access	Limited Access
Waterford	Very Limited Access	Very Limited Access
Cork CUH	No Access	Limited Access

Note that not all centres responded to this question

Table 7: Self Report from Centres: Access to Post Acute Inpatient Neurorehabilitation Services 2015/2020

Centres which reported a deteriorated level of access between 2015 and 2020 responses are marked with a ^x

	2015	2020
Sligo ^x	Limited Access	No Access
Tallaght ^x	Very Good	Limited Access
St Vincent's ^x	Limited Access	No Access
St James ^x	Moderate	Very Limited Access
Limerick	No Access	Very Limited Access
Galway	Very Limited Access	Very Limited Access
Beaumont	Very Limited Access	Very Limited Access
Mater	Moderate	Very Good Access
Waterford	Very Limited Access	Very Limited Access
Cork CUH ^x	Limited Access	Very Limited Access

Note that not all centres responded to this question

Fig 3: Access to Community Neurorehabilitation Services 2015-2020

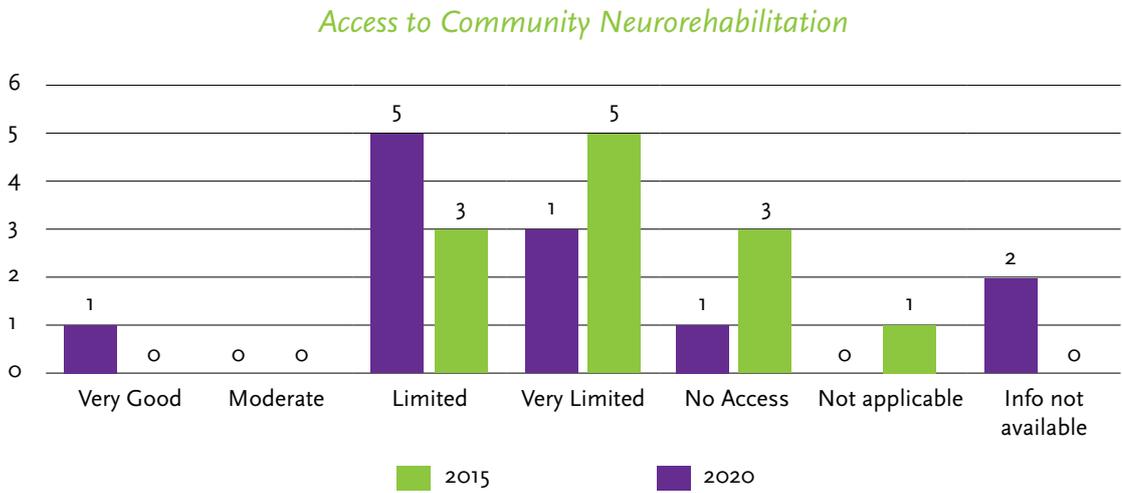


Fig 4: Access to Post-Acute Inpatient Neurorehabilitation Services 2015-2020

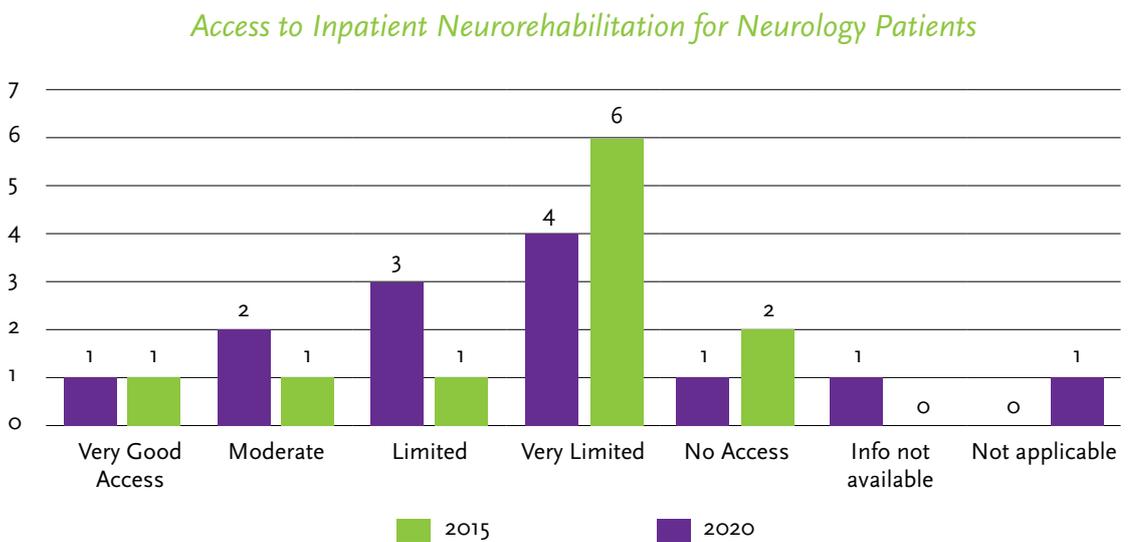
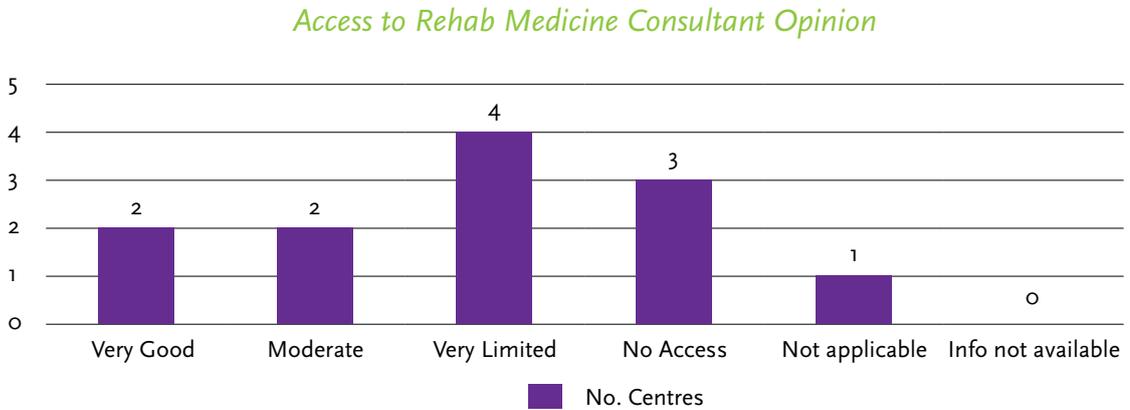


