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Regional Review of Neurology Services

Final Report

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Glossary

Ataxia: Ataxia is a term for a group of disorders that affect coordination, balance and speech. Ataxia usually results from damage to a part of the brain called the cerebellum. This damage can be part of an underlying condition such as multiple sclerosis (MS), or can be caused by a head injury, lack of oxygen to the brain or long-term excessive alcohol consumption.

Epilepsy: Epilepsy is the set of conditions in which individuals have a tendency to recurrent, usually unprovoked seizures (fits). Seizures happen when there is a sudden interruption in the way the brain normally works. In between seizures the brain often functions normally.

Functional Neurological Disorder: FND is one of the most common diagnoses made in neurology. Presentation is varied and includes seizure-like episodes, motor symptoms (paralysis, movement disorders such as tremor and involuntary contraction of muscles), sensory symptoms (numbness), cognitive symptoms, pain and fatigue. The symptoms of functional neurological disorder are caused by altered function of the nervous system, rather than altered neurological structure.

Headache: Headache disorders include a number of primary headache disorders, namely migraine, tension-type headache, cluster headache and other autonomic cephalalgias. Headache can also be caused by or occur secondarily to a long list of other conditions; medication-overuse headache is one of the most common causes of chronic headache.[1]

Huntington's Disease: Huntington's disease is a genetic disorder that is passed on from a person's parents. The gene that causes Huntington's is called the huntingtin gene. When the huntingtin gene is faulty, the abnormal protein it produces results in damage to brain cells, leading to abnormal movements, cognitive difficulties and psychiatric symptoms.

[1] Headache disorders (who.int)

Motor Neurone Disease: Motor neurone disease (MND) is a rapidly progressive disease of the brain and central nervous system. It attacks the nerves that control movement – motor neurones – which means that muscles no longer work. Some people with MND will experience cognitive symptoms which impact on thinking, reasoning and behaviour.

Movement Disorders: Movement disorders (MD) encompass a wide range of different disorders, the commonest of which is Parkinson's disease (PD). This is due to loss of dopamine-generating cells in the brain and results in a complex array of symptoms. Parkinson's disease is a progressive neurodegenerative disorder, associated with loss of motor control, as well as many more non-motor symptoms. Other movement disorders include atypical parkinsonian disorders such as multiple system atrophy (MSA) or progressive supranuclear palsy (PSP) and dystonia and Tourette's syndrome (TS).

Multiple Sclerosis: Multiple sclerosis (MS) is an acquired chronic inflammatory condition that can affect the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance. It's a lifelong condition that can sometimes cause serious disability, although it can occasionally be mild. In many cases, it's possible to treat symptoms.

Neuromuscular Disorders: Neuromuscular disorders are diseases that can cause problems with the nerves outside the brain and spinal cord, the muscles and the communication between nerves and muscles. These conditions can cause a wide range of symptoms including loss or alteration of sensation, pain, muscle weakness and fatigue.

Foreword

There have been significant developments in neurology services since the last review was undertaken in 2002; we have seen the development of new treatments for some conditions which have significantly improved outcomes for many and continue to see research and clinical trials which we hope will ultimately provide the basis for further new treatments in the coming years.

In 2002, when neurology services were last reviewed, we had six Neurologists with an ambition to grow that to 16. We currently have 25.3 and now estimate that we need between 40-45 to meet the growing needs of people with neurological conditions in NI. In many ways this need has been driven by the emergence of positive developments in terms of assessment and treatment.

While services have evolved locally over the last number of years, it is clear that a much more strategic view is required. Over the course of this Review, we have identified significant gaps in service provision that cannot be addressed in isolation:

- In Northern Ireland (NI), patients are five times more likely to be admitted as a neurological emergency to a hospital that does not have access to an on-site Neurologist compared with patients in England;
- Over 11,000 people have been waiting for a first outpatient appointment for more than a year. Over 11,000 people have overdue review appointments;
- Our analysis suggests the number of dedicated neurology inpatient beds needs to double to meet current levels of need;
- We need to expand our neurology nursing workforce by 43% to reach recommended levels.

The analysis in this report is sobering. The recommendations we present set out the steps required to underpin the development of a high quality, responsive and patient-centred neurology service.

I do not underestimate the challenge the recommendations present to policy makers, commissioners and service providers; I also recognise that many patients will be disappointed that some recommendations will take time to deliver. While acknowledging the challenge and frustration, it is important to reflect the opportunity we now have to build a neurology service that is suitably structured and resourced to meet the needs of people in NI over the coming decades.

Dr John Craig
Chair, Neurology Review Team

Executive Summary

Long-term neurological conditions are common. There are an estimated 40,000 people in Northern Ireland (NI) living with a chronic neurological condition who rely on regular access to neurology services to help manage their condition. In addition, there are a large number of people with functional neurological disorders and conditions such as migraine, dementia and certain types of stroke, which, while largely managed outside neurology services, may require access to specialist neurology services.

In the context of a significant shortfall in outpatient clinic capacity, challenges in terms of waiting list size, length of wait and vulnerabilities in neurology services, the Department established a Regional Review of Neurology in December 2018. The Review is tasked with identifying the optimum configuration of adult neurology services for the next 10-15 years.

To inform this, a programme of analysis of current services and user experience was undertaken. This included a gap and constraints assessment, a detailed analysis of inpatient activity and an assessment of workforce pressures among the medical, nursing, Allied Health Professional and psychology workforce. We also reviewed developments elsewhere in the UK and Ireland, and how best to ensure that resources and services reflect the needs and preferences of people living with neurological conditions. A summary of observations from our analyses is set out below.

Workforce

- Medical – A 2017-2024 Neurology Medical Workforce Planning Report for NI indicates that 45 Whole Time Equivalent (WTE) consultant neurologists are needed in NI in order to provide a 7-day acute unscheduled care service and a 5-day outpatient service. We currently have 25.3 WTE consultant neurologists and have concluded that without significant intervention it will be a challenge to achieve the required consultant workforce within the next 15 years.

- Nursing – A review of the nursing workforce identified that the current baseline of 55 WTE adult specialist neurology nursing posts needs to increase by 41 WTE in order to meet the growing needs of the population by 2028 increasing to 47 WTE to meet the population need by 2035. The review also estimates that 17% of specialist neurology nurses in NI are estimated to be eligible to retire by 2025. The development of Advanced Nurse Practitioners was noted as being key to unlocking capacity challenges in other areas of the service.
- AHP – A review of the AHP workforce identified that there are a total of 36 WTE Neurology AHPs in NI. Almost two thirds of these posts are based in inpatient hospital settings, with a small number based in outpatient, community and specialist services. An additional 38 WTE neurology AHPs is estimated to be required to support multi-disciplinary working and to create additional community capacity. This growth should be underpinned by a skill mix of generic and advanced practice roles, including the development of consultant AHP roles.
- Psychology – A review of the psychology workforce identified that the only access to neuropsychology for most neurology patients is through the Adult Acute Neuropsychology Services Team based in the Neurosciences Centre at RVH. In addition, there is no community level access to psychology services in any Trust area in NI. The review has identified the need to strengthen the current service at the Neurosciences Centre, and to develop community support in each Trust area through the establishment of local neurology teams. An additional 22 Psychologists are required to address this need.

Inpatient Care

- 23% of patients presenting to emergency departments with a neurological condition in NI are admitted to a hospital without a dedicated neurology service. This is five times more common than for patients admitted as a neurological emergency to a hospital in NI compared with patients in England.

- Current neurology bed provision in the N1 Neurosciences Centre at the Royal Victoria Hospital site in Belfast would need to increase from 18 to 36 beds to ensure equitable provision for all neurology patients across NI, requiring admission to a Neurosciences Centre. This increase should be supported by a proportionate increase in the wider neurology workforce.

Long-Term Support

- Access to a well-coordinated service with the right skill mix to meet the needs of patients is key to maximising outcomes for patients and ensuring an effective use of resources.
- However, there are significant barriers preventing services and professions from working together to best meet the needs of patients. In addition, challenges accessing some services including mental health services are causing inequity in some areas.

The overarching vision of the Review is to ensure that future neurology services are person centred, joined-up, responsive, evidence-based and suitably resourced to meet the needs of people with neurological conditions in NI. The recommendations set out in this Report provide the roadmap to achieving that vision.

To support the delivery of the vision we have identified four priority areas with associated recommendations to drive improvement.

<u>Priority One: A Person-Centred Service</u>

The recommendations within this priority area focus on the development of person-centred care through the introduction of the House of Care Model currently used in NHS England. We also recommend the identification of a designated point of contact for all patients with a long-term or complex neurological condition to ensure a coordinated approach for those people who require access to care from multiple professions during the lifetime of their condition.

Priority Two: Developing Additional Workforce Capacity

The recommendations within this priority set out the requirement for the development and growth of the entire neurology workforce in the context of significant shortages, in particular within the consultant, nursing, AHP and psychology roles. While an increase in overall numbers across professions is recommended, the development of advanced roles such as Advanced Nurse Practitioners, Advanced Practice AHPs and GPs with enhanced roles is also advised. This will ensure that patients are seen in the right place, at the right time by the right person. It will also increase the overall capacity of the consultant workforce in an effort to reduce waiting times for those patients who need to be seen by a consultant neurologist.

Priority Three: Addressing Gaps in Current Services

This priority area focuses on actions needed to address the gaps identified in our analysis to ensure that all neurology patients have equitable access to the care and support they need. In this context an increase in the inpatient bed capacity is recommended to ensure sufficient provision to meet the needs of the population. In addition, the development of Specialist Neurology Clinics in each Trust for the most common conditions including epilepsy and multiple sclerosis alongside General Outpatient Clinics for all other neurological conditions and for those referred for assessment is recommended. The development of local neurology teams is also recommended with a focus on rehabilitation and symptom management.

Access to services which sit outside of neurology, in particular mental health services, was identified as a particular gap for many people with neurological conditions including functional neurological disorders. A specific recommendation to increase the psychology workforce is intended to address this gap and ensure that neurology patients have the access to psychology and mental health support at all stages of their journey, regardless of diagnosis. The finalisation of condition specific pathways is recommended as a priority commitment during the implementation stage of the Review, which will include analysis of the resource required to ensure that care is delivered in line with recognised principles and standards. Finally, it is recommended that the commissioning of specialist services in NI is in alignment with similar services in NHS England to ensure that patients in NI are not disadvantaged.

Priority Four: Using Current Resources More Effectively

This priority area considers opportunities to make better use of current resources through new and innovative ways of working. These have been developed in some Trust areas already. The focus of these recommendations is around the introduction of services such as referral management; management of suitable patients in primary care settings through advice and guidance; and access to rapid access neurology appointments when required.

