

NEUROLOGICAL ALLIANCE OF IRELAND

# Towards an Integrated Equitable Neurology Service for Ireland

## About the Neurological Alliance of Ireland

The Neurological Alliance of Ireland brings together nearly 40 non-profit organisations to advocate for the rights of the over 860,000 people throughout Ireland living with a neurological condition. Neurological conditions affect the brain and spinal cord and now represent the leading cause of disability worldwide. Founded in 2003, the NAI advocates for the development of quality services for people living with neurological conditions. Our campaigns are rooted in the experiences of our members and the individuals and families with whom they work. We provide a united and expert voice on neurological care through advocacy, policy development and awareness raising. More information can be found at [www.nai.ie](http://www.nai.ie).

## Member Organisations of the Neurological Alliance of Ireland

Acquired Brain injury Ireland  
 Alzheimer Society of Ireland  
 An Saol  
 Aphasia Ireland  
 Ataxia Foundation Ireland  
 Bloomfield Health Services  
 Brain Tumour Ireland  
 Cheshire Ireland  
 Chronic Pain Ireland  
 Crann Centre  
 Croí  
 Dystonia Ireland  
 Dublin Neurological Institute  
 EOPD Ireland  
 Enable Ireland  
 Epilepsy Ireland  
 FND Ireland  
 Headway Ireland  
 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  
 Neurofibromatosis Association of Ireland  
 Neurology Support Centre  
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 Parkinson's Ireland  
 Peamount Healthcare  
 Polio Survivors Ireland  
 PSPA Ireland  
 Spinal Injuries Ireland  
 Spina Bifida Hydrocephalus Ireland  
 The Rehab Group  
 Vision Ireland

## About This Report

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**sanofi**

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## FOREWORD

Neurological conditions affect one in six people across Ireland. Behind this statistic are individuals, families, and communities navigating complex, lifelong conditions that demand timely diagnosis, coordinated care, and sustained support. As demand for neurology services continues to grow, driven by an ageing population, advances in diagnostic capability, and expanding treatment options the need to ensure that services are fit for purpose has never been more urgent.

Nearly a decade has passed since the publication of the Model of Care for Neurology Services in Ireland in 2016. During that time, demand for neurology services has grown and health policy reform has set a clear direction toward more integrated, person-centred care delivered closer to where people live. This report represents an important and timely contribution to that agenda. It provides a comprehensive and up-to-date insight into neurology service provision, resourcing, and patient experience across the country, and it offers a detailed evidence base to support the continued development of a modern neurology service aligned with national health policy.

What distinguishes this report is the breadth and depth of engagement that underpins it. Through clinical deep dives into Multiple Sclerosis, Parkinson's disease, and headache, a national survey of neurology resources, and a wide-ranging programme of lived experience focus groups, we have sought to bring together clinical expertise and real world experience. The voices of people living with neurological conditions have been central to this work. Their willingness to share their stories has ensured that the recommendations within this report are grounded in the realities of daily life and focused on delivering meaningful improvements in care and outcomes.

A central finding emerging from this work is the clear need for a resourced, connected neurology network that ensures the right care is available in the right place at the right time. The development of a hub and spoke model of care, strengthened workforce capacity, and the creation of coordinated condition-specific pathways are all essential steps toward achieving this vision. These priorities align closely with the principles of Sláintecare and reaffirm the ambitions first set out in the 2016 Neurology Model of Care.

The Neurological Alliance of Ireland has, for over two decades, worked to advocate for better services and supports for people living with neurological conditions. This report further strengthens our role as an informed and trusted partner in shaping the future of neurology care. We look forward to engaging constructively with stakeholders across government, the health service, and the not-for-profit sector to ensure that the insights and recommendations presented here translate into tangible improvements for those who depend on these services.

On behalf of the Neurological Alliance of Ireland, I would like to express our sincere appreciation to our member organisations, consultant neurologists, and the National Clinical Programme for Neurology for their expertise, collaboration, and guidance throughout this project. Most importantly, I extend my deepest thanks to the individuals with neurological conditions whose lived experiences have been instrumental in shaping this report.

Magdalen Rogers  
Chief Executive Officer  
Neurological Alliance of Ireland

## Report Summary & Recommendations

Nearly a decade on from the publication of the Model of Care for Neurology Services in Ireland in 2016, this report by the Neurological Alliance of Ireland aims to provide an up to date insight into neurology service provision and resourcing and to examine neurology in the context of health system reform towards providing more integrated care at regional level and closer to where people live.

The report presents findings from an extensive programme of clinical engagement, service analysis, and lived experience research, drawing on clinical deep dives into three neurological conditions Multiple Sclerosis (MS), Parkinson's disease (PD), and headache alongside a national resource survey across neurology centres and a nationwide series of lived experience focus groups with individuals with neurological conditions.

The aim of the report is to provide a detailed evidence base to inform the Hub and Spoke Model currently being developed by the National Clinical Programme for Neurology based on the framework outlined within the 2016 Neurology Model of Care. The purpose of this report is to provide policymakers and clinical leaders with a credible evidence-based series of recommendations to inform the future design of neurology services. The NAI looks forward to engaging with stakeholders to ensure that the insights and learnings from this report are realised to deliver better outcomes for people living with neurological conditions across Ireland.

*The central finding of this report is that Ireland needs a resourced connected neurology network that delivers specialist care effectively and ensures that the right care is available in the right place at the right time. This echoes the core principles of SlainteCare and the 2016 Neurology Model of Care.*

## Key Recommendations

- Develop a hub and spoke model of regional hubs and national centres to provide specialist care in the right place at the right time. [11]
- Invest in neurology staffing to address the deficits highlighted in this report and based on the recommendations outlined within the 2016 Model of Care for Neurology Services in Ireland which identifies the need to increase consultant, specialist nursing and multidisciplinary workforce capacity in line with international standards. [1][3]
- Develop and resource condition-specific coordinated pathways to provide better access to timely diagnosis and appropriate specialist treatment and ongoing care [4]
- Develop long term specialist services and supports in the community for people with neurological conditions in partnership with not-for-profit providers.

## Chapter 1 Methodology

### Clinical Interviews

The project involved a series of clinical interviews in relation to three neurological conditions: Multiple Sclerosis, Parkinson's disease, and headache. These conditions were selected because they collectively represent a substantial proportion of neurology workload, span a wide range of service complexity, and offer instructive contrasts in terms of current service organisation and the challenges experienced. Each clinical deep dive involved detailed engagement with sub-specialist neurologists through surveys, structured interviews, and individual & group discussions. The process examined current service configuration, workforce, pathways, and access. Importantly, it also captured perspectives on what good looks like drawing on both national experience and relevant international models. The engagement noted that these very different neurological conditions share similar system needs in common and highlights the need to strengthen the overall resource base and organisation of neurology services to improve the delivery of services and the care of people with neurological conditions regardless of their condition or where they live across the country.

*The next step following on from the publication of the report is to share these clinician insights with relevant stakeholders, including patient organisations and their lived experience partners to inform future pathway development and implementation in these areas. Neurology provides a practical example where networked specialist expertise can be organised around patient need rather than geography, distributed specialist care supported by shared expertise and governance.*

### National Survey of Neurology Centres

A resource survey was conducted across all designated neurology hospitals in Ireland. The survey gathered data on consultant staffing, overall staffing resources available to neurology including specialist nursing and multidisciplinary staffing, access to diagnostics, referral options to external supports and outpatient infrastructure. The findings provide a snapshot of resources currently available and of neurology service capacity across the country. A summary of the survey results is contained in the Appendix. The survey was designed to be inclusive of all neurological conditions which come under the remit of neurology services, including but not limited to those conditions covered by the three deep clinical dives. The survey form was sent to the ten designated neurology centres from October 2025 to December 2025, and responses were received from that initial date to February 2026. All data in the Appendix is self-reported from the ten Neurology centres.

## Lived Experience Workshops

A series of workshops were conducted with 37 people living with neurological conditions across Ireland. Participants were recruited with the support of NAI member organisations and workshops were designed to be inclusive of a wide range of neurological conditions those with conditions. Sessions were facilitated independently and used structured but flexible approaches to capture experience across the patient journey from initial symptoms through to ongoing management and community support. The insights have been incorporated throughout this report and have been instrumental in shaping the recommendations for the development and delivery of neurology services going forward.

## Chapter 2 Background: The Current Landscape of Neurology Services in Ireland

### The Scale and Diversity of Neurological Conditions

The breadth of neurological disease creates a fundamental challenge for service design. No single specialist or clinical team can possess expertise across all conditions. Neurology has become increasingly subspecialised, with recognised expertise developing around, movement disorders, MS, neuromuscular disease, epilepsy, headache, and other areas. This subspecialisation is clinically appropriate and has driven significant improvements in outcomes, but it also means that access to the right expertise is uneven, with a challenge to ensure that people with neurological conditions can get access to specialist diagnosis and care regardless of where they live.

### Growing Demand and Systemic Pressure

Demand for neurology services in Ireland is increasing. An ageing population drives higher prevalence of neurodegenerative conditions. Advances in diagnostic imaging, genetic testing, and biomarker science are identifying conditions earlier and more precisely, generating new referrals. Current outpatient waiting times for neurology in Ireland are among the longest of any specialty when early diagnosis and treatment initiation has been shown to be key to long term outcomes across neurological conditions.