Fig 5: Access to Rehabilitation Medicine Consultant Opinion for Patients in Your Neurology Centre (2020 survey findings)



“Poor investment in developing clinical nurse specialist roles for AHPs with expertise in neurology”

“No dedicated Neurophysiology has ever been provided”

“Excessive waits for diagnostics particularly outpatient”

“Insufficient supports/ staffing to provide effective outreach to other hospitals”

“The dearth of Neurorehabilitation Services is a long-standing critical concern for everyone involved in Neurology in Ireland: this has been further worsened by curtailment of existing services due to COVID-19 restrictions.”

Professor Orla Hardiman:
National Clinical Lead for
Neurology

NEUROREHABILITATION SERVICES IN IRELAND

Neurorehabilitation Services in Ireland are critically underdeveloped with less than half the number of inpatient rehabilitation beds required for our population and a dearth of long-term community supports at every level from community multidisciplinary teams to day services, vocational supports and transitional and long-term residential facilities. A three-year Implementation Framework (2019-2021) for the National Neurorehabilitation Strategy was published in 2019 committing to:

WHAT WAS PROMISED

Priority development of multidisciplinary community neurorehabilitation teams for each of the Nine CHO's (Community Health Organisations)

Mapping and Needs Analysis within each CHO in order to provide a network of community neurorehabilitation services including residential, day and vocational services

Investment in inpatient rehabilitation units: recognising the critical dearth of rehabilitation beds and its impact on the wider health system in terms of delayed transfers of care and implementation of the National Trauma Strategy

WHAT HAS BEEN DELIVERED

Two years on from publication of the Implementation Framework and a decade since the Neurorehabilitation Strategy was first launched in December 2011:

Fewer than thirty new neurorehabilitation beds have been brought into the system: despite the redevelopment of the National Rehabilitation Hospital

Only two community neurorehabilitation teams have been (partially) funded

There has been no new investment to develop community neurorehabilitation supports such as day services, vocational services and transitional and long-term care

RECOMMENDATIONS FROM THIS REPORT

1. ADDRESS ONGOING CRITICAL UNDERSTAFFING ACROSS NEUROLOGY SERVICES THROUGH YEAR-ON-YEAR INVESTMENT

There has been recent investment to tackle geographical inequities within regional centres by funding five new Consultant Neurology posts. However, there is a need to address critical gaps in multidisciplinary staffing across neurology services through continued year on year investment in staffing to increase the numbers of clinical nurse specialists, neuropsychologists and other multidisciplinary staff which continues to fall far below what is required.

2. INVEST IN NEUROREHABILITATION SERVICES

Findings from the 2020 survey of neurology centres show that access to neurorehabilitation services has deteriorated even further since poor levels of access were reported in 2015. Section 2.5 of this report highlights the lack of progress in implementing the Three-Year Implementation Framework for the National Neurorehabilitation Strategy 2019-2021. The ongoing lack of commitment to address serious gaps in neurorehabilitation service provision, particularly in the community, continues to impact significantly on longer term outcomes for neurology patients.

3. ADDRESS CAPACITY ISSUES TO ENABLE NEUROLOGY SERVICES TO MEET CURRENT AND EMERGING NEEDS

A comparison of the 2015 and 2020 surveys highlighted many of the same issues for centres in accessing space for clinics, dedicated beds, access to diagnostic tests etc. There is a vital need for significant investment in neurology to enable the service to develop and expand to take advantage of new treatments and develop new services in response to the needs of specific groups.

4. TACKLE THE FUNDING CRISIS AMONG NOT-FOR-PROFIT PROVIDERS OF NEUROLOGICAL CARE

Neurology services are critically reliant on a network of not-for-profit patient organisations which provide specialist supports and services in the community. These services are under serious threat because of a legacy of funding cuts and the collapse of fundraising due to the COVID19 pandemic. NAI echoes the call across the disability sector for Section 39 organisations to be funded by the State to reflect the true cost of providing these services.

LIST OF NAI MEMBER ORGANISATIONS

Acquired Brain injury Ireland

Alzheimer Society of Ireland

An Saol

Aphasia Ireland

Ataxia Ireland

Aware

Bloomfield Health Services

Cheshire Ireland

Chronic Pain Ireland

Dystonia Ireland

Enable Ireland

Epilepsy Ireland

Headway

Huntington's Disease Association of Ireland

Irish Heart Foundation

Irish Hospice Foundation

Irish Motor Neurone Disease Association

Migraine Association of Ireland

Move4Parkinsons

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

National Council for the Blind

Neurofibromatosis Association of Ireland

Neurology Support Centre

North West MS Therapy Centre

Parkinson's Association of Ireland

Polio Survivors Ireland

PSPA Ireland

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Rehab Group

Associate Members

Brain Tumour Ireland

Syringomyelia Chiara Malformation Support Group



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