In addition, a risk stratification approach is recommended to better understand the levels of need among people with a neurological condition and to inform the commissioning of services to meet those needs.

Next Steps

The recommendations presented in this Report have been identified following careful consideration of our findings. The recommendations are set out in a phased multi-year implementation programme which will allow for continuous review of progress and the assessment of the impact of each recommendation on service provision to ensure flexibility as services evolve. While we recognise that this is an ambitious programme, it represents the consolidated view of the Review Team regarding what is needed to ensure an optimum service.

A Neurology Delivery Team (NDT) will now be established to lead on the implementation of the Review recommendations. The role of the NDT is considered further on page 77.

Summary of Priorities and Recommendations

Priority	Recommendations
1. A Person-Centred service	1a) Person-centred care must be the focus of all patient-healthcare interactions for those with neurological conditions.
	1b) Patients and their carers/families should be clear about their care and available supports, including the use of Patient Portals.
	1c) Patients must have a designated point of contact as part of an effective care delivery network.
2. Developing additional workforce capacity within Neurology	2a) A regional approach to workforce management is required to support the growth of the neurology consultant workforce to 45 WTE. This should include increased exposure to neurology at early and middle grade level training and the development of research posts within neurology.
	2b) Two additional WTE neurophysiologist posts are required to increase the workforce to six posts in line with guidance. This will ensure timely access to Neurophysiology services across all Trust areas.
	2c) Timely access to neuroradiology must be available across all Trust areas.
	2d) An additional WTE neuropathologist post is required to increase the workforce to two in line with guidance. Consideration needs to be given to the sustainability of the Training Programme to facilitate this.
	2e) An Action Plan is urgently required to expand and sustain the Training Programmes within the neurology specialty.
	2f) Trusts should consider the expansion of Specialty and Specialist Doctor (SAS) roles to create capacity in the neurology medical workforce.
	2g) GPs with Enhanced Roles should be developed in neurology through the provision of Fellowships or Integrated Training Posts.
	2h) An additional 41 neurology nurses are required by 2028 increasing to 47 by 2035 including 12 Advanced Nurse Practitioner trainee posts.
	2i) A Neurology Nursing Team should be established in each Trust area.
	2j) An additional 38 WTE neurology AHPs are required to support multi-disciplinary working and to create additional community capacity across the four core professions (Physiotherapy, OT, Dietitian, SLT). Future workforce planning will ensure access to other AHP professions such as Orthoptists, Podiatry, Arts Therapies. Growth in the AHP workforce should be underpinned by a skill mix of generic

	and advanced practice roles, including the development of consultant AHP roles.
	2k) Seven additional psychologists are needed within the team at the Regional Neurosciences Centre to ensure equitable service provision. In addition, the establishment of hospital based local neurology services requires a minimum of 1 WTE consultant psychologist, 1 WTE specialist psychologist and 1 WTE associate psychologist per Trust area.
	2l) Four WTE consultants in neuropsychiatry are required as a minimum to meet current levels of need within neurology.
	2m) Neuropharmacy capacity needs to be developed both at the Neurosciences Centre and across Trusts. In the immediate term, an additional nine pharmacists, two pharmacy technicians and one consultant pharmacist are required to meet demand.
3. Addressing gaps in Current services	3a) Access to specialist neurology opinion must be available at all acute hospitals receiving unscheduled admissions in line with ABN Standards. Trusts must identify the measures required to achieve the Standard. Options such as tele-neurology should be considered as an interim measure.
	3b) Neurology inpatient beds must be managed as a regional resource and protected against non-neurology unscheduled care bed pressures. Capacity at the Neurosciences Centre should be doubled from 18 to 36 beds supported by a proportionate increase in the workforce to provide an equitable regional service. Variation in care based on Trust of Residence must be addressed.
	3c) General Neurology Clinics, alongside Specialist Clinics for the most common conditions including epilepsy and MS, must be available in each Trust area. Regional Specialist Clinics must be further developed for less common conditions and to support complex interventions and treatments.
	3d) Condition-specific pathways based on accepted best practice must be finalized within the first two years of implementation. Progress towards the delivery of the pathways and accompanying standards should be a key metric during the implementation of the Review.
	3e) A service specification for local neurology services focused on rehabilitation and symptom management is required. Local Neurology Teams must then be established in each Trust.
	3f) Trusts must ensure that barriers to accessing general mental health services for neurology patients, regardless of diagnosis are addressed.

	3g) The commissioning of highly specialised services should be aligned to NHS England commissioning decisions to ensure patients in NI have equitable access to highly specialised services.
4. Using current resources more effectively	4a) All Trusts must develop an approach to referral management for outpatient referrals.
	4b) Strategies for best meeting the needs of patients requiring neurological review should be considered. These should include Patient Reported Outcome Measures and Patient Initiated Follow-ups. This approach will first be piloted for those with epilepsy.
	4c) Trusts must ensure that Neurology Clinics include protected slots for patients at risk of hospital admission.
	4d) There is a need to broaden and develop data capture within neurology and the use of that data across Trusts to inform service developments. This should extend to capturing the breadth of all clinical activity undertaken as well as coding of diagnoses and interventions. Data should be used by the Commissioners to support the further development of approaches to risk stratification and to compare performance across Trusts to identify opportunities for improvement.
	4e) Effective partnership working between Trusts and the community and voluntary sector must be specifically addressed in service planning.
	4f) Training in neurology is required for non-neurology hospital specialists and the wider HSC workforce to support the management of people with neurological conditions.
	4g) Trusts should ensure that care environments are age appropriate and are aligned with the physical and cognitive needs of people with neurological conditions.

Implementation of the majority of these recommendations will require additional funding. This is considered further on page 83.

The table below provides an overview of our assessment of the challenges with current services at key points of the patient pathway and of the impact of the above recommendations in improving services.

Service	Challenges in current service	What good looks like
Baseline	Services constrained by availability of local resources leading to capacity gaps and unwarranted variability.	Condition-specific pathways provide a framework for service development, promoting consistency and a basis for performance management.
Symptom onset – presentation to primary care	Lack of support for GPs could result in inappropriate referrals for Outpatient appointments. Lengthy waits for outpatient appointments. Patient managing symptoms without appropriate support while on waiting list. Risk stratification exercise shows 1 in 4 attend ED and 1 in 3 have an inpatient episode. Tests often ordered after first outpatient appointment. Only two Trusts have referral management processes.	All Trusts to have referral management processes. This will enable: • Timely advice to GPs to support people in the community. This means patients who do not need an Outpatient appointment do not face an extended wait; • Timely ordering of tests to inform next steps; • Reduced waiting lists for outpatient appointments as referrals are made only for those patients who require them. Improved knowledge among GPs driven by expansion in GPERs – increased capacity to manage patients locally where appropriate.
Outpatients	Equity of availability for timely Outpatient appointments across Trusts Some Trusts reliant on outreach due to workforce constraints. NICE timescales for Outpatient appointments not being met. For example: First seizures within 2 weeks, MS within 2-4 weeks, Parkinsons within 13 weeks.	Improved, timely access to Outpatient services: • All Trusts will have General Clinics and Specialist Clinics for most common conditions – removing reliance on visiting consultants; • Development of Regional Specialist Clinics for less common conditions suitably resourced to meet regional need; • Broader skill mix and new roles providing more service options for example the development of Advanced Practitioner roles such as ANPs.

	Outpatient waits at September 2023 indicate a median waiting time of 1 year 26 weeks, 95th percentile 6 years and 32 weeks. 89% of the 19,536 patients on the waiting list are waiting for more than 13 weeks or more.	
	Environment - access issues and lack of privacy.	Environment meets the needs of patients including access and private space for discussion on diagnosis and treatment.
Management of Conditions	Lack of care coordination - unclear who to contact	Care Conversation leading to agreed care plan for patients with the most complex needs. All patients will have a Designated Point of Contact. Access to Patient Portals as central resource of information.
	Experiencing a change in condition but: • Reviews at set intervals, not necessarily when they're needed; • Lengthy waiting lists; • Presentation for urgent care in ED in the absence of an alternative pathway for review.	Trial of Patient Initiated Reviews to make system more responsive to changing needs. All Trusts will have protected slots in clinics for quick assessment. Role of Designated Point of Contact and Patient Portals to ensure effective coordination of care and access to information.

	Limited services to support management in the community. Patients reliant on small teams.	Local Neurology Teams in each Trust area. Commissioning of services informed by extended risk stratification exercise which will identify levels of need.
	Highly specialist services – access delayed by protracted process resulting in poorer outcomes.	Patients in NI will have equitable access in line with patients in England. Development of all-island services where appropriate.
Inpatient Care	23% of admissions are to hospitals without an on-site Neurologist resulting in poorer outcomes and longer stays.	All patients will be seen by a Neurologist within 24 hours in line with standards. Training for non-neurology specialists will improve symptom recognition and appropriate referral, optimizing outcomes.
	Insufficient regional inpatient beds – not everyone who would definitely or probably benefit from being in a dedicated neurology bed will receive this level of care. Equity in access to dedicated neurology beds across Trusts – Southern and Western Trust residents least likely to get access to dedicated neurology bed.	Recommended increase in dedicated neurology beds in Regional Centre. As workforce capacity increases, Trusts to cohort beds and consider potential for establishment of dedicated neurology beds outside the Regional Centre.

Workforce	Insufficient to meet needs: • Consultant capacity 57%-64% recommended level; • Nursing capacity 57%; • AHP 49%; • Psychology 20%. Results in limited – in some cases no – access to services. For example there is currently no community psychology service. Services are often reliant on one or two individuals. Overall – fragile services unable to meet the needs of the population resulting in growing waiting lists, post code lottery and suboptimal outcomes	Each Trust area resourced to provide outpatient and inpatient care in line with demand. NICE and ABN standards are achieved. Emphasis of new services to support people in the community, avoiding unnecessary referrals and hospital admissions – improvements in outcomes and efficiency.

SECTION 1: INTRODUCTION

About This Review

On 31 July 2018, in the context of the commitment in Health and Wellbeing 2026: Delivering Together[2] to undertake a programme of service configuration reviews, the Department announced a comprehensive Regional Review of Adult Neurology Services covering all aspects of neurology.

The Review was tasked with identifying an optimal service configuration of adult neurology services through to 2035 to include consideration of:

- Future demand taking into account demographics and interlinking specialties;
- The role of technology in improving neurology services;
- New models of care which are more effectively integrated across primary, community, secondary and tertiary care;
- The workforce and training required to deliver the optimum configuration; and
- Actions required to ensure services are underpinned by effective governance and quality assurance mechanisms.

Terms of Reference (ToR) for the Review are outlined at Appendix 1. A summary of how the Review Team addressed the above issues and objectives set out in the ToR, including the role of the Workstreams established as part of the Review, is included at Appendix 2.