### Variability Between Hospitals and Regions

There is substantial variation in the availability and resourcing of neurology services across Ireland. The impact of this variation was highlighted in the Neurological Alliance of Ireland's 2025 report, "Right Care, Right Place", based on a nationwide patient experience survey of over 800 respondents which found marked regional variation in access to and waiting times for key services, waiting times to see a neurologist, access to specialist nurses, and access to neuro-rehabilitation and other specialist supports across the country. Those living near major neurology centres have potentially better access to specialist expertise and coordinated support, while individuals and their families in regional and rural areas face longer waits, greater travel burdens, and more fragmented care. [6][7][8][9][10]

### The Case for Equitable, Resourced Neurological Care

Sláintecare's central ambition is prioritise access closer to where people live, and promote equity, and integrated care across a reformed public health system. The HSE Neurology Model of Care 2016 recommends the development of an integrated neurology service through a managed clinical network to ensure coordinated, equitable and consistent delivery of care across regions [11]

The Neurology Services Review published in 2024 by the Saolta University Health Care Group represents a comprehensive and proactive in-depth review and planning process for neurology needs in the region, aligned with the 2016 Model of Care for Neurology.

The NAI welcomed the opportunity to be involved in the 2024 Saolta report and continues to support its recommendations to facilitate the provision of more equitable access to neurology services for people in the West and Northwest of the country. [35]

## Chapter 3 Lived Experience Engagement & National Resource Survey

A consistent set of themes emerged from the lived experience engagement from people with neurological conditions through the nationwide series of focus groups carried out as part of this project. While participants described highly positive encounters with individual clinicians and services, the dominant picture was of a system that is difficult to access, unevenly resourced, and often poorly coordinated around the needs of the person. Participants' experiences pointed not only to long delays and service gaps, but also to the human impact of these shortcomings: anxiety at the point of diagnosis, confusion about where to turn and significant practical and financial strain in trying to secure care.

Participants repeatedly described a need for earlier diagnosis, clearer care plans, local access to specialist input where possible, stronger multidisciplinary and specialist nursing support, and far better coordination between hospital, community, and rehabilitation services. Taken together, these insights point to a strong case for a more structured, equitable and person-centred approach.

This chapter also highlights findings from the National Resource Survey of Neurology Centres and the details are summarised here and detailed in the appendix.

### Regional Inequity and Service Navigation Challenges

Regional inequity was one of the most prominent themes in the focus groups. Participants spoke openly about a “postcode lottery” in access to services, with large differences between regions in consultant access, waiting times, specialist supports, and rehabilitation. This created a strong perception that access to care depended heavily on location rather than need.

These geographic disparities created major navigation challenges. Participants often had to figure out for themselves where services existed, how to access them, and how to piece together support across different providers. In the absence of a clear pathway or designated coordinator, individuals and families often became the de facto navigators of care. This placed an additional burden on people already coping with complex and life-changing neurological conditions and frequently shifted responsibility for coordination from the system onto the individual and their family.

### Inconsistent Access to Specialist Expertise

A strong theme was the inconsistency in access to specialist neurological expertise across the country. Participants recognised that some centres offered high-quality specialist input and valued this deeply, but they also described how such expertise was concentrated in a limited number of locations. Access to subspecialist care was reported as uneven and, for many, highly dependent on where a person lived. Participants

noted that specialist services for conditions, or specialist professionals with condition-specific expertise, were simply not available in many parts of the country. While some were willing to travel occasionally for highly specialist interventions, frequent long-distance travel for routine reviews or ongoing care was seen as burdensome, costly, and difficult to sustain, especially for people with mobility limitations or progressive conditions.

Participants consistently described their care as fragmented, with poor coordination across settings and unclear pathways through the system. Many felt that once they had entered the system, care was not organised around a coherent plan but instead consisted of disconnected interactions with different professionals and services. This fragmentation created a strong sense that care was reactive rather than proactive.

## Fragmented Care Pathways

A recurring issue was the need to repeat the same story multiple times to different providers, suggesting weak information-sharing and limited continuity. Transitions were especially vulnerable points, particularly the move from paediatric to adult neurology services or when a person relocated. In these situations, participants felt they could easily fall through the cracks. The absence of a joined-up pathway also made it difficult for people to know who was responsible for what, how to access the next step in care, or where to turn when their condition changed

## Limited Support After Diagnosis

An important additional theme was the lack of support when diagnosis was delivered and in the immediate aftermath. Participants described receiving diagnoses in a highly clinical manner, often with heavy use of medical terminology and little emotional support or explanation. Many left without a clear understanding of what the diagnosis meant, what to expect next, or what supports were available to them. The period after diagnosis was frequently described as one of isolation, confusion, and emotional distress. Engagement with voluntary sector organisations was consistently highlighted as crucial and frequently cited as the only source of ongoing support following diagnosis.

## Delayed Diagnosis

Delayed diagnosis emerged as one of the clearest and most damaging issues described by participants. Long waiting times were seen as particularly severe at the point of first access to neurology services, with some describing the effort to obtain a diagnosis as extremely prolonged and uncertain. Delayed diagnosis impacts timely access to treatment, access to supports, and deterioration in symptoms while waiting to enter the system.

Participants' accounts suggest that the period before diagnosis is often marked by uncertainty, repeated attempts to seek help, and a sense that symptoms are escalating without timely specialist assessment. In some cases, individuals described progression and exacerbation of symptoms during the waiting period. The consequence is that people may reach specialist care later, at a point when opportunities for earlier intervention, symptom management, or rehabilitation have already been missed.

### Absence of Personalised Care Planning

Participants repeatedly pointed to the lack of an individualised management plan. They wanted a clearer roadmap following diagnosis: what happens next, who to contact, what therapies or supports might be needed, and what signs should prompt review. In the absence of this, many felt they were simply discharged back into uncertainty.

This lack of care planning reinforced a reactive model of care. Rather than anticipating likely needs and intervening early, services often appeared to respond only when deterioration had already occurred. Participants believed this contributed to missed opportunities for physiotherapy, rehabilitation, symptom management, and maintenance of function. There was also a strong sense that care focused too narrowly on medication and did not sufficiently account for the broader physical, emotional, and social impact of living with a neurological condition.

### Uneven Specialist Nurse Availability

Uneven access to specialist nurses was a significant feature of participants' experiences. Where a clinical nurse specialist was available, participants described this as highly valuable. Specialist nurses often provided a clear point of contact, guidance during deterioration, reassurance between consultant appointments, and practical help in navigating the service.

However, for many participants, this type of support was absent. Many had no clear point of contact with medical services and described themselves as being left in limbo between infrequent specialist appointments. In practice, this meant that when new symptoms developed or deterioration occurred, people were forced to rely on GPs or emergency departments, even where those services did not have specialist neurological expertise. This uneven availability of specialist nursing support contributed directly to poorer continuity, weaker navigation, and greater anxiety for patients and families.

### Gaps in Multidisciplinary Services

Participants described major gaps in multidisciplinary care particularly in the community. Even where multidisciplinary care was recognised by clinicians as best practice, it was often unavailable. People spoke of

being told what should ideally be available but then being informed that such services did not exist in their area or were limited. Some participants reported periods of beneficial input that were time-limited while others had no access at all and were forced either to pay privately or use generalist services that they felt were not appropriate for neurological conditions. The lack of sustained access to therapeutic multidisciplinary support in the community was seen as directly affecting function, independence, and quality of life.

## Public Private Disparity and Financial Burden

Participants believed that private care offered faster and more extensive access, and some felt compelled to pay privately out of desperation. While those who could do so sometimes gained earlier access to diagnosis or treatment, many emphasised that this came at substantial personal financial cost. This introduced a further layer of inequity, as not everyone could afford to bypass public waiting lists. The result was a two-tier experience of neurological care in which timely access was often linked to ability to pay. Participants described this not only as unfair, but as a major source of stress for individuals and families already under pressure.

## Rare Neurological Disease Input

There was an underrepresentation of rare disease in the focus groups and therefore an engagement took place with not-for-profit organisations in this area facilitated by the Neurological Alliance of Ireland to provide insight on the needs of this group. While the needs varied by condition, the issues raised were consistent and point to the need for a more structured, specialist, and person-centred model of care. A central theme was delayed diagnosis and frequent misdiagnosis. People described long waits from first symptoms to correct diagnosis, with some initially labelled as having psychological or non-neurological problems. Participants felt that GPs and non-specialist professionals often did not recognise early signs of rare neurological disease, leading to delayed referral to appropriate specialists. Delays were also linked to limited access to diagnostic testing and long turnaround times. For progressive conditions, these delays were seen as especially damaging because opportunities for early intervention, support, and planning were lost.

A second major theme was limited access to specialist expertise and condition-specific services. Patients stressed the importance of rapid referral to the right specialist team, including movement disorder services, neuromuscular expertise, neuropsychology, neurophysiotherapy, occupational therapy, speech and language therapy, and other condition-specific supports. Participants noted that some excellent specialist services do exist, but they are concentrated in a small number of centres and are not available consistently across the country. Access to interventions such as Botox clinics, DBS, specialist

beds, outreach services, and appropriate rehabilitation was described as highly uneven.