The Review was paused in March 2020 in the context of pressures arising from the COVID-19 pandemic. Work resumed in June 2021.

In the context of the timeframe that this report applies to and with the potential for emerging treatments, the recommendations in this report should be kept under review during its 10-15 year implementation period.

[2] health-and-wellbeing-2026-delivering-together (health-ni.gov.uk)

The focus of the Review is on neurology services for the adult population. Paediatric neurology services are considered under the Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016-2026)[3]. It is recognised, however, that there are specific challenges associated with the transition from children's services to adult services.

The Neurology Review does not include Traumatic Brain Injury services. Separate to this Review, the Department of Health is also considering the need for further work on the development of services for Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS).

Neurological Conditions

Neurological conditions such as epilepsy, multiple sclerosis, Parkinson's disease and motor neurone disease result from damage to the brain, spinal cord or peripheral nervous system. Some neurological conditions are life threatening, with many severely affecting an individual's quality of life.

There are over 600 types of neurological conditions which can be separated into four broad categories[4]:

- Sudden onset conditions such as such as encephalitis, meningitis and Guillain-Barré syndrome;
- Intermittent and unpredictable conditions such as epilepsy, migraine and the early stages of multiple sclerosis;
- Progressive conditions such as Parkinson's disease, motor neurone disease and later stages of multiple sclerosis;
- Stable neurological conditions with changing need such as cerebral palsy in adults or spina bifida.

[3] paediatric-strategy-hospital-andcommunity.pdf (health-ni.gov.uk)
[4] https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2022/06/Neurology-Sept21g.pdf

Prevalence

Long-term neurological conditions are common. There are an estimated 40,000 people in NI living with a chronic neurological condition such as epilepsy, Parkinsons and MS who rely on regular access to neurology services to help manage their condition. In addition, there are a large number of people with functional neurological disorders and conditions such as migraine and cerebral palsy which, while largely managed outside neurology services, may require access to specialist neurology services. This figure also does not include those with stroke or dementia.

Many neurological conditions are associated with older people and so an ageing population will present increased prevalence. People with a learning disability often have an associated neurological condition (typically, but not always, epilepsy). It is unclear changing and economic conditions will impact on neurological conditions presenting to the health service, for example, the prevalence of drug and alcohol induced seizures. Generally, however, we can expect the number of neurological conditions which require medical treatment to increase in NI, largely due to our ageing population but also due to improved life expectancy. There is also a hidden prevalence for various conditions which do not always present to the health service. Some of the more common conditions are outlined below.

Epilepsy

In NI, there are approximately 22,000 people diagnosed with epilepsy according to data from Epilepsy Action; this represents roughly a 10% increase in the past decade. Recent research suggests that NI has the highest prevalence of epilepsy in the UK, with research also suggesting that epilepsy is increasingly becoming a condition of the elderly.[5] In 25% of cases the age of onset is over 65.

Alongside the increase in the number of those with a learning disability (around 20% of people with epilepsy also have a learning disability[6]) at 1-2% per year into the foreseeable future, we could have close to 30,000 people living with epilepsy in NI in

[5] The incidence and prevalence of epilepsy in the United Kingdom 2013–2018: A retrospective cohort study of UK primary care data (seizure-journal.com)
[6] Learning disabilities | Epilepsy Society

the 2030s, possibly levelling off by 2040, as the growth in the ageing population slows and stabilises.

Multiple Sclerosis (MS)

Approximately 5,400 people in NI have MS[7] and this is projected to increase to around 6,000 in the next decade based on demographics, levelling off at around 6,000-7,000 by 2040. Average life expectancy is slightly reduced (7-12 years) however new treatments are likely to improve life expectancy. In the UK there is an annual growth rate of 2.4% of people with MS with a 6-10% increase in demand for MS services per year as people live longer with the condition requiring more complex care. It is likely that treatments will continue to improve enabling a higher quality of life for those living with the disease.

Parkinson's Disease (PD)

There are approximately 4,000 people in NI with PD[8], with a significant number of others with other Parkinsonian disorders, due to drug induced states, atypical Parkinsonian and other neurodegenerative and genetic disorders[9]. This figure is projected to continue to rise in line with an ageing population to over 4,700 people in the next decade, levelling off to approximately 5,000 by 2040 in line with population projections for older people. PD prevalence is driven principally by ageing and rates in the future could increase due to increasing longevity as well as social and environmental factors.

Neuromuscular Disease

Approximately 1,000 people in NI have an inherited or acquired neuromuscular disease[10]. There are many conditions in this group. Some are rare or very rare, such as inherited muscle and nerve disorders. While often progressive and sometimes life-limiting, new treatments for some conditions have become available.

[7] Number of people living with MS in UK increases | MS Society
[8] https://www.parkinsons.org.uk/sites/default/files/201801/CS2960%20Incidence%20and%20prevalence%20report%20branding%20summary%20report.pdf
[9] Oxford Handbook of Neurology, Second Edition, 2014.
[10] https://pubmed.ncbi.nlm.nih.gov/8845721/

Other conditions, often presenting in adulthood, such as myasthenia gravis, are not uncommon; the actual figure is not reported, but extrapolating from the UK-wide figure, we estimate that around 350 people in NI are affected by myasthenia gravis[11] and, while this rate is not expected to grow significantly as a result of demographic change, improved diagnostic capability could increase the known population.

Motor Neurone Disease (MND)

A person's lifetime risk of developing MND is around one in 300. The incidence and prevalence of MND in NI has increased over the last 10 years, in line with increasing rates in other European countries, likely due to the ageing of the population; the median age of onset is 60 years (with 10% onset for those under 40 years of age). There are presently 140 people with MND in NI, expected to rise to around 200 people in the next decade[12].

Huntington's Disease (HD)

Estimates of prevalence of HD in the UK range from 25–100 cases per million population; NI is estimated to have approximately 250 cases[13], with a wide range for average age of onset. HD is a genetic disorder in which children of an affected parent have a 50% chance of inheriting the causative gene. With advances in genetic screening and genetic testing, known prevalence could rise.

Headache disorders

Migraines are one of the most common neurological conditions, with a large impact on both primary care and emergency hospital services. Lifetime prevalence is estimated at between 18%-30% in women and 6%-15% in men[14]. For a significant

[11] Oxford Handbook of Neurology, Second Edition, 2014
[12] https://www.mndassociation.org/sites/default/files/2023-02/Northern-Ireland-Report-PDF.pdf
[13] https://pubmed.ncbi.nlm.nih.gov/7562964/#:~:text=A%20survey%20of%20Huntington's%20disease,over%20the%20last%2020%20years.
[14] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7704513/

proportion of these people, migraines are very disabling. Cluster headache, the pain of which has been described as one of the most excruciating pain ever experienced, affects approximately 1 in 1,000 people, which equates to 1,900 people in NI.

Functional Neurological Disorder (FND)

FND is likely to be more common than MS and PD and has similar rates of long-term disability and impaired quality of life. Symptoms are multiple and there are no standard tests. It is estimated that there are several thousand people in NI with FND, and that 25% of demand for neurological services is generated by FND[15]. As understanding of FND improves, it is possible that increased awareness and focus could increase known prevalence. It is also important to recognise that people with some other neurological disorders may have functional components.

Cerebral Palsy (CP)

Estimates of the prevalence of CP in adults NI are around 2.38 per 1,000 population according to a population-based study conducted by the NI Cerebral Palsy Register (NICPR)[16]. This would suggest that there are approximately 4,500 adults living with CP in NI. The needs of people with CP are diverse and are expected to change with age. People with CP require ongoing coordination and management of their condition across a wide range of services, many of which sit outside of neurology services. Management and regular review of CP is typically provided in the primary care setting. Access to specialist neurology services however may be needed if managing the symptoms of the condition becomes more challenging.

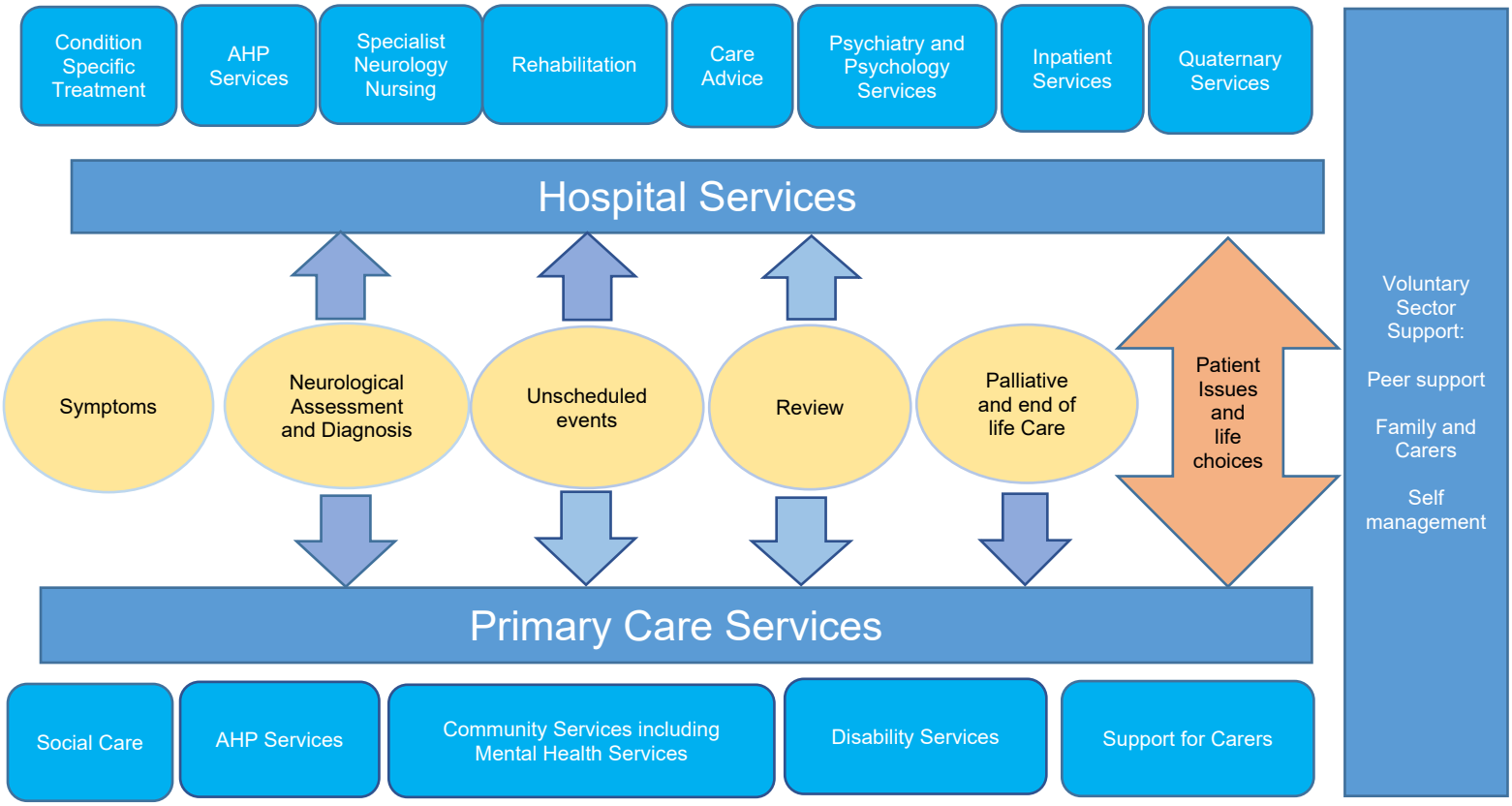
Current Neurology Services

Care and Support is provided to people with neurological conditions from a broad range of services. Some of these are specialist neurology services. Others have a broader community-based focus which are provided by general practice, community based allied health professionals and other community and voluntary based

[15] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10064068/ (Estimated at 16-30%, NI Neurology group DoH used 25% as an agreed rule of thumb.)
[16] e044614.full.pdf (bmj.com)

services. For those admitted to hospital, in addition to specialist neurology services, care is delivered by a wide range of specialisms, including Emergency Medicine, Acute and Internal Medicine, Care of the Elderly, Intensive Care Medicine and Neurosurgery.

The interdependence of these services is outlined in the diagram below:



While the current neurology service model in NI and elsewhere in the UK has largely focused on outpatient delivery, there is considerable demand for neurology support within unscheduled care, with neurological disorders (including stroke) accounting for about 15% of Emergency Department (ED) attendances and about 10% of emergency medical admissions (excluding stroke).

Neurology services are provided across each Trust area in NI. There is one Regional Neurosciences Centre at the Royal Victoria Hospital (RVH) in Belfast. The Centre provides 18 dedicated neurology inpatient beds for all of NI. Due to the support needed from non-consultant doctors, dedicated neurology nursing and reliance on

wider specialties, in particular neurophysiology, inpatient beds are only provided in the Neurosciences Centre at present. The establishment of neurology inpatient beds in other Trusts should be considered over time, in line with the growth of the workforce and the development of services throughout the implementation period of this Review. In this context, individual Trusts could cohort patients with neurological conditions and consider providing admission under neurology where local volumes and staffing levels make this possible.

In addition to providing outpatient and acute unscheduled neurology services to the greater Belfast population, the Centre also provides sub-specialist services for epilepsy, movement disorders, MS / Neuro-inflammatory, Neuro-disability / Rehabilitation, Cognitive, neuro-muscular and headache alongside specialist inpatient care to the wider NI population.

In addition to the Neurosciences Centre, there is also a 23 bedded inpatient rehabilitation unit in Musgrave Park Hospital, Belfast. Thompson House Hospital, Lisburn has 35 beds, some of which are dedicated to providing care to patients who have complex chronic neurological disability for whom care cannot be supported in the community.

Neurology services rely heavily on the skills and expertise of associated specialities including Neuroradiology, Neurophysiology, Neuropathology, Neurosurgery and Psychiatry as well as Specialist Neurology nurses, Psychologists, Pharmacists and Allied Health Professionals (AHPs), including Physiotherapists, Occupational Therapists, Speech and Language Therapists, Dieticians and Orthoptists. There are also links with other medical specialisms, including Ophthalmology, Infectious Diseases, Ear, Nose and Throat services and Ventilator and Endoscopy services.

SECTION 2: OUR VISION

Strategic Context

Health and Wellbeing 2026 Delivering Together sets out the Department's ambition for everyone to lead long, healthy and active lives. It sets out four key aims:

- people are supported to keep well in the first place with the information, education and support to make informed choices and take control of their own health and wellbeing;
- when they need care, people have access to safe, high-quality care and are treated with dignity, respect and compassion;
- staff are empowered and supported to do what they do best; and
- our services are efficient and sustainable for the future.

In setting out these aims, Delivering Together notes that failing to modernise current service models is having increasingly negative impacts on the quality and experience of care for many service users, while constraining the ability of the system to transform. Delivering Together also establishes the need to work across traditional boundaries to underpin a new model of person-centred care focussed on prevention, early intervention, supporting independence and wellbeing.

In this context, the Review Team has agreed the following vision for Neurology:

> Neurology services should be person-centred, joined-up, responsive, evidence-based and suitably resourced to meet the needs of people with neurological conditions in NI.

Principles and Standards

The Neurology Review Team has agreed the following Principles as a basis for the development of neurology services:

- Person-centred with involvement from patients, clinicians, AHPs, nursing and other stakeholders;

- Safe and effective;
- Comprehensive provision across primary, secondary and community settings;
- Available on an equitable basis;
- Designed to develop multidisciplinary team (MDT) working;
- Evidence-based and benchmarked against best practice and NICE guidance;
- Appropriately resourced; and
- Care of patients will recognise that mental wellbeing is a central and independent determinant of quality of life for patients with neurological conditions.

The Review has also endorsed the adoption of Quality Standards for Neurology developed by the Association of British Neurologists (ABN) and the National Institute for Health and Care Excellence (NICE). These Standards have now been further strengthened by a review of standards and clinical guidance by neurological condition. These are summarised at Appendix 3. It is intended that the Standards will strengthen the Principles by establishing desired performance levels against which progress can be measured. This approach will be further strengthened by the development of condition specific pathways based on a review of best practice pathways across the UK which set out what good treatment, care and support looks like. Further information on the development of condition specific pathways can be found at Appendix 4.

As will be outlined later in this report, there are significant challenges within current services which means achievement of many of the Standards and Pathways are not currently possible. It is intended that the recommendations of this Review will address these challenges building towards achievement of the Standards and Pathways and the provision of an equitable, patient centred service.

People

People are at the centre of our vision for neurology services: those who work in neurology services and people with neurological conditions. Later in this report we will set out specific recommendations for both.

A Teams Based Approach

With over 600 neurological conditions, it is unsurprising that there is a broad spectrum of presenting symptoms, with the type, frequency and nature of support needed to ensure the right level of care for people with neurological conditions varying from person to person.

Assessing and responding to those needs requires input from multiple health and care professionals. It is clear that there is a significant challenge in ensuring that professions and services work together to best meet the needs of people with neurological conditions. For example, in a recent UK-wide survey, 38% of adult respondents with a neurological condition disagreed that information about their care and support was passed effectively between Health and Social Care professionals.[17]

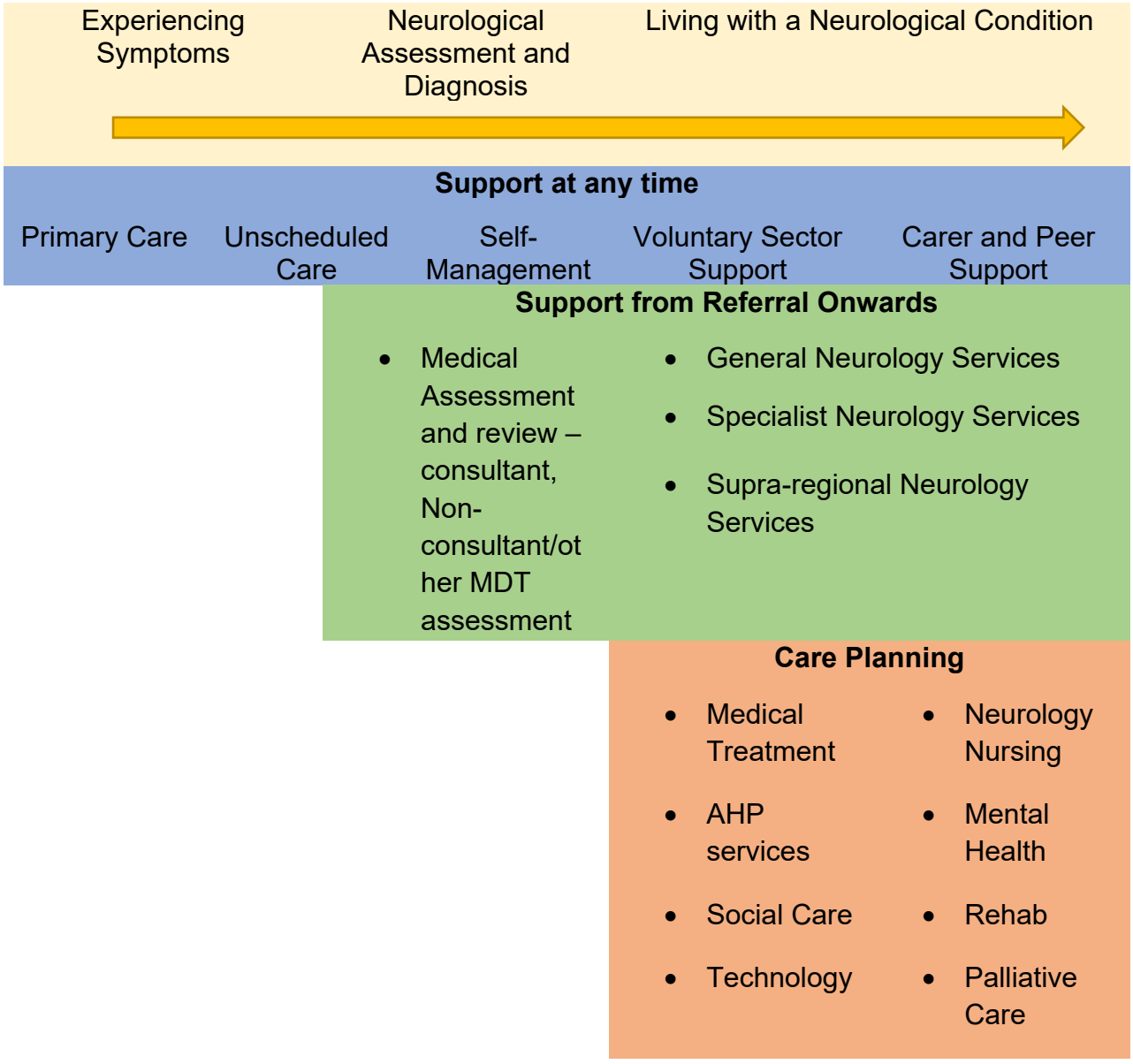
An uncoordinated approach can contribute to poor care, resulting in poorer outcomes for patients and, potentially, an inappropriate and inefficient use of resources through, for example, unnecessary hospital admissions or duplication of services. Access to a well-coordinated service with the right skill mix to meet the needs of individual patients is key to the provision of good care and maximising outcomes.