A further theme was the lack of coordinated multidisciplinary care. Patients called for formalised MDTs aligned to international standards, rather than ad hoc arrangements that depend on local relationships or individual effort. There was a strong desire for named care coordinators or advanced nurse practitioners who could guide patients through the system, organise referrals, and provide continuity between appointments. In the absence of this, patients and families often had to manage referrals, follow up services, and navigate complex care needs themselves.

Participants also highlighted poor transition planning and inappropriate care settings. Transition from paediatric to adult services was described as weak and inconsistent. For younger patients with progressive conditions, there were concerns about the lack of suitable beds or specialist settings, with some ending up in inappropriate placements such as nursing homes. This reinforced a broader concern that the system is not designed around the actual needs of people with rare neurological disease.

Another strong theme was the burden placed on families and patient organisations. Families often became the main coordinators of care and were left without enough emotional, practical, or training support. This was especially evident where complex needs such as PEG feeding, behavioural symptoms, or progressive dependency arose. Participants also described over-reliance on charities and advocacy groups for information, equipment, and service navigation. While these organisations were highly valued, there was a clear view that core supports should not depend on voluntary groups stepping in where statutory services are lacking.

Finally, participants emphasised the need for better infrastructure and planning, including disease registries, education for GPs, faster access to diagnostics, specialist clinics, outreach models, and equitable funding supports. They felt rare neurological conditions require planned pathways, not piecemeal responses.

## Conclusion from Lived Experience Insights

The findings point to a service that is experienced by many patients as slow to access, unevenly distributed, and insufficiently supportive at key points in the care journey. The major issues were not confined to one stage of care or one region; rather, they cut across diagnosis, specialist access, ongoing management, crisis response, rehabilitation, and transitions between services.

The overall message from the lived experience engagement is clear: people want a neurology service that enables early access and

prompt diagnosis, closer to home where possible, better coordinated, and more person centred. The findings echo the observations and recommendations outlined in the 2025 Review into Neurology Services in Northern Ireland [12] and the Model of Care 2016 [11] for a more person-centred responsive neurology service.

## Findings from National Resource Survey

The national survey across neurology centres was carried out to provide an as is picture of service provision and staffing across the country.

The following summary observations below can be noted in relation to staffing and resourcing of neurology services.

- Total Consultant Neurology staffing remains below the minimum recommendation of 1: 70,000 outlined in the 2016 Model of Care for Neurology Services in Ireland
- Specialist Nurse Staffing remains significantly below the recommended level for the Irish population
- Significant gaps in dedicated multidisciplinary staffing to support neurology services are evident across all neurology centres. The Model of Care for Neurology recommends that all neurology services are supported by a full multidisciplinary team.
- Limited or no access to inpatient and community neurorehabilitation services was a frequent finding across neurology centres
- Reporting and follow up analysis of outreach from neurology centres to other sites outlined concerns around levels of coverage and ongoing service provision to several regional Model 3 hospitals. The 2016 Model of Care for Neurology Services in Ireland outlines that all Model 3 hospitals should have dedicated neurology services.

Overall, the findings tie in with many of the key concerns outlined in the 2016 Model of Care for Neurology Services in Ireland, and previous surveys and reports by the Neurological Alliance of Ireland [34], highlighting significant gaps in staffing, service provision and resourcing of neurology services.

Summary Tables are outlined in the Appendix of this report. The findings from the survey will be reviewed in a separate briefing document by the Neurological Alliance of Ireland.

**Important Note:** The data represented is self-reported from each of the neurology centres on specific reporting dates in late 2025, early 2026.

## Chapter 4 Condition Specific Deep Dives: MS, Parkinson's Disease and Headache

The next three chapters present focused deep dives into three selected neurological conditions Multiple Sclerosis, Parkinson's disease, and headache disorders. These conditions were intentionally chosen to reflect a mix of chronic, progressive, and high-volume presentations to inform the design of a hub and spoke model for neurology to meet the requirements across very different conditions.

By exploring each condition in detail and engaging with individual subspecialist neurologists in depth, this part of the project sought to understand how a common hub and spoke model for neurology could be developed, based on insights across conditions, to deliver more integrated and equitable neurological care.

This condition specific analysis highlighted common themes which a hub and spoke model should aim to address: the variability in patient need and journeys, the critical role of specialist expertise and multidisciplinary care and the importance of delivering care closer to home where appropriate while maintaining access to specialist hubs for specialist needs and rapid diagnosis and treatment.

**Important Note:** This work with individual subspecialist neurologists was undertaken for a specific purpose, namely, to generate insights that would inform the development of a hub-and-spoke model for neurology services. It was not intended as a formal consultation on the management of these specific neurological conditions. Such decisions require a much broader process of stakeholder engagement, including collaboration with patient organisations, individuals with lived experience, clinical staff, and service providers across the wider stakeholder community.

### Multiple Sclerosis (MS)

Multiple sclerosis is the most common disabling neurological condition affecting young adults in Ireland. Ireland is recognised as a high-prevalence country for Multiple Sclerosis, with rates among the highest reported internationally. [13]

An estimated 10,000 people are living with MS in Ireland, with incidence continuing to rise. The condition is characterised by episodes of demyelination affecting the central nervous system, with progressive accumulation of disability in many cases. Multiple Sclerosis is typically diagnosed in early adulthood, often in the second and third decades of life, and carries a significant long-term economic and social burden for both individuals and wider society due to its impact on employment, productivity, and ongoing care needs.

### Management of MS in Neurology

The treatment landscape has transformed over the past two decades, with a growing range of disease-modifying therapies (DMTs) capable of significantly reducing relapse rates and slowing progression but only if

initiated appropriately and monitored carefully. MS services in Ireland have developed considerably over the past decade. Ireland has several centres with recognised MS expertise, established multidisciplinary team structures, and well-developed specialist nurse services in some locations. There is a strong clinical community committed to the delivery of high-quality MS care, as can be seen through initiatives such as the National Stem Cell Transplant MDT for people with MS.

Ireland has developed strong clinical and academic expertise in Multiple Sclerosis, with many hospitals contributing significantly to research, clinical trials, and advances in patient care. This growing research ecosystem positions Ireland as an important contributor to international MS research and innovation.

There are examples of excellent MS care being delivered across the system, with highly skilled clinicians and teams providing high-quality, specialist support to patients. However, this level of care is not yet consistently enabled at a system level, with variation in resourcing and access meaning that not all patients can benefit from the same standard of care, and this care is highly dependent on location.

Despite these strengths, significant gaps remain. Access to MS specialist Neurologists expertise is unevenly distributed, with patients in some regions facing long waits for initial assessment and ongoing specialist support limited due to demand. No centre is currently resourced with sufficient specialist capacity across the full multidisciplinary team to meet the growing demand for MS services, with shortages in consultant neurologists alongside specialist nurses and allied health professionals with MS expertise. These constraints are evident in delays to diagnosis, slower initiation of treatment, and limited provision of patient education and support.

Once treatment is commenced, the demands on services increase further, as many therapies require complex and ongoing monitoring due to potential high-risk side effects. Without adequate specialist oversight, there is a real risk that patients are not monitored to the standard required, with implications for both safety and treatment effectiveness. Access to multidisciplinary rehabilitation physiotherapy, occupational therapy, speech and language therapy, and neuropsychology is frequently inadequate across the country and hampers the effective management of the disease for clinicians, this is particularly relevant in more rural/regional settings.

Access to the full range of approved DMTs is generally available within specialist centres, some exceptions exist due to staffing pressures and there is growing experience with high efficacy therapies in appropriate patient populations. However, even in centres where these services are available, patients may not be able to access them in a timely manner. This is often due to pressures on shared infusion suites and limited specialist nursing capacity.

## Service Design Implications for MS

MS care requires a service model that positions specialist expertise including subspecialty consultant MS neurology, infusion services for high-efficacy DMTs, and multidisciplinary rehabilitation at designated hubs, while extending the reach of that expertise through supported shared care arrangements with local services (spokes).

Specialist nurse roles are central to this model. MS specialist nurses (clinical nurse specialists and advanced nurse practitioners) provide continuity of care, support treatment monitoring, manage relapse pathways, and connect patients with the wider range of support they need. Investment in specialist nurse capacity and in clear, structured roles for specialist nurses within a hub and spoke network is essential to delivering effective MS care at scale.

Governance arrangements for MS care should include clear standards for DMT prescribing and monitoring, defined criteria for hub and spoke designation, and mechanisms for regular audit and peer review. The development of coordinated care pathways, covering diagnosis, treatment initiation, ongoing monitoring, and management of relapse and progression, should be a priority.

If MS care is structured as a coordinated network rather than a set of standalone clinics, patient and clinical experience can benefit significantly. Ireland already has a blueprint in the National Clinical Programme for Neurology's Model of Care, 2016, which identifies MS as a condition requiring a defined diagnosis and treatment pathway and references international best practice timeframes from referral to assessment and diagnosis. Building on that foundation, a networked MS model would organise services around the reality of MS care: most people once diagnosed and on the correct DMT need consistent management closer to home, while a smaller proportion require escalation for specialist input for diagnostic complexity, treatment escalation, DMT switching, complications, pregnancy planning, advanced symptom control, or complex rehabilitation needs.