This coordinated approach is already present in some elements of the neurology service, including a multi-disciplinary approach to the assessment of people with particularly complex conditions and regarding the availability of Disease Modifying Therapies for MS. Going forward, this way of working should be expanded across neurology services. To achieve this, it is critical that staff are supported to work together to undertake holistic assessments of need and joined-up care planning. This means addressing structural barriers, including Trust boundaries and consideration of approaches to commissioning.

[17] Together-for-the-1-in-6-UK-Findings-from-My-Neuro-Survey-v6.pdf (neural.org.uk)

Person-centred Care

As illustrated below, people experiencing neurological symptoms for which they need to access help or support, or those with long-term and complex neurological conditions, will follow many different paths and will require access to a multitude of different services over the course of their conditions. These might change significantly over time. For those who would benefit from neurological input, their journey will commence when they are referred for assessment and diagnosis of the cause of their symptoms. The teams-based approach to care we wish to see strengthened across neurology services will ensure that the patient is at the centre of their care, that services are responsive to their needs and that those delivering their care are able to co-ordinate care to achieve the best possible outcomes.



The individual with a neurological condition, supported by their family and other carers, should be at the centre of their care. Putting the patient at the centre of their care is an evidence-based approach that has been shown to provide better outcomes for patients. Our vision for neurology services has at its core, clear pathways to ensure care and support is provided consistently and equitably to all patients. These pathways will help ensure delivery of high-quality care throughout the patient journey and will help providers consistently meet national and best practice standards in the delivery of neurology services. Significant work has been undertaken to develop condition-specific pathways for NI as part of the Review. Completion of those pathways will be a priority during the implementation phase.

Carers

The Review Team recognises the vital contribution of carers who support family members and friends with neurological conditions. It is critically important that carers are supported in this role.

To that end, the Review Team notes work being progressed by the Department of Health to find ways to provide support to carers. This includes proposals included in the recent consultation on the Reform of Adult Social Care. In addition, the Social Care Collaborative Forum has established a workstream specific to carers which will consider issues including improving information for carers, evaluating the implementation of the current Carers Strategy, and establishing a cross departmental senior officials' group to promote cross government approaches. The Review Team anticipates that this work will result in much needed improved support for carers.

SECTION 3: OUR ANALYSIS

People with Neurological Conditions

Our analysis has been shaped by discussion with a broad range of stakeholders including people with neurological conditions, carers, neurological charities, members of the workforce and professional bodies.

Service users have told us that the pathway to accessing services can be complex and difficult due to the wide variety of support required for the management of some neurological conditions. Engagement during the early stages of the Review identified priorities including timely access, care coordination, access to emotional and psychological support and the importance of clear pathways.

We have also considered feedback provided by service users via the Care Opinion Platform. This new Online User Feedback service provides an open and transparent platform for service users, families and carers to share feedback on any service within Health and Social Care in Northern Ireland. The platform supports feedback to be shared safely as stories are independently moderated prior to publication on the Care Opinion website[18]. Since the launch in August 2020 service users have been providing feedback specific to their experience within neurology services. This feedback provides insight into the lived experience of engaging with Neurological services and demonstrate what matters most to service users, families and carers.

In summary the feedback has highlighted the following elements as key to a positive experience:

- Clear explanation of conditions and treatment to service users & families;
- Empathy and understanding on the impact of the condition;
- Professionalism;
- Responsiveness to concerns and questions;
- Role of Multi-Disciplinary Teams (MDTs) in care; and
- Effective communication between organisations.

[18] www.careopinion.org.uk

The feedback also highlights the challenge of the pandemic, reflecting upon telephone consultations, access and restrictions for inpatient and outpatient services.[19]

The word clouds below are compiled from information provided by service users through the Care Opinion service and highlight what service users have told us is working well within neurology services and which areas have been highlighted as needing to be improved.

What was Good About Your Experience?

[19] https://tinyurl.com/mucabcjx

What Could Have Improved Your Experience?

Following the recommencing of the Neurology Review in June 2021, the Neurology Review Team agreed to engage with service users through a Neurology Engagement Platform established by the Patient Client Council. The Platform, comprising people with neurological conditions, carers and neurological charities, provides a forum for discussion on issues considered as part of the Review and the Independent Neurology Inquiry. We have engaged with Platform members five times during the course of the Review and it is intended that the Platform will continue to play a central role during the subsequent implementation phase.

In addition to direct feedback from people with neurological conditions, we have also worked closely with the NI Neurological Charities Alliance (niNCA) which is represented on the Neurology Review Team. Review Workstream Leads met with niNCA members, providing an opportunity for feedback on work and an opportunity to help shape the focus of each workstream. Workstream leads also undertook engagement within their workstreams. This was primarily focused on workforce engagement and included primary care, nursing and AHP workforce representatives.

Outpatient Services

We undertook a demand and capacity analysis of both first outpatient appointments and review appointments. First or new referrals to adult neurology outpatients for face-to-face assessment or for 'virtual' clinic advice average just under 18,500 per year in Northern Ireland; included in this figure are patients who get removed from the waiting list without being seen. This will include patients who cancel appointments several times, those who make alternative arrangements to be seen privately, or decide that they do not want the appointment. However, the capacity of the system to see these patients is just under 12,000 per year. In England, rates of access per 100,000 population range between 400-1,600, with the equivalent figure for NI being just over 600.

The gap between capacity and demand in NI has resulted in a 73% rise in patients waiting for a first appointment from 10,850 at the end of March 2016 to 18,804 at the end of March 2023. By the end of March 2023, just over 60% (11,353) had been waiting more than one year to be seen. It is the view of the Neurology Review Team that this position is unacceptable and at odds with ABN Standards.

There are on average 22,500 neurology review attendances every year. There is a considerable backlog of patients needing follow-up appointments. In April 2023 11,383 patients had been waiting past the date that their clinician had proposed for review. Of those, 8,708 patients had been waiting more than 3 months past that date with 1,205 patients waiting more than 2 years past that date. In addition, it should be noted that a large section of the neurology population is not on a waiting list for a review appointment for a variety of reasons including stability in a person's condition or disengagement with services.

It is widely recognised that there is a need to ensure that referrals are effectively managed, early management advice is given, clinic waiting times are improved and "Did not Attend" (DNA) rates are reduced, as much as possible. This is consistent with recommendations from NHS England and Getting it Right First Time (GIRFT) for Neurology. The ABN have reported that by triaging outpatient neurology referrals, between 8 and 23% of referrals can be provided with direct and prompt advice.

We reviewed two approaches to referral management already being used in NI:

- Non-Contact Specialist Assessment (NCSA) – Southern Trust

  In some cases a Neurologist or potentially another member of the MDT (Non-consultant hospital doctor, neurology nurse, AHP) is able to provide remote advice directly to a GP through an electronic system, recommending appropriate investigation or symptom management, sometimes resolving the issue without the need for a face-to-face appointment.

  A GP Advice and Guidance service has been in operation in the Southern Trust for a number of years. GPs in the Southern Trust can request advice and guidance on the management of suitable patients via the existing Clinical Commissioning Gateway (CCG) system. The GP then takes on the shared responsibility of implementing the advice and treatment plan agreed with the consultant neurologist.

  The Southern Trust model estimates around 10 advice requests per 100,000 population are received per week with 7% of initial requests triaged directly to outpatients and a further 7% triaged to outpatients following receipt of test results done after initial contact. When referrals for advice and guidance are taken into account, Southern Trust residents appear to be less reliant on traditional neurology outpatient attendances than other Trusts. This supports the hypothesis that Advice and Guidance may reduce demand on hospital outpatient services.

- Neurology Advanced Referral Management System (NARMS) – South Eastern Trust

  An electronic triage service, Neurology Advanced Referral Management System (NARMS), is currently being piloted in the South Eastern Trust. NARMS was introduced to enable effective triage of new referrals from GPs to identify those patients who could be better managed as an alternative to face-to-face assessment in response to the Covid Pandemic. Using the Trust's existing electronic systems, referrals from GPs are received by email and triaged to either advice, investigations or a face-to-face clinic.

Results of a survey conducted over a 6-month period from June to December 2020 indicate that 27% of patients referred by their GP were managed with advice only and discharged from the clinic, 17% of referrals were managed by telephone follow up; 23% were referred for investigations and 33% of all patients referred required a face-to-face consultation.

Further information on our analysis of approaches to referral management is set out at Appendix 5.

Inpatient Services

Neurological symptoms account for 10% of ED attendances and are significantly more likely to require acute hospital admission than other attendances.

Following review of the methodology set out in the Getting it Right First Time (GIRFT) Neurology Report, an analysis of inpatient data for NI was undertaken using the same methods covering the same time period (2018/19) to enable a comparison between services[20]. The analysis categorised hospital admissions for a neurological condition by the likelihood of benefit from inpatient neurology care based on primary diagnosis – *definitely*, *probably*, *possibly* and *rarely*. Hospital sites were categorised by the availability of relevant facilities.

Further information on the methodology and findings is outlined at Appendix 6.

Comparison with Acute Neurology Services in England

Despite having a younger population than England during the analysis period, NI experienced 16.3% more unscheduled admissions per head of population than England for neurological conditions.

In NI, 23% of all unscheduled neurological admissions were to sites that had no specialist neurology input (N5), in contrast to only 4% in England. Only 3% of acute neurology cases in NI were admitted under the care of a neurologist, less than half the proportion in England (6.7%).

[20] Definitions: N1 Neuro= Neurology inpatient beds; N1 non-neuro/N3= Neurology liaison service; N5=no local acute Neurology presence

Neurological Conditions utilising most Unscheduled Resource

Headache and epilepsy were the most common neurological reasons for unscheduled hospital admission, in combination accounting for 49% of long stay admissions.

Usage of the Regional Neuroscience Centre

Clinical triage was evident where inpatient beds were available –

- 47% of unscheduled neurological cases in RVH classified as definitely benefitting from neurology care were admitted under Neurology, compared with only 11% for those classified as possibly benefitting.
- 73% of long stay bed usage in the Regional Neuroscience Centre were for cases classified as definitely or probably benefitting from neurology care.

Inequity across NI

The level of neurology service available to unscheduled admissions was inconsistent across NI, with the percentage of admissions to each hospital type varying according to Trust of Residence.