In this proposed model, MS specialist centres (hubs) would concentrate specialist expertise and governance functions, including high efficacy therapy decision making and monitoring protocols, complex case MDT review, neuroimmunology sub-specialist support. Also providing leadership across the network by developing and disseminating evidence-based treatment algorithms, audit and quality standards, and up-to-date clinical guidance, while supporting spoke sites through structured education, training, and ongoing clinical support; they could also enable neurologists from networked sites to spend time in hubs to build expertise, maintain skills, and strengthen network wide capability.

Spokes, typically general neurology services with defined MS capability would deliver routine follow-up, stable disease monitoring, relapse

assessment, and symptom management, with rapid access to hub advice when clinical thresholds are reached. The specialist nurse role becomes the key connection that makes the network work.

The international literature and experience consistently describe MS nurses as central to education, treatment initiation and management, adherence support, and coordination across services [15][16]; NICE evidence reviews similarly emphasise the coordination value of MS specialist nurses within MS pathways [15][17][18]. This means nursing capacity must be planned as part of the network model.

For a hub and spoke network for MS to succeed in Ireland, several key points stand out.

- **First**, there must be explicit scope of service definitions who manages what, where, and with what escalation triggers so patients move smoothly between spoke and hub without “resetting” their care.
- **Second**, the network needs minimum staffing and MDT standards, because hub and spoke models fail when spokes are left unsupported or when hubs become overwhelmed with work that should be performed at the spokes but cannot because of resourcing. Administration support is also key as some of the audited sites reported clinicians taking on administration tasks to enable the running of outpatient clinics.
- **Third**, consistent measurement is required, including access times, treatment initiation timelines, safety monitoring compliance, relapse pathways, and patient-reported outcomes, to enable continuous improvement. [19][20]
- The network must be seen as one system where the care setting may be different, but the patient messaging is the same. The care and support the patient receives from first diagnosis all the way through their journey is consistent just delivered in the most appropriate setting.

*MS specialist centres (Hubs) should have the **clinical expertise and capacity to diagnose the disease quickly and start on DMT promptly**. Manage the patient through the initial DMT and change treatment appropriately and get the patient to a place where they are stable and can be managed appropriately closer to home. As a lifelong condition typically diagnosed in early adulthood, MS requires a network model that is responsive, capable of adapting to the individual’s evolving needs across different stages of the disease.*

<b>National Centre (High-Complexity Rare Neurological Diseases / Low-Volume)</b>	<b>Hub (High-Complexity / Low-Volume)</b>	<b>Spoke (High-Volume / Protocol-Driven)</b>	<b>Community (Continuity of care, Education, Patient Support)</b>
<p><b>Core capabilities required</b></p> <p>Consultant neurologists with rare disease or condition subspecialist expertise                      Dedicated Clinical Nurse Specialist (CNS) capacity acting as the national coordination and escalation function                      Access to advanced MRI and expert neuroradiology interpretation, neurophysiology, and specialist laboratory diagnostics (autoimmune, genetic, metabolic) onsite or networked                      Capability to initiate and oversee high-risk, high-cost or first-in-class therapies                      Embedded multidisciplinary team (MDT)                      Formal connectivity with European Reference Networks (ERNs) for rare neurological diseases, including structured case discussion and pathway alignment</p> <p><b>Clinical responsibilities</b></p> <p>Clinical Trials                      Definitive diagnostic confirmation if doubt exists                      Initiation, escalation, or switching of advanced therapies                      Management of aggressive, rapidly progressive neurological disease                      Oversight of complex relapse or deterioration episodes, including rapid-access review and escalation                      Clinical governance and assurance of national shared-care protocols delivered in Spokes/Hubs                      Regional and national MDT leadership, including escalation support, second opinions, and ERN-linked case review</p>	<p><b>Core capabilities required</b></p> <p>Consultant neurologists with subspecialist MS expertise                      Dedicated MS Clinical Nurse Specialist (CNS) capacity                      Access to advanced MRI interpretation and neuroimmunology                      Infusion / high-efficacy DMT initiation capability                      Embedded MDT (neuropsychology, physio, OT)</p> <p><b>Clinical responsibilities</b></p> <p>Diagnostic confirmation where uncertainty exists                      Initiation and switching of high-efficacy DMTs                      Management of aggressive or highly active disease                      Complex relapse management                      Clinical governance of shared-care protocols                      Regional MDT leadership and escalation support</p>	<p><b>Minimum capabilities required</b></p> <p>Access to consultant neurologist oversight (on-site or network)                      CNS with defined sessions                      Access to physiotherapy and OT (on-site or community)                      MRI access in line with defined patient management protocols                      Clear escalation routes to hub</p> <p><b>Clinical responsibilities</b></p> <p>Routine follow-up for stable MS                      CNS led monitoring                      Blood monitoring                      Symptom management within agreed protocols                      Early identification of relapse or progression                      Coordination with community and voluntary supports</p>	<p><b>Services Offered</b></p> <p>Rehabilitation (Neuro Rehab Teams)                      Fatigue management, falls prevention                      Self-management and education                      Carer support and coordination                      Integration with disability and social care services</p> <p><b>Clinical responsibilities</b></p> <p>GP care, non-disease related                      Delivered under Neurology governance                      Close linkage to CNS and Spoke services                      Clear triggers for escalation back to Spoke or Hub</p>

Fig 1. MS Service Design Characteristics

This proposed network aligns naturally with Sláintecare's direction of travel care closer to home, with specialist capacity used where it adds most value while remaining implementable even without major structural reform.

Likewise, the move toward a National Electronic Health Record can enhance a networked MS model by enabling shared results, standardised datasets, and cross-site visibility, but the model should not be dependent on the EHR: shared-care clinical protocols, virtual MDTs, and hub advice lines can be implemented now using existing digital tools, appropriate resourcing and agreed governance. [33]

A hub and spoke approach has the potential to create a positive, realistic route to more equitable MS care one that protects specialist excellence and capacity, strengthens local delivery, and ensures people living with MS receive consistent treatment standards regardless of where they live.

## Parkinson's Disease (PD)

Parkinson's disease is the fastest growing neurological condition globally and one of the most common neurodegenerative disorders. In Ireland, an estimated 18,000 people are living with Parkinson's disease, with this number projected to increase substantially over the coming decades as the population ages. Parkinson's is a complex, multisystem condition that requires coordinated input from a range of clinical disciplines across its entire course.

## The Importance of Specialist Assessment

Accurate diagnosis of Parkinson's disease and differentiation from other parkinsonian syndromes requires specialist assessment, ideally by a clinician with movement disorder expertise. Movement disorder specialism in Ireland spans both neurology and geriatric medicine, reflecting the age of the population most affected and the importance of shared care arrangements between these specialties.

This shared care model is a distinctive feature of Parkinson's services and has important implications for service design. Any proposed network model must accommodate and support the contribution of geriatricians with movement disorder expertise, ensuring that pathways facilitate appropriate referral and collaboration rather than creating artificial barriers between specialties.

## Multidisciplinary Input Across Disease Stages

Parkinson's disease evolves over time, and the relative importance of different clinical inputs changes as the condition progresses. In the early stages, specialist review for diagnosis and treatment initiation is paramount. As the condition advances, the contribution of

physiotherapy, occupational therapy, speech and language therapy, neuropsychology, and palliative care becomes increasingly central to maintaining quality of life. Some of these phases of treatment could/should be provided in centres closer to the patient's home without the need to travel to specialists' centres.

Current MDT provision for Parkinson's is inconsistent across Ireland. Some centres have established Parkinson's MDT clinics with input from multiple disciplines; others have limited allied health profession access, with patients and families having to seek rehabilitation support through separate pathways, different locations, both voluntary and provided by the health service, often with long waiting times and varying coordination or oversight due to capacity constraints with specialist neurology review.

*Movement Disorder clinicians describe the experience of managing a complex, progressive condition through multiple separate services that are rarely integrated with each other. The aspiration is not simply for more services, but for services that work together organised around the needs of the person rather than the availability of those services in any one region. The clinical condition is different with different needs but with a common systemic need.*

## Multidisciplinary Care for People with Parkinson's Disease

For people with Parkinson's disease, community-based support is not an optional add on it is central to maintaining independence and quality of life. Community physiotherapy, occupational therapy, and speech and language therapy, delivered by practitioners with Parkinson's expertise, can substantially improve functioning and reduce the burden on hospital-based services.

The National Audit of Movement Disorders in Ireland, published in 2024, found significant gaps in multidisciplinary care including access to specialist nursing across the country. [22]

It is important to acknowledge that significant work is already underway to develop Parkinson's care pathways in Ireland. The proposed connected network framework is designed to complement and amplify this work providing the organisational structure within which pathway development can be implemented, resourced, and sustained. The integrated network model provides a natural architecture for Parkinson's care, with specialist movement disorder assessment and advanced therapies at hub level, supported shared care at spoke level, and community-based MDT and palliative care support closer to home.

Clinical knowledge, symptomatic therapies, and multidisciplinary interventions can meaningfully improve mobility, function, and quality of life across the disease course, yet services are increasingly challenged by rising demand, uneven access to expertise, and variable availability of specialist nursing and allied health supports.