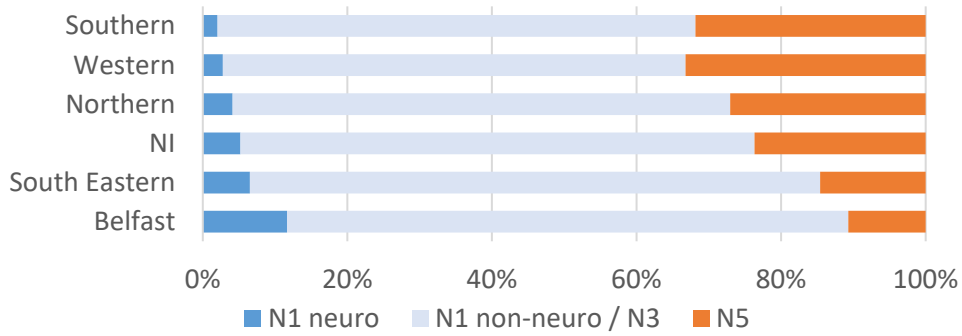


Figure 1: Breakdown of unscheduled admissions by level of Neurology care available. Belfast Trust residents had more access to the Regional Neurosciences Centre (N1 neuro) than other Trust residents. In contrast, residents of other Trusts, particularly Western and Southern, had a higher rate of admission to hospitals without any Neurology input (N5).

Additionally, beds in the Regional Neuroscience Centre were not used equally by residents of all Trusts.

BHSCT	NHSCT	SEHSCT	WHSCT	SHSCT
30%	29%	23%	9%	7%

Table 1: Breakdown of bed day usage in the Regional Neurosciences Centre by patient Trust of residence - Residents from Belfast and Northern Trusts occupied Neuroscience Centre beds more frequently than residents from other Trusts. Southern and Western Trust residents had the lowest usage.

Projected Neurology Inpatient Bed Requirements

Bed estimations below are based on an assumed bed occupancy rate of 83% and are presented as a range that depends on the desired range of activity to be covered. The lower limit covers only cases classified by GIRFT as definitely or probably benefitting from neurology care, while the upper limit covers the full current case mix for activity within the Neuroscience Centre or all GIRFT neurological cases for activity outside it. Detailed description of methods, admissions, sites and classification are included at Appendix 6.

Unscheduled activity

In 2018/19, there were 3,885 unscheduled long stay neurological admissions across NI accounting for 34,227 bed days.

Of these, 202 were under neurology in the Regional Neuroscience Centre, occupying 4,052 bed days. Although Belfast Trust residents appeared to have access to the Centre when clinically indicated, residents from other Trusts were admitted less frequently. If sufficient beds were available to allow all Trusts the same rate of bed day usage in the Neuroscience Centre as Belfast Trust residents, the unscheduled bed requirement would be 18 – 25 beds.

In addition, a total of 46 - 88 beds are required across all Trusts in NI to accommodate unscheduled long stay neurological patients who, while they require to be in hospital, do not need to be in the Regional Neurosciences Centre.

Elective activity

Complex neurological cases may require elective admission to the Regional Neuroscience Centre for investigation, diagnosis and treatment where outpatient investigation is less appropriate. Examples include inpatient Video EEG monitoring, assessment for intrathecal baclofen, PD assessment, complex management of those with conditions such as MND, and diagnostic assessment for rare/genetic or undiagnosed neurological conditions.

During 2018/19, there were 284 elective long stay admissions under neurology at the Regional Neuroscience Centre accounting for 2,050 bed days. However, similar to unscheduled activity, a higher bed day usage rate was observed for Belfast Trust residents than residents of other trusts.

For residents of all Trusts to have an equal rate of elective admission under neurology to Belfast Trust residents, 9-11 elective care inpatient beds are required.

It is also important to note that, while inpatient rehabilitation did not fall within the scope of the bed modelling exercise, in 2018/19 there were 477 admissions to Musgrave Park Hospital under neurology and 1,106 under Rehabilitation while there were 40 admissions to Thompson House Hospital.

Population Changes

The above bed requirement estimates are based on the level of long stay neurological inpatient activity observed in 2018/19. Between 2018 and 2040, the NI population is projected to increase by 3%. Additionally, it will age significantly, with the number of people aged 65 and over projected to increase by 53%. As some neurological conditions are age related, the ageing population is expected to disproportionately increase their prevalence by 2040.

In 2018/19, epilepsy, MS and parkinsonism were the conditions requiring the greatest access to inpatient beds. As an indicator of how population changes increase future inpatient demand, prevalence projections (outlined in Section 1) have been used to estimate neurology bed requirement increases for these conditions between 2018/19 and 2040.

Estimates are based on 83% bed occupancy and assume that bed usage per neurological condition will continue at a similar rate between 2018 and 2040. For the N1 Neurosciences Centre, provision for equitable bed access across all Trusts has been built into the estimations, as discussed above.

N1 Neurosciences Centre Beds – elective + unscheduled

GIRFT Condition Subgroup	2018/19 bed usage	2018/19 equitable bed provision	2040 equitable bed provision	Increased bed demand
Epilepsy, MS & PD	**6.6**	**10.4**	**14.3**	**3.9**

Unscheduled beds outside of N1 Neurosciences Centre if N1 expanded

GIRFT Condition Subgroup	2018/19 bed usage	2018/19 bed usage if N1 expanded	2040 beds if N1 expanded	Increased bed demand
Epilepsy, MS & PD	**20.1**	**18.2**	**25.2**	**7.0**

By 2040, projections suggest epilepsy, MS and movement disorders alone would require an extra 4 beds in the N1 Neurosciences Centre, bringing requirements up to at least 40 inpatient neurology beds. Future increased provision for all other neurological conditions in the Neurosciences Centre due to population changes would be additional to these 40 beds. Similarly, outside the N1 Neurosciences Centre, an extra 7 unscheduled beds would be needed to accommodate the projected increase in people with epilepsy, MS and movement disorders. Future increased provision for other conditions would be additional.

Community-Based Services

There is no central data source on services provided to support people with neurological conditions in the community. In order to identify future priorities, a Gaps and Constraints analysis of neurology services was undertaken by the Review's Long Term and Complex Conditions (LTCC) workstream. A wide range of areas were studied including headache, MS, epilepsy, PD, neuromuscular, FND, MND, HD and services provided by AHPs.

This analysis highlighted that access to support from various professions varies significantly from Trust to Trust and even within the same Trust and there is regional variation in access to some treatments.

While challenges have been identified across services which support people to live with their neurological conditions, and information on these will be shared with Commissioners, a number of priority areas have been identified:

- A need to develop Local Neurology Teams, with a focus on rehabilitation and symptom management;
- A need to address barriers currently preventing equitable access to mental health and neuropsychiatry services;
- A need for closer working between Trusts and the voluntary and community sector in the planning of services to ensure that the resources of both are better utilised;
- A need to consider ways to reduce restrictions in access to supporting services based on diagnosis.

A summary of the findings of the Gaps and Constraints analysis is attached at Appendix 7.

In addition to the Gaps and Constraints analysis, a Proof of Concept (PoC) Risk Stratification Project was undertaken by the Care Coordination workstream. The aim of the PoC was to establish if it was possible to join up different datasets to better understand levels of need and inform commissioning of services. Further information is provided at Appendix 8.

This approach successfully used existing data associated with people currently on a neurology waiting list such as ED attendances, admissions and prescribing data over the time period November 2018 and November 2022 to understand how they interact with the system and therefore determine how to plan resources to achieve the right level of care depending on their health and social care needs rather than the “one-way traffic” approach. An initial review of the data has provided the following insights:

- 1 in 4 patients on a neurology waiting list have also attended ED at least once;

- 1 in 3 patients on a neurology waiting list have also had an inpatient episode; and
- Average age of patient on a neurology waiting list is 48 and median age 50.

Further work will now be undertaken to build on this approach.

Workforce

Medical Workforce

Consultants

Our analysis of the current consultant workforce indicates that there are 25 consultant neurologists employed across all Trusts in NI, providing capacity of 25.3 WTE. A breakdown of this workforce is provided in the table below.

Trust	Belfast	South Eastern	Southern	Northern	Western	Total
Consultants	13	5	4	0	3	25

This analysis highlights a particular gap regarding capacity in the Northern Trust. In the context of this pressure, support is currently provided to the Northern Trust by Belfast Trust consultants to ensure a minimum of 0.5 WTE capacity within the Trust. Support is also provided by Belfast Trust consultants to the Southern Trust and Western Trust.

This is a significant shortfall compared with the recommended consultant workforce set out in the Public Health Agency Medical Workforce Planning Report for NI 2017-2024.

The Planning Report notes the ABN recommendation of 1 WTE consultant neurologist per 70,000 population as an absolute minimum which suggests a need for 27 WTE consultants in NI. However, the Report also notes the need for additional capacity to support acute and unscheduled care. In this context an overall requirement of 40-45 WTE is required to provide access to neurological assessment

for all patients admitted to hospital in Northern Ireland with a neurological problem, in line with ABN standards and a 5-day outpatient service.
In order to plan for consultant expansion we subsequently assessed the potential for the current trainees in the Neurology Training Programme to make up the shortfall. It is estimated that all 10 current trainees will complete their training by 2028, potentially adding 10 consultants to the workforce. However, when considering this potential additional capacity, several other factors have to be taken into account. Not all newly-qualifying consultants will choose to work in NI. In addition, in the context of the impact of Shape of Training, newly qualified neurology consultants could be expected to contribute to stroke and, in some cases, internal medicine on-call rotas, resulting in them being employed less than full-time in neurology.

The number of neurology training places increased from 11 to 13 in 2023. However, in previous years at least 2 training posts have remained unfilled. It is clear, therefore, that additional action is needed to grow interest in neurology to ensure that we maximise our training programme going forward.

Over the same period, we also anticipate a number of potential retirements among the current workforce. Taken together, while there is potential to grow the workforce, the net impact of expected developments will fall considerably short of the recommended level of 40-45 WTE consultants in the short term.

Neurophysiology

Access to neurophysiology services is an important part of delivering high-quality neurology care to patients with acute neurological disorders. Guidance from the Royal College of Physicians (RCP) and the ABN recommends that all sites with neurology inpatients should have local access to neurophysiology, something that is far from the case in NI. A neurophysiology workforce of 1 WTE per 300,000 population is recommended to provide access to standard neurophysiological services. More advanced techniques including the provision of specialist EEG and neuromuscular services, including ambulatory-EEG and inpatient video-telemetry and EMG guided treatment of dystonia and spasticity and intra-operative monitoring require additional investment. In NI funding is available for four posts. However,

there is presently only 1 filled permanent Consultant Neurophysiologist with the service being reliant on locum cover for additional capacity, which is not a sustainable position going forward.

At present, those sites without access to Neurophysiology will either have to manage their patients requiring neurophysiological assessment either less than optimally or by arranging for transfer for investigations. Requiring a transfer acts as a significant barrier for access, particularly for the sickest patients and those in intensive care. The use of technology, including remote reporting of Electroencephalograms (EEGs), home video telemetry services and improved access to prolonged EEG can provide alternative pathways for those hospitals without an onsite Neurophysiologist.