The current service reality is characterised by variability. Some centres have developed strong movement disorder expertise and more structured Parkinson's clinics, while other regions rely on general neurology or older-person services with limited protected capacity for complex Parkinson's care, advanced therapy assessment, or proactive non-motor management. This unevenness matters because Parkinson's is not a single "movement" problem; non-motor symptoms such as cognitive impairment, falls, mood disorders, autonomic dysfunction, sleep disturbance, and impulse control disorders often drive disability, carer burden, and unplanned presentations to acute clinical settings. The survey also highlighted limited access to psychosocial supports, with difficulty accessing counselling which is an example of the wider challenge of embedding neuropsychology and mental health supports within chronic neurology pathways.

Workforce configuration is central to these gaps. International best practice consistently emphasises that people with Parkinson's should have a reliable point of contact with specialist services, commonly a Parkinson's disease nurse specialist, to support continuity, advice between reviews, and proactive management. NICE's Parkinson's quality standard explicitly recommends a point of contact and explains its role in continuity and timely access to support. In Ireland, initiatives to expand specialist nursing capability are underway, including national neurology nursing education developments that reference the need to expand specialist neurology nursing to support chronic conditions such as Parkinson's. However, our neurology service survey describes systemic constraints, clinic capacity, staffing mix, and infrastructure that can limit the effectiveness of chronic neurology pathways if not addressed as part of a neurology network plan.

The potential to deliver Parkinson's care in a hub-and-spoke network would involve designated Parkinson's hubs to concentrate movement disorder expertise and provide the functions that are difficult to deliver everywhere: complex diagnostic assessment (including atypical parkinsonism), advanced therapy evaluation and governance (deep brain stimulation, infusion therapies), specialist neuropsychiatry/neuropsychology access, and network MDT standards and protocols.

Spokes anchored in general neurology would provide accessible local care for stable and moderately complex patients (within agreed clinical guidelines), including medication optimisation, routine monitoring, falls and frailty screening, and referral into local neurorehabilitation and community supports. Patients would move "up" to the hub for defined

triggers (treatment complications, refractory motor fluctuations, diagnostic uncertainty, complex hallucinations/psychosis, advanced therapy consideration) and return to the spoke for ongoing local management, providing appropriate care close to home. For this model to work, several necessities are fundamental and consistent across other neurological conditions.

- 1.** There must be explicit service specifications and escalation criteria, so the hub supports spokes without displacing them, detailed in the illustration below.
- 2.** Specialist nursing capacity must be planned across the network so every patient has a dependable point of contact and spokes can run nurse enabled triage, education, and follow-up aligned to agreed protocols.
- 3.** Multidisciplinary access physiotherapy, OT, speech and language therapy, and psychology must be integrated into the pathway, not treated as optional, because Parkinson's outcomes are highly dependent on coordinated MDT input.
- 4.** Governance and measurement must be built in, including agreed metrics on access, pathway adherence, advanced therapy wait times, falls and admission rates, and patient-reported outcomes.
- 5.** The network must be seen as one system where the care setting may be different, but the patient messaging is the same. The care and support the patient receives from first diagnosis all the way through their journey is consistent just delivered in the most appropriate setting.

This design aligns with Sláintecare's emphasis on timely access and appropriate treatment closer to home, while retaining specialist escalation where it adds most value. It is also strengthened by national digital direction: shared records and standardised datasets across hubs and spokes become much easier as Ireland progresses toward a National Electronic Health Record (EHR). Importantly, a Parkinson's hub and spoke approach does not depend on the EHR or any single initiative to begin delivering value. Clear pathways, virtual MDTs, shared care protocols, and nurse enabled continuity can be implemented now using existing systems, with appropriate resourcing, while future national infrastructure accelerates consistency and scale. With a positive, networked approach, Ireland can reduce regional inequity, protect specialist excellence, and ensure people with Parkinson's receive coordinated, high-quality care throughout the disease journey.

Specialist Centre (Hub) Characteristics	Spoke Characteristics
<ul style="list-style-type: none"> <li>• Principle moves from <b>“One to one”</b> to <b>“One to many”</b> model, <b>“Diagnose disease quickly, accurately and start on treatment promptly”</b></li> <li>• Regional specialist centre serving health region</li> <li>• Provides complex, care including: <ul style="list-style-type: none"> <li>» Advanced diagnostics</li> <li>» Complex case management (e.g. cases with comorbidities)</li> <li>» Specialist treatments</li> </ul> </li> <li>• Staffed by multidisciplinary teams, including: <ul style="list-style-type: none"> <li>» Specialist Consultant (PD interest)</li> <li>» Specialist PD nurses</li> <li>» Neuropsychologists, OT/Physio/SLT</li> <li>» Research and academic staff</li> </ul> </li> <li>• Houses tele-neurology infrastructure to support Spoke sites</li> <li>• Maintains oversight &amp; Governance of clinical pathways across the network</li> <li>• Provides supervision, training and continuing professional development (CPD) for spoke teams</li> <li>• Leads case review meetings, (MDTs).</li> <li>• Manages shared care protocols and referral guidance (physician discretion due to patient differences) to ensure standardised decision making, regardless of location</li> <li>• Interfaces with research, innovation, and education systems</li> <li>• Post diagnosis education for patients and informs patients on the role Hub and Spoke plays in care (Hub &amp; Spoke is one system not two)</li> </ul>	<ul style="list-style-type: none"> <li>• Delivers appropriate care locally to improve patient experience and access</li> <li>• Delivers localised, routine neurological care to improve access and equity for stable, long-term patients:</li> <li>• Staffed by: <ul style="list-style-type: none"> <li>» General Consultants or outreach clinics</li> <li>» PD nurse specialists</li> </ul> </li> <li>• Offers services such as: <ul style="list-style-type: none"> <li>» Medication reviews</li> <li>» Ongoing monitoring and assessment</li> <li>» Patient education and self-care</li> <li>» Referral to rehabilitation or social care</li> </ul> </li> <li>• Refers patients to the hub for: <ul style="list-style-type: none"> <li>» All Diagnosis</li> <li>» Rapid deterioration / dyskinesia</li> <li>» When unresponsive to DMT’s</li> </ul> </li> <li>• Supported by: <ul style="list-style-type: none"> <li>» Virtual Hub (tele-neurology)</li> <li>» Hub led training and remote clinical advice lines</li> <li>» Community Neuro Rehab Teams to preserve mobility, reduce falls &amp; delay escalation to the Hub</li> <li>» IGPOP maintenance programmes</li> </ul> </li> <li>• Plays a key role in: <ul style="list-style-type: none"> <li>» Reducing unnecessary attendances at Hub of stable patients</li> <li>» Reducing outpatient wait times at the Hub</li> <li>» Promoting local continuity of care</li> <li>» Delivering patient-centered support closer to home</li> </ul> </li> </ul>

Fig 2: Parkinsons Hub and Spoke Characteristics

## Headache

Headache disorders represent one of the highest-volume components of neurology practice. Global prevalence of headache disorders in adults is approximately 40% (symptomatic more than once in the last year). The Global lifetime prevalence of headache disorders is quoted at approximately 90%.

The 1-year prevalence of migraine is estimated at 15% worldwide, but it varies across geographical regions. The Eurolight project (data from nine European countries), reported a 1-year migraine prevalence of 35%. [23] Migraine alone affects approximately 15% of the general population, making it one of the most common neurological conditions globally.

In Ireland, headache and migraine account for a significant proportion of neurology outpatient referrals, placing substantial pressure on already stretched services. Despite this, headache has historically been under resourced. The work that was undertaken in developing the headache pathways in certain centres as part of the Slaintecare Integrated Care Pathway for Headache has yielded significant improvements in patient care and efficacy.

The approach to Headache in this report was to engage with 3 hospitals who had and had not implemented the headache pathway, comparing and gathering inputs from the clinicians involved.

## Challenges in Headache Care

The primary challenge in headache services is volume. Neurological presentations have increased by a factor of 4 from 2019 to 2024. [24] The sheer scale of headache presentations and the reality that the majority can be effectively managed in primary care with appropriate support means that a traditional model of one-to-one consultant neurology review is not sustainable or necessary for most patients. The key clinical challenge is triage: identifying the minority of patients who require specialist neurology input, including those with red flag presentations, refractory migraine, or complex headache disorders, and ensuring that this group is seen promptly and appropriately.

Referral management is a significant issue. Headache represents a substantial proportion of neurology demand in Ireland, accounting for approximately 30% of new neurology outpatient appointments. [29]

Many headache referrals to secondary care could be appropriately managed in primary care if GPs had access to better headache education, clear guidelines, and support from specialist advice services. Conversely, patients with genuine need for specialist review can face long waiting times in a system where overall headache demand is high.

## Lessons from the Slaintecare Headache Pathway

Ireland has significant experience in headache pathway development through the Integration Fund Programme for Headache. This work has generated important lessons about what is required for effective headache care at a system level, and a compare-and-contrast analysis of pathway implementation across different sites provided this report valuable insights for the recommended service in the future.

Where pathways have been successfully implemented, the key enablers have been clear triage criteria that support appropriate referral and redirect straightforward presentations; specialist nurse involvement in assessment, patient education, and follow-up; access to rapid neurology advice for GPs; and engagement with primary care to support the management of the majority of headache patients closer to home.

Where implementation has been less successful, the barriers have typically included insufficient or absence of specialist nurse resource, not backfilling positions when vacated, lack of engagement from primary care, and absence of governance structures to support pathway adherence and audit.

The Slaintecare headache pathway introduced a structured pathway that enabled care to be delivered at the lowest appropriate level of complexity, supported by specialist nurses working alongside neurologists with headache expertise, and strengthened integration with general practice, community pharmacy, and patient support organisations. This represented a change of service delivery, moving towards a scalable and sustainable model aligned with Sláintecare principles of integrated and community-based care.[25][26]

The outcomes achieved during the pilot phase provide clear evidence of effectiveness. The programme delivered a 23% reduction in waiting lists in one pilot site, a significant improvement in the new-to-return ratio in specialist clinics, and a threefold increase in nurse-led headache activity. Rapid-access headache clinics were established, improving timely access to specialist input, while the extension of care into the community demonstrated uptake of care, with pharmacist engagement and patient referrals supporting the safe decentralisation of care.

Collectively, these results indicate that the redesigned pathway improved access, optimised specialist capacity, and enhanced patient experience, while reducing reliance on traditional outpatient models. [26][27]. This strengthens the call to resource the pathways to achieve these improvements in care.

*Headache services have demonstrated the value of structured pathways, CNS involvement, and tiered models of care. The lessons learned are directly applicable to the broader network model proposed in this report. In summary, the recommendation in headache service delivery is to continue the pathway work through appropriate resourcing, governance and management.*

## Supporting Evidence for Headache Pathway Implementation

The priority for headache services is to resource and manage the rollout of structured headache pathways across all regions of Ireland, building on the learning from existing pathway development and addressing the identified barriers and lessons learned to implementation.

This requires investment in regional services and specialist nurse capacity specifically for headache services, development of primary care headache education and support, and clear governance structures to ensure consistency and quality across the network. Clinical input gathered in this report referenced the need to ensure that there is a consistent approach to headache management and resources in order to achieve expected outcomes across all the six regional neurology networks.

The development of specialist headache services including rapid access clinics for timely assessment, unnecessary admission avoidance pathways, access to advanced pharmacological treatments, and neuropsychology support for patients with chronic daily headache should be designated at specialist centres within the proposed network, with spoke services supported to manage the majority of headache patients through clear pathways, appropriate triage, education and training and nurse specialist support.

The implication is clear, headache services in Ireland do not require further redesign, but rather full implementation and resourcing of the model as already defined.

The Sláintecare Integration Fund was explicitly designed to test and evaluate models of care as proof of concept, with successful projects intended for mainstreaming and scale. The headache programme met this requirement, demonstrating the potential to reduce waiting times through a shift from hospital-based to community-based care.

The priority now is to resource the workforce, infrastructure, and governance required to deliver this model consistently at national scale, ensuring equitable access and sustained service improvement. [27][28]

## Chapter 5 Informing a Hub and Spoke Model for Neurology Services

The evidence we collected through this project supports the development of a hub and spoke model for connected neurology services based on the Model of Care for Neurology Services in Ireland (2016)

- **Equity:** every person in Ireland, regardless of where they live, should have access to high-quality neurology care appropriate to their needs.
- **Coordination:** care should be organised around the patient, with clear pathways, designated care coordinators, and effective communication between all parts of the system.
- **Connection, not centralisation:** specialist expertise should be organised to extend its reach across the network, not to concentrate access in a small number of locations.
- **Workforce sustainability:** the model should make best use of the full range of neurology workforce consultants, specialist nursing, allied health professionals and other specialties and create career structures that support retention and development.
- **Quality and governance:** clear standards, regular audit, and peer review mechanisms should support consistent, high-quality care across the network.
- **Patient and carer involvement:** the voice of people living with neurological conditions should be embedded in the design, delivery, and evaluation of services at every level.

Clinical engagement across three very different neurological conditions MS, Parkinson's disease, and headache converges on the same organisational solution. Each condition, for its own reasons and through its own clinical logic, points towards a tiered network in which specialist expertise at hub level supports local delivery through spoke services, with community-based care playing an increasingly important role.

For MS, the hub is where subspecialty MS expertise, DMT infusion services, and complex rehabilitation sit; the spoke is where ongoing monitoring, CNS support, and shared care with primary care are delivered. For Parkinson's disease, the hub is where movement disorder assessment, advanced therapies, and specialist MDT input are concentrated; the spoke is where physiotherapy, OT, and SLT with Parkinson's expertise operate in close coordination with hub specialists. For headache, the hub is where complex presentations are assessed and treated; the spoke in this case, often primary care is where the majority of headache patients are managed through structured pathways with CNS support.

Across each of these conditions and indeed the wider spectrum of neurological conditions the centre of gravity of care shifts, based on the commonality or rarity of the disease and condition. More common conditions such as headache will have the majority of patients receiving most care and interventions in community or spoke settings. Rarer neurological conditions and/or rarer presentations with diseases will require specialist review and care in hub or national centres.

The engagement across the three template conditions, and the information collected across this report, provides insights to inform the design of future service frameworks involving national specialist centres, regional hubs, local spoke services and community services to meet the long-term needs of people with neurological conditions.

## National Specialist Centres

National specialist centres provide the highest level of subspecialty expertise for conditions or treatments that require concentration of rare skills, infrastructure, or volume to maintain quality, expertise in rare neurological conditions. Functions at national centre level include:

- Highly specialised investigations and interventions not available elsewhere (e.g., deep brain stimulation programmes, advanced MS therapies, complex neuromuscular diagnostics).
- National clinical leadership, guideline development, and quality standards.
- Research and innovation, including participation in international trials and registries.
- Training and education for the wider neurology workforce on rare disease or conditions.
- Oversight of national audit and outcomes data.
- Rare Neurological Disease specialist services with established links to European Reference Network (ERN) for rare neurological diseases (RND)

## Regional Hubs

Regional hubs form the backbone of the connected neurology network. Each hub serves a defined population and geographic area, providing a range of neurology services including subspecialty expertise across the most common and significant neurological conditions.

Functions at hub level include:

- Consultant neurology service with subspecialty expertise across MS, movement disorders, epilepsy, headache, neuromuscular disease, and general neurology.
- Dedicated CNS and ANP teams with condition-specific expertise.
- Full MDT provision including neuropsychology, physiotherapy, occupational therapy, speech and language therapy, and social work.
- Inpatient neurology beds and access to neurology input for patients admitted under other specialties.
- Diagnostic infrastructure including MRI, neurophysiology, and laboratory services.
- Coordination and governance of the hub's spoke network.
- Advice and support lines for spoke services and primary care.

## Local Spoke Services

Spoke services extend the reach of the network into local communities, delivering ongoing management and monitoring of established neurological conditions closer to patients' homes. Functions at spoke level include:

- General neurology outpatient clinics with access to a networked hub specialist support.
- Specialist Nurse led clinics for ongoing management of stable conditions.
- Shared care monitoring for stable patients on disease-modifying therapies.
- Coordination with primary care, community therapy, and social care.
- Clear referral pathways to hub services for complex presentations or deterioration.
- Participation in hub governance, audit, and quality improvement.

## Community Services

The chronic long-term nature of many neurological conditions means that hospital-based neurology services require access to integrated, responsive services at community level to meet long-term need and reduce reliance on hospital services to manage issues that could be prevented with the right supports in the community.

The lived experience workshops carried out as part of this report found that many patients were unable to access appropriate expertise and support in the community outside of their limited appointments with the neurology service. Clinicians recognised that lack of options in the community for referral and ongoing management of neurological conditions is increasing the demands on already overstretched neurology services.

The Recommendations section of this report outlines in detail a number of recommendations for meeting the long-term needs of people with neurological conditions in the community, in line with the 2016 Model of Care for Neurology in Ireland through:

- Advancing chronic disease management of common neurological conditions in the community through training, structured care plans, specialist nursing support and improved access to diagnostics
- Developing inpatient and community neurorehabilitation services
- A strategic approach to ongoing and long-term care for people with disabling neurological conditions in the community
- Sustaining and expanding the capacity of not-for-profit providers as key enablers of neurology service delivery.

## Key features of a Hub and Spoke Model for Neurology Services

The following characteristics of a hub and spoke model for neurology services have been developed through the evidence from this report and are presented as actionable next steps in the design and delivery of neurology services to promote greater equity and access to specialist care. They are framed as achievable, building on existing structures and investment, and fully aligned with the 2016 Neurology Model of Care.

- Defined service standards and workforce requirements for each tier detailed in Figure 8.1 below.
- Governance arrangements including network oversight, clinical leads, and accountability frameworks.
- A funded implementation plan with clear milestones and performance indicators.
- A process for regular review and designation renewal based on demonstrated quality and capacity.
- Clear referral pathways so patients move to the right level of care at the right time and can step back to local services when specialist input is no longer required.
- Shared multidisciplinary working across the network, with defined roles for consultants, specialist nurses, AHPs, rehabilitation, mental health, and community teams at each level.
- Common clinical protocols, information-sharing, and outcome reporting so care is delivered consistently, variation is reduced, and equity of access can be monitored across the region.

**Note:** A key feature of an effective Hub and Spoke model is robust referral pathways and clinical arrangements to other regions to facilitate access to specialist care and timely diagnosis for neurological conditions.