In this context, it is recommended that an additional 2 WTE neurophysiologists are required as a minimum to ensure timely access to neurophysiology services across all Trust areas and that Trusts take all steps possible to minimise unfilled positions.

Neuroradiology

Equitable access to neuroradiology services is important in ensuring an early diagnosis and implementation of the best treatment at the earliest possible time.

Currently there are eight neuroradiologists in NI, although not all are WTE. All are based in the Belfast Trust. While there is a formal link between the Belfast Trust and the Western Trust, this only occurs once a month. Additionally, there are general neuroradiologists, based in a number of hospitals who have an interest in neuroradiology.

Access to specialist neuro-radiological input therefore falls short of what has been recommended in GIRFT which recommends that all sites should have access to a Neuroradiology MDT, either in person or virtually. As increasing demands are placed on neuroradiology in other areas, notably the expansion of thrombectomy for stroke patients, the service, which is critical to an efficient neurology service, is likely to come under even greater pressure.

In this context, consideration needs to be given to increasing the number of neuroradiology trainees. Consideration should also be given for radiologists, with an interest in neuroradiology, but not based in the Neurosciences Centre being involved in regional work and specialist MDMs as well as local MDMs. Digital solutions such as imaging networks whereby access to images and diagnostics can be provided virtually should also be enhanced.

Neuropathology

Access to neuropathological assessment is important in the definitive diagnosis of a wide range of neurological diseases including many inflammatory and degenerative diseases of the central and peripheral nervous system and muscle. Neuropathology provides information on prognosis and guides patient management which often cannot be obtained by other methods. This information assists neurologists in the provision of advice and effective treatment to enhance the quality of life for people with neurological conditions. Neuropathology will usually be provided in tertiary referral centres, where neurosurgical and neurology services are also provided.

The Royal College of Pathologists Code of Practice for Histopathology Services has recommended that there should be one full-time equivalent neuropathologist per 1,000,000 population, to achieve adequate neuropathology cover. A workforce of 2 WTE neuropathologists is needed for the population of NI.
Currently, there is 1 WTE substantive consultant neuropathologist based at the Royal Hospital in Belfast, providing a regional service. The service is currently reliant on locum cover for additional capacity which is not a sustainable position going forward.

Training in neuropathology is currently in a vulnerable position due to the capacity of the limited workforce to deliver training. In this context, consideration needs to be given to ensuring that the neuropathology training programme is secured in NI going forward to ensure the sustainability of the workforce in future years.

Nursing Workforce

As part of the work of the Neurology Review, a Nursing Workforce Review was undertaken. The Workforce Review included an assessment of the recommended staffing levels needed to support people with neurological conditions. In the context of this assessment, the review identified a need for a neurology nursing workforce of 96 WTE to support the delivery of neurology services in Northern Ireland by 2028 which compares with a current workforce of 55 WTE. In addition to overall workforce numbers, the Workforce Review also identified the potential to develop and maximise the role of nursing within neurology, with the development of Advanced Nurse Practitioner (ANP) roles.

To support the development of advanced roles, a career pathway has also been developed using the NI Practice and Education Council (NIPEC) Guidance Framework. The Pathway identifies a range of key nursing roles that support the delivery of high quality, safe, effective, person-centred care. The Pathway also sets out the competencies, education requirements and job descriptions for these roles. This pathway will enable a standardised approach to development and will support nurses in taking on a range of extended roles

The Workforce Review also identifies challenges in respect of sustainability of services, with some services dependent on individual members of the nursing workforce which are then vulnerable to unplanned absence, resulting in no service being available to patients with a particular neurological condition.
To address these pressures, the Workforce Review also makes a recommendation for the establishment of a neurology nursing team in each HSC Trust.

Further information on the Workforce Review and supporting Career Pathway is outlined at Appendix 9.

AHP Workforce

As part of the Neurology Review, an analysis of the current workforce was undertaken. This indicated a total commissioned permanent staff working as neurology AHPs in NI of 36.34 WTE broken down by Profession below.

Profession	Hospital-Based WTE	Community-Based WTE	Total WTE
Physiotherapist	8.54	10.85	19.39
OT	8.5	1.0	9.5
Dietitian	3.15	1.5	4.65
SLT	2.7	0	2.7
Orthoptics	0.1	0	0.1

Within these overall figures it is important to note that there are significant gaps within Trusts. For example, our analysis indicates there are no neurology physiotherapists or occupational therapists in the Southern Trust, no neurology speech and language therapists in the Northern or Southern Trust and no orthoptics in the Belfast, Northern, South Eastern or Western Trusts.

In addition, the analysis identifies a number of constraints within the neurology AHP service. The majority of posts are hospital-based with a small number (13.35 WTE) based in outpatient, community and specialist services. In addition, variance in provision and pathways across Trusts was identified along with challenges regarding multiple referral sources; repatriation from regional centres; training needs of core staff; and limited specialist AHP neurology staff.

This analysis indicates that AHPs are underutilised within neurology outpatient services across NI. However, models have been introduced in other specialties where AHPs, working within a MDT can support specialist service outpatient clinics to increase capacity. Examples include orthopaedics where an enhanced MDT has delivered assessment clinics for new and review patients.

In this context, a significant increase in the AHP workforce is recommended to support multi-disciplinary working and to create much needed additional community

capacity. Following a review of the British Society of Rehabilitation Medicine guidelines, it is recommended that an additional 38 WTE neurology AHPs across the four core professions (Physiotherapy, OT, Dietitian, SLT) are required as a minimum to support multi-disciplinary working and create additional community capacity.
In addition, further consideration will be required in future workforce planning to ensure access to other AHP professions which provide support and interventions to patients with neurological conditions e.g. Orthoptists, Podiatry, Arts Therapies. Growth in the AHP workforce should be underpinned by a skill mix of generic and advanced practice roles, including the development of consultant AHP roles.

Further information on the AHP Workforce Review is outlined at Appendix 10.

Psychology

Psychological services play an important role in delivering clinically effective neurological care, helping to deliver better outcomes and cost effectiveness. The importance of commissioning a good neuropsychology service across the wide range of neurological conditions is clearly evidenced in commissioning guidelines, Condition-specific NICE guidelines and NHS Service Frameworks as well as a growing research evidence base. Current staffing and access to psychological and neuropsychological services in Northern Ireland for neurology patients is extremely limited, with services provided solely from within the Adult Acute Neuropsychology Services Team based in the Neurosciences Centre in the Belfast Trust. In addition, there is no community level access to psychology services in any Trust area in NI and there is currently no commissioned psychology service for FND in NI.

Further information on Psychology Workforce is outlined at Appendix 11.

Neuropsychiatry

There is a need to develop Specialist Neuropsychiatric services in Northern Ireland and it should be an integral part of the Regional Neuroscience Service. This would include bringing the workforce in neuropsychiatry to nationally acceptable levels. It would also necessitate an increase in both consultant posts and the development and funding of training opportunities in the area of neuropsychiatry. Based on

evidence nationally and insight from local HSC Trusts, it is recommended that a team should consist of consultant neuropsychiatrist, psychology, speech and language, occupational therapy and nursing input. A neuropsychiatry workforce of 2 WTE consultants in neuropsychiatry per million population is recommended. In this context, 4 WTE consultants would be required for Northern Ireland. This is in addition to the resources required to address the needs of patients in acquired brain injury services.

Neuropharmacy

Critical and complex medicines are key treatments in many of the most prevalent conditions such as epilepsy, Parkinson's and MS. Pharmacists have a well-defined expert role in the medicines management of complex patients and can also offer support to other multi professional team members working in neurology services. When pharmacists are members of the multi professional teams, published evidence shows a reduction in medication errors and improved outcomes for patients by individualisation of patients' medications and cost reduction by optimisation of medicines.

Currently there are some pharmacists and pharmacy technicians working with neurology specialities within the interface specialist medicine teams but these teams are beyond capacity. In this context there is a need to develop additional capacity to support the Regional Neurosciences Centre and across Trusts.

Additional capacity would facilitate increased support for dedicated Neurology Teams as well as out-reach to Emergency Departments and Outpatients. It would also provide capacity to support GP practises in the safe, long-term management of conditions managed with complex medicines. This is particularly relevant for the safe prescription of sodium valproate (used for the treatment of epilepsy and certain psychiatric and other neurological disorders) in women and men of childbearing age. Pharmacists working with neurologists and other clinicians and specialist nurses can contribute to the safe and effective implementation of regulatory requirements.

Further information on Pharmacy Workforce is outlined at Appendix 12.

Care of the Elderly/Psychiatry of Old Age

The prevalence of many neurological conditions increase significantly with age. For conditions such as dementia and Parkinson's disease, it is important to recognise the role of care of the elderly and psychiatry of old age physicians with a special interest in neurological conditions. These physicians are often well placed to be involved in the management of such patients. It is important therefore to ensure good links between neurology, care of the elderly and psychiatry of old age services.

Primary Care

Patients rely on primary care services to assess, investigate and treat wherever possible. Where diagnosis is less clear or symptoms are of a type and severity that specialist neurological assessment is required, a referral for an Outpatients appointment will be arranged.

Research undertaken by the Neurological Alliance suggests this can be a lengthy process and involves multiple visits to a GP before receiving referral to a specialist.[21] Throughout the Review, the need to provide adequate support to primary care, through increased awareness and training has been identified.

Wider developments

Our Review has also been informed by wider developments in NI which have important implications for neurology services here and by consideration of developments across the UK and Ireland. These are summarised below.

Developments in NI

Independent Neurology Inquiry

The Independent Neurology Inquiry (INI), established by the Permanent Secretary of the Department of Health in May 2018, was one of a series of actions in response to the recall of Neurology patients by the Belfast Health and Social Care Trust in

[21] 2016-08-neuro-and-primary-care.pdf (neural.org.uk)

2018. The Inquiry was converted in December 2020 from a non-statutory inquiry to a statutory inquiry.

The INI Report[22] was published on 21 June 2022 and includes a total of 76 recommendations with an overarching principle to enhance patient safety, directed towards the Department of Health, Healthcare Organisations, the General Medical Council (GMC) and Independent Healthcare Providers.

An overarching INI Implementation Plan was published on 27 July 2023 followed by an Action Plan in March 2024. Work on implementation of the Inquiry's recommendations is ongoing. Further information is available on the Department's website at https://www.health-ni.gov.uk/topics/independent-neurology-inquiry-ini .

Rare Diseases Action Plan

The Northern Ireland Rare Diseases Action Plan was published in March 2022. The Action Plan sets out 14 high-level actions that have the potential to help more people with a rare disease benefit from better co-ordination of care, improved access to clinical trials and research, increased education and training, and collaboration among specialist teams across these islands.

The Northern Ireland Rare Diseases Action Plan is now in its fourth year of operation and good progress is continuing. A Year 3 Progress Report, setting out implementation progress across the Action Plan in 2024/25, is currently being developed and will be published in due course.

Further information on the Action Plan and progress to date is available on the Department's website at: https://www.health-ni.gov.uk/publications/northern-ireland-rare-diseases-action-plan-202223-and-reports

[22] Independent Neurology Inquiry

Reform of Stroke Services

The Department published the Reshaping Stroke Care Action Plan[23] on 20th June 2022. The Action Plan sets out six priority areas, including the establishment of a new process to identify a preferred option for the establishment of Hyperacute Stroke Care in NI.

It will be essential to align future neurology services for unscheduled patients with any future reconfiguration of stroke services to ensure that services can be maintained efficiently. In addition, the new Shape of Training Curriculum for neurology trainees was introduced in August 2022. The new 5-year training programme contains 18 months training in Stroke and General Internal Medicine. This will impact on the future neurology consultant workforce numbers, as newly qualified neurology consultants will take part in stroke and, in some cases, internal medicine on-call rotas, resulting in them being employed less than fulltime in neurology.

Developments across the UK and Ireland

Scotland

The Scottish Government published 'Neurological Care and Support in Scotland: A Framework for Action 2020-2025[24]' in December 2019. To date, 35 projects have been funded to improve the delivery of the care and support to people with neurological conditions. These meet many of the 17 Commitments made in the Framework, including development of information resources for patients, carers and clinicians, improved co-ordination of care and delivery of joined up care, local collaborative improvement and use of digital technology to improve patient access to services. National work has also been undertaken to improve care pathways and workforce training and capacity building.

A self-evaluation tool developed by Healthcare Improvement Scotland will now be used by services, in partnership with people with neurological conditions, to assess how the General Standards for Neurological Care and Support are being delivered at

[23] doh-Stroke Action Plan June 2022.PDF (health-ni.gov.uk)
[24] Neurological care and support: framework for action 2020-2025 - gov.scot (www.gov.scot)

a local level. The Scottish Government will support this by facilitating improvement networks which will provide an opportunity to spread and adopt effective approaches, including the work delivered through funded projects.

England

NHS England (NHSE) has established the Neuroscience Transformation Programme, a multi-year, clinically led programme aimed at improving specialised adult neuroscience services in England and developing a new model of integrated care for neurology services.

The Neuroscience Transformation Programme seeks to support emerging regional teams in addition to Integrated Care Systems in the NHS, through establishing 'what good looks like' for specialised neuroscience services for a local population, and providing data and commissioning tools to support local systems to commission integrated whole pathway neurological care. Responsibility for the commissioning of specialist neuroscience services for adults and children has been delegated to Integrated Care Boards since April 2023. Integrating the commissioning of neuroscience services with ICBs allows local systems to simplify and strengthen care pathways with other services through effective local partnerships, ensuring continuity for patients and improved health outcomes.

Wales

A Quality Statement for Neurological Conditions was published by the Welsh Government on 30 November 2022, with a 3-year plan to identify and prioritise service developments to be led by a Neurological Conditions Implementation Group (NCIG). The NCIG has identified four priorities:

- Develop a nationally agreed model for delivering neurology services;
- Deliver Bevan Commission Planned Care Project – improving the experience of neurological symptoms to a diagnosis;
- Oversee the development of equitable pathways for people who require neurorehabilitation; and
- Develop appropriate local, regional and national options for psychological support for people living with neurological conditions.

A Neurological Conditions Strategic Clinical Network was established in October 2023 to take forward and develop the work of the Neurological Conditions Implementation Group.

Republic of Ireland

The Health Service Executive National Clinical Programme for Neurology aims to provide patients with equitable access to a high-quality responsive service which provides accurate diagnosis and appropriate management for all neurological conditions. The Programme aims for excellence in neurology care and the best outcome for patients.

The overarching goal of the National Clinical Programme is to improve safety and quality in the delivery of patient centred care, improve access to appropriate services and improve cost effectiveness of services delivered.

In order to meet these objectives the Neurology programme identifies themes and associated recommendations in a number of areas, including:

- Optimising service delivery and multidisciplinary care;
- Staffing and resourcing within Neurology;
- Service configuration and managed clinical networks;
- Medicines management and access to diagnostics; and
- Research and Programme metrics.

SECTION 4: PRIORITY ACTIONS

In the context of the Vision set out in section 2 of this report and the analysis of current services set out in section 3, four priorities for improvement have been identified:

- Priority One: A person-centred service;
- Priority Two: Developing additional workforce capacity within Neurology;
- Priority Three: Addressing gaps in current services; and
- Priority Four: Using current resources more effectively.

It will be critical to ensure that the priorities are progressed in parallel to ensure a joined-up approach to improvement.

Priority One: A person-centred service

Patients with neurological conditions and their families should be at the centre of their care.

Typically, patients spend just a few hours each year in contact with health care services and are self-managing their conditions most of the time. The availability of information and advice via interactive tools such as Patient Portals alongside resources available from the voluntary sector as well as health care providers are important to support self-care.

For those with more complex needs, the effective support and care of people living with a neurological condition requires the expertise of many different professionals working in medical, nursing, mental health, social care and the allied health professions. Many people living with a neurological condition also benefit from the support offered by relevant community and voluntary organisations.

The Review has agreed that the House of Care model[25] should be adopted in neurology. This model, used in NHS England and internationally, has been shown to improve physical health, depression, confidence and self-efficacy.

[25] Delivering better services for people with long-term conditions | The King's Fund (kingsfund.org.uk)

The House of Care approach puts the patient at the centre of their care and provides the framework for local teams to redesign the way they work using Care Support and Planning. At the centre of this approach are care conversations between two experts: the patient who is expert in their own lives and the Health Care Professional as the expert in the condition and its management.

Recommendations

1a) Person centred care must be the focus of all patient-healthcare interactions for those with neurological conditions.

1b) Patients and their carers/families should be clear about their care and available supports, including the use of Patient Portals.

1c) Patients must have a designated point of contact as part of an effective care delivery network.

Priority Two: Developing Additional Workforce Capacity within Neurology

The availability of a suitably skilled and resourced workforce is a fundamental requirement for neurology services. Our analysis has identified significant gaps in the neurology workforce, often exacerbated by difficulties in filling posts as they become vacant. Going forward, it is essential that additional capacity is directed to support services that are particularly vulnerable and under resourced such as MND and neuromuscular services to ensure that patients have appropriate access to the services they need to manage their condition.

While there is undoubtedly a need to increase capacity, it is also important to recognise the position outlined in Delivering Together that recruiting additional staff – where possible – to prop up models of care which in some cases are outdated, is not the answer. The development of the right skill mix among the workforce to support people with neurological conditions in the right way in the right place must be at the centre of our approach to workforce development.

It is also important to recognise, however, that developing new roles and increasing capacity in some elements of the workforce will have implications for other areas of the workforce, for example the requirement for access to other services such as neurophysiology and neuroradiology and this will have to be kept under review.

We need to significantly increase the current medical workforce to meet current and projected demand. In order to achieve this, we need to consider ways to make neurology an attractive specialty for future local recruitment to ensure that those trainees who qualify as neurology consultants remain in NI and strengthen the workforce.

We also need to increase exposure for medical trainees at the earlier stages of their training to improve confidence in neurology as a specialty and increase the likelihood of medical students or junior doctors choosing to apply to the neurology training programme. An example of how exposure to neurology is being increased is an initiative in the South Eastern Trust which offers Internal Medicine Trainees (IMTs) a 6 month rotation into neurology.

This initiative provides the opportunity for an increased number of IMT trainees to gain experience in neurology and develop their understanding of the specialty. The experience at the South Eastern Trust indicates that increased exposure to neurology at IMT training tier is likely to lead to more applications for the Neurology Specialist Registrar (StR) training programme.

The development of research capacity also has a key role in attracting talent and expertise to neurology, inspiring and nurturing clinicians and scientists and stimulating growth and professional expertise in the specialty. Given pressures within the current workforce, it is recommended that further work is undertaken to explore these requirements with a view to developing the necessary research capacity as overall workforce capacity is increased.

Neurology services rely heavily on the skills and experience of linked specialties including neurophysiology, neuroradiology, neuropathology, neuropsychiatry and neuropharmacy. Access to this workforce is critical and capacity needs to be increased in parallel with development of the consultant workforce.

While this report has identified a need for growth based on the current workforce, it is critical that workforce levels are sustained in the medium and longer term. In this context, it is recommended that a Neurology Training Action Plan is developed. This should include consideration of approaches within other specialties to increase interest in training programmes. The Department will work with the Northern Ireland Medical and Dental Association (NIMDTA) to take this forward.

Neurology nurses play an important role in the care of neurology patients throughout the lifetime of their condition providing holistic assessment, establishing long-lasting relationships and, in some cases, acting as a designated point of contact. A critical part of the nurse's role is providing clinical advice and support through telephone triage and helplines. The Neurology Nursing Workforce Model and Career Pathway, developed as part of this Review, recommends that the nursing workforce needs to increase by 41 WTE in order to meet the growing needs of the population by 2028 increasing to 47 by 2035.

In addition, the model proposes investment in new and higher levels of practice including the introduction of the Advanced Nurse Practitioner (ANP) role to create development opportunities for some experienced neurology nurses. The role of the ANP has already been introduced in NI, with the first candidate in the South Eastern Trust completing their training in September 2023. The creation of Neurology Nursing Teams within each Trust is also recommended to improve the cohesion and professional support for neurology nurses, address challenges and capacity issues and reduce the risk of service disruption through unplanned absence of neurology specialist roles. As Neurology Nursing Teams are developed, consideration will also be given to the potential development of consultant neurology nurse roles.

Allied Health Professionals (AHPs) are an essential part of the Multi-Disciplinary Team (MDT) providing inpatient care to neurology patients either via the emergency department, general core AHP teams or within specialist neurology teams. An initial review of the existing inpatient AHP workforce highlights the need to increase AHP numbers for inpatient services to meet current and future demands. In addition, the review also identified a very small complement of commissioned AHP services across the region for the provision of specialist neurology care and rehabilitation in the community.

In order to support multi-disciplinary working and to create much needed additional community capacity, it is recommended that an additional 38 WTE Neurology AHPs are required as a minimum to support multi-disciplinary working and to create much needed additional community capacity. Further work will be needed to identify the additional AHP capacity to support inpatient care. In addition, it is recommended that AHP roles within the workforce should be developed, with an appropriate skill mix of AHP staff within MDTs