National Centre (High-Complexity Rare Neurological Diseases / Low- Volume)	Hub (High- Complexity / Low- Volume)	Spoke (High-Volume / Protocol-Driven)	Community (Continuity of care)
Core capabilities required	Core capabilities required	Minimum capabilities required	Services Offered
<p>Consultant neurologists with rare disease and/or subspecialist expertise Dedicated Clinical Nurse Specialist (CNS) capacity acting as the national coordination and escalation function Access to advanced MRI acquisition and expert neuroradiology interpretation, neurophysiology, and specialist laboratory diagnostics (autoimmune, genetic, metabolic) Capability to initiate and oversee high-risk, high-cost or first-in-class therapies Embedded multidisciplinary team (MDT) Formal connectivity with European Reference Networks (ERNs) for rare neurological diseases, including structured case discussion and pathway alignment</p> <p><b>CLINICAL RESPONSIBILITIES</b></p> <p>Clinical Trials Definitive diagnostic confirmation Initiation, escalation, or switching of advanced therapies Management of aggressive, rapidly progressive neurological disease Oversight of complex relapse or deterioration episodes, including rapid-access review and escalation Clinical governance and assurance of national shared-care protocols delivered in Spokes/Hubs Regional and national MDT leadership, including escalation support, second opinions, and ERN-linked case review</p>	<p>Consultant neurologists with subspecialist expertise Dedicated Clinical Nurse Specialist (CNS) capacity Access to advanced MRI interpretation and neuroimmunology Infusion / high-efficacy DMT initiation capability Embedded MDT (neuropsychology, physio, OT)</p> <p><b>CLINICAL RESPONSIBILITIES</b></p> <p>Diagnostic confirmation where uncertainty exists Initiation and switching of high-efficacy DMTs Management of aggressive or highly active disease Complex relapse management Clinical governance of shared-care protocols Regional MDT leadership and escalation support</p>	<p>Access to consultant neurologist oversight (on-site or network) CNS with defined sessions Access to physiotherapy and OT (on-site or community) MRI access in line with defined patient management protocols Clear escalation routes to hub</p> <p><b>CLINICAL RESPONSIBILITIES</b></p> <p>Routine follow-up for stable patients CNS led monitoring Blood monitoring Symptom management within agreed protocols Early identification of relapse or progression Coordination with community and voluntary supports</p>	<p>Rehabilitation (Neuro Rehab Teams) Fatigue management, falls prevention Self-management and education programs Carer support and coordination Integration with disability and social care services Nursing Home link End of Life Care Clinical responsibilities GP care Close linkage to specialist nursing and Spoke services Clear triggers for escalation back to Spoke or Hub*</p>

Fig 3. Hub and Spoke Characteristics

## Chapter 6 Next Steps in Equitable Neurology Care

The following recommendations for neurology service design and delivery emerge from the findings of research and engagement across this report.

### Recommendation 1:

#### Development of a Hub and Spoke Model for Neurology

The evidence collected in this project provides a strong base, as described in the previous chapter, to inform the development of a Hub and Spoke Model for Neurology under the Leadership of the National Clinical Programme for Neurology and comprising of national specialist centres, regional hubs and local spoke services. The model should aim to provide equitable access to neurology services across the country and promote timely access to specialist diagnosis and treatment regardless of where you live. [30][31]

### Recommendation 2:

#### Investment in Neurology Staffing

Neurology service development must be underpinned by adequate workforce planning. The NAI recommends that neurology consultant, specialist nursing and multidisciplinary staffing numbers be reviewed against population need and network requirements, and that a planned expansion programme be initiated to address the deficits highlighted in this report in recognition of the commitment to investing in Neurology staffing within the current Programme for Government. With the launch of the first postgraduate diploma in specialist nursing in neurology earlier this year, a strategic approach is needed within neurology to develop clear pathways for specialist nursing roles in line with wider nursing policy. Investment in specialist posts will allow for the expansion of services offered to patients and options for treatment and triage within clinical governance, improving the efficacy and efficiency of neurology service delivery. [3][18]

### Recommendation 3: Development of Long-Term Specialist Services and Supports in the Community for People with Neurological Conditions

Hospital-based neurology services typically operate at the secondary and tertiary levels of care, providing specialist assessment, diagnosis, and acute management. However, the effectiveness of these services and, most importantly, the long-term outcomes for individuals living with neurological conditions depends heavily on the availability of well-resourced pathways for ongoing care and rehabilitation. Without sustained access to community supports, multidisciplinary follow-up, and rehabilitation services, the benefits of acute neurological care can be significantly diminished for both patients and their families.

The following recommendations are in line with those of the Model of Care for Neurology and supported by the evidence gathered in this report.

### **Advancing chronic disease management of common neurological conditions in the community through training, structured care plans, specialist nursing support and improved access to diagnosis.**

The successful outcomes where the Slaintecare headache pathway has been implemented, as outlined in the clinical deep dives in our report, show that working models are available to develop and strengthen community based approaches to neurological conditions. The 2017 National Model of Care for Epilepsy provides a comprehensive framework for the management of epilepsy in the community.

Policy action and investment is required to implement the recommendation within the 2016 Model of Care for Neurology to advance chronic disease management in neurology.

### **Developing inpatient and community-based neurorehabilitation services**

The 2016 Neurology Model of Care highlights neurorehabilitation services as a critical enabler for effective neurology service delivery, significantly improving outcomes for people with neurological conditions, reducing hospital stays and preventing delayed discharges. Phase 2 of the Neuro-Mapping Project, published in 2024 by the Neurological Alliance of Ireland, Disability Federation of Ireland and Health Services Executive examining service provider and lived experience of neurorehabilitation services found that access to neurorehabilitation services varies significantly across the country. The onboarding of new community neurorehabilitation teams in recent years is a very positive first step with a need to increase the size of these teams and provide effective pathways from inpatient through to longer term neurorehabilitation services in the community in partnership with not for profit providers and in line with the 2019 Implementation Plan for the National Neurorehabilitation Strategy.

### **Long Term Services and Supports for People with Neurological Conditions**

The Phase 2 Neuro-Mapping Report highlighted the need for longer term neurorehabilitation and other specialist supports in the community for people living with disabling neurological conditions. This was also clear in the current report with a recognition that current service provision is limited and often not designed to meet the requirements of people with neurological conditions. This includes a wide range of service needs from ongoing access to therapeutic support in the community for people who do not meet the criteria for community neurorehabilitation teams,

intensive home care packages, residential care, respite, multidisciplinary care, family supports and a range of services to support employment, social inclusion and community participation. The lack of a focused strategic approach to identifying and meeting the long term needs of people with neurological conditions is perpetuating systemic problems across the health services of lengthy hospital stays, delayed discharges, inappropriate placements and care breakdown and lack of vocational and other opportunities but most importantly it continues to have a devastating impact on the lives of people with neurological conditions and their families.

### **Not for Profit Partnerships in Neurological Care**

This current report provides further evidence in support of the recognition within the 2016 Model of Care of the importance of not-for-profit organisations as critical enablers for neurology service delivery. Throughout all strands of engagement in this project, all stakeholders highlighted the wide range of specialist supports provided by the not-for-profit sector and the experience and expertise in delivering specialist community-based services, developing new initiatives in response to need and commissioning and supporting research to inform better models of service design and delivery. The 2023 Phase 1 Neuromapping Report, a collaboration between the Neurological Alliance of Ireland, Disability Federation of Ireland and the Health Services Executive showed that not for profit neurological organisations are responsible for delivering nearly 100 unique types of specialist services in the community for people with neurological conditions and their families. An integrated, sustainable not for profit sector is integral to effective delivery of neurology services and better outcomes for people with neurological conditions and their families.

### **Recommendation 4: Development and Resourcing of Coordinated Care Pathways**

The condition specific clinical deep dives carried out as part of this report highlights the value of co-ordinated condition specific approaches to care for individual neurological conditions which enables expertise to be delivered within a hub and spoke framework in order to ensure that people receive prompt access to expert diagnosis, care and treatment regardless of their neurological condition or where they live across the country.

Condition specific pathway development should:

- Be produced with clinicians, patient organisations, specialist nurses, and people with lived experience.
- Address the full patient journey from referral through to community management.
- Include clear criteria for referral between levels of the network.
- Be accompanied by the workforce, infrastructure, and governance required for effective implementation. [2]

## Appendices

### Resource Survey Findings Across Neurology Hospitals

The national resource survey, conducted across all designated neurology hospitals in Ireland, gathered data in the following domains: consultant neurologist workforce (whole-time equivalent and subspecialty areas); clinical nurse specialist and advanced nurse practitioner availability; availability of diagnostic services and access to other services in the community to support the needs of people with neurological conditions.

#### Appendix A: Survey Data Tables

Neurology Centre	Abbreviation
St James University Hospital	SJUH
Galway University Hospital	GUH
Tallaght University Hospital	TUH
Sligo University Hospital	SUH
St Vincents University Hospital	SVUH
University Hospital Waterford	UHW
Limerick University Hospital	LUH
Beaumont Hospital	Beaumont
Mater Misericordiae University Hospital	MMUH
Cork University Hospital	CUH

	SJUH	GUH	TUH	CUH	SUH	SVUH	UHW	LUH	Beaumont	MMUH
	Total Permanent WTE (Locum WTE)									
Consultant Neurologist	7.6	6.75	7	9	3 (1)	4.8	4	6	8.2	8.2
NCHD	7 (1)	7	10	15	5	8	2	9	13	14
Physiotherapist	1	0	3.5 (0.5)	1	1	1	0	0	No Data	0
Occupational Therapist	1	0	1	1	0.5	0.5	0.5	0	No Data	0
Speech & Language Therapist	0	0	1.5	0.5	0	0.5	0	0	1.8	0
Dietician	0	0	0	0	0	0	0	0	1.5	0
Medical Social worker	0.6	0	1	0	0	0	0	0	1.3	0
Psychologist	1	0	0	0	0	1	0	0	No Data	0

Table Cont.

Neuro Psychologist	0	0	1	0	0	1	0	0	No data	0
Clinical Nurse Specialist	3	8	3	5	2	4	3	6	10	10
Candidate Advanced Nurse Practitioner	2	2	6	2	2	4	0	0	3	2
Advanced Nurse Practitioner ANP	5	1	1.5 (0.5)	2	2	1	0	1	4.6	2
Podiatrist	0	0	0	0	0	0	0	0	0	0
Administration	4	4	11.6 (1)	3	2.2	2.5	4	4	9	9.5

**Table 1: Permanent Staffing Posts Reported Across Ten Neurology Centres Note Locum Positions are indicated in brackets**

	SJUH	GUH	TUH	CUH	SUH	SVUH	UHW	LUH	Beaumont	MMUH	NATIONAL TOTAL
Clinical Nurse Specialist	3	8	3	5	2	4	3	6	10	10	54
Advanced Nurse Practitioner	5	1	1.5 (0.5)*	2	2	1	0	1	4.6	2	20.1
Candidate ANP	2	2	6	2	2	4	0	0	3	2	23
Total across all 3 grades	10	11	10.5 (0.5)	9	6	9	3	7	17.6	14	97.1

**Table 2: Specialist Nursing Staffing Reported Across Neurology Centres**

	Reported Nurse Staffing from 2025/2026 Survey
SJUH	10
GUH	11
TUH	10.5 (0.5)
CUH	9
SUH	6
SVUH	9
UHW	3
LUH	7
Beaumont	17.6
MMUH	14
<b>Totals National</b>	<b>97.1</b>

**Table 3: Total Specialist Nurse Staffing**

	SJUH	GUH	TUH	CUH	SUH	SVUH	UHW	LUH	Beau- mont	MMUH
<b>Access to Rehabilitation Medicine Consultant opinion for neurology patients in your neurology centre</b>	Limited access	Limited access	Yes, access via referral	Yes, access via referral	Limited access	Yes, access via referral	No	No	Yes, Shared access within region	Yes, access via referral
<b>Access to post-acute inpatient neurorehabilitation services in your neurology centre</b>	Limited access	Limited access	Yes, access via referral	No	Limited access	Yes, access via referral	No	No	Yes, Shared access within region	No
<b>Access to dedicated neurorehabilitation services in the community</b>	No	No	Limited access	Limited access	Limited access	Limited access	No	Yes, Shared access within region	Yes, Shared access within region	No
<b>Home care packages</b>	Yes, access via referral	Yes, access via referral	Limited access	Yes, Full access onsite	Limited access	Yes, access via referral	Yes, Shared access within region	Yes, Shared access within region	Yes, Full access onsite	Yes, access via referral
<b>Nursing Home Care</b>	Yes, access via referral	Yes, access via referral	Limited access	Yes, Full access onsite	Yes, access via referral	Yes, Shared access within region	Yes, Shared access within region	Yes, Shared access within region	Yes, Shared access within region	Yes, access via referral
<b>Appropriate respite care</b>	Limited access	Limited access	Limited access	Yes, access via referral	Limited access	Limited access	Yes, Shared access within region	Yes, Shared access within region	Yes, Shared access within region	Limited access
<b>Palliative care teams in community</b>	Limited access	Yes, Shared access within region	Limited access	Yes, Shared access within region	Yes, access via referral	Yes, access via referral	Yes, Shared access within region	Yes, Shared access within region	Yes, access via referral	Yes, access via referral
<b>Hospice based palliative care team</b>	Yes, access via referral	Yes, Shared access within region	Limited access	Yes, Full access onsite	Yes, Full access onsite	Yes, access via referral	Yes, access via referral	Yes, Shared access within region	Yes, access via referral	Yes, access via referral

Table 4 Neurology Service Access to Key Services

	SJUH	GUH	TUH	CUH	SUH	SVUH	UHW	LUH	Beaumont	MMUH
MRH Mullingar										*
St Lukes Kilkenny						*	*			
Wexford General							*			
Our Lady's Navan										*
MRH Portlaoise			*							
University Hospital Kerry*										
Mercy University Hospital Cork				*						
South Tipp Hospital							*			
Bantry General Hospital				*						
Connolly General Hospital									*	
Cavan General Hospital										*
MRH Tullamore	*									
Naas			*							
Mayo University Hospital		*								
Letterkenny University Hospital					*					
Our Lady of Lourdes Drogheda									*	
Bloomfield Hospital			*							
Cork Maternity Hospital				*						
Additional Inclusion Health, Intellectual Disability Services	*									

**Table 5 Outreach from Neurology Centres to Other Hospital Sites**

- \* Consultant Posts are being progressed which will provide additional cover to hospitals in Tralee, Portlaoise, Letterkenny, Wexford and Mayo following on from the announcement of funding in Budget 2024.

	SJUH	GUH	TUH	CUH	SUH	SVUH	UHW	LUH	Beaumont	MMUH
Wait times										
<b>MRI</b>	18 months	24 weeks	> 24 months	<6 months; much improved	1.5 -2 years	12 months	No data	No data	No data	18 months
<b>Neuroradiology</b>	By request to Beaumont 12 months	No data	N/A	excellent service with colleagues	on an individual case basis only	available when needed	No data	No data	No data	N/A
<b>Interventional Neuroradiology</b>	by request to Beaumont 12 months	No data	* Case by case discussion with BH team	excellent service with colleagues	on an individual case basis only	usually, urgent intervention	No data	No data	No data	N/A
<b>PET scanning</b>	12 months	No data	4 to 6 weeks (SJH & Blackrock clinic)	6-8 months	2 weeks	3 months	No data	No data	No data	4 weeks
<b>CT</b>	18 months	No data	> 18 months	6-8 months	6 months-1 year	4 months	No data	No data	No data	4 months
<b>Video Fluoroscopy</b>	6 months	No data	< 3 weeks* (OPD W/L for initial SLT assessment up to 22 months)	<3 months; shorter if urgent	6 months	1 month	No data	No data	No data	4 months
<b>Electroencephalography</b>	12-18 weeks	No data	9 months	14 months	2 years	12 months	No data	No data	No data	20 months
<b>Video EEG</b>	6 months	No data	12 months	6 months	1.5-2 years	12 months	No data	No data	No data	N/A
<b>NCS (incl PN, CTS, QST, etc)</b>	36 - 48 months	No data	22 months	>3 years for routine referrals	4 months	12 months +	No data	No data	No data	2 years
<b>Electromyography</b>	36 - 48 months	No data	3 years;	>3 years for routine referrals	4 months	12 months +	No data	No data	No data	2 years
<b>Ultrasound</b>	9-12 months	No data	up to 24 months	<2 months	6 months	6 months	No data	No data	No data	6 months
<b>Myelography</b>	by request to Beaumont - 12 months	No data		<1 month, if urgently sought	on an individual case basis only	not routinely done	No data	No data	No data	N/A
<b>Genetic counselling</b>	Crumlin - wait 2-3 years	No data	up to 10 months	estimate >6 months	at least 6 months	24 months	No data	No data	No data	3 months
<b>DaTScan</b>	18 months	No data	18 months	approx. 6 months	2-3 months	3 months	No data	No data	No data	4 months
<b>Lumbar Puncture</b>	6-12 weeks	No data	< 6 weeks	4 weeks	4 weeks	2 weeks	No data	No data	No data	10 weeks

**Table 6 Access and Waiting Times for Diagnostic Testing (all wait times are outpatient nonemergency)**

## Appendix B: Glossary of Terms

**ANP:** Advanced Nurse Practitioner  
**CNS:** Clinical Nurse Specialist  
**DMT:** Disease-Modifying Therapy  
**HSE:** Health Service Executive  
**MDT:** Multidisciplinary Team  
**PD:** Parkinson's Disease  
**MS:** Multiple Sclerosis  
**NAI:** Neurology Association of Ireland  
**OT:** Occupational Therapist  
**SLT:** Speech and Language Therapist  
**DMT:** Disease Modifying Therapy  
**RND:** Rare Neurological Diseases  
**ERN:** European Reference Network

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NEUROLOGICAL ALLIANCE  
of IRELAND

## NAI Contact Details

Find us on Facebook @naiireland  
Follow us on Instagram @nai\_ireland  
Follow us on TikTok @nai\_ireland  
Follow us on X @naiireland

Neurological Alliance of Ireland  
Coleraine House  
Coleraine St.  
Dublin 7

Neurological Alliance of Ireland Registered  
Charity Number (RCN) 20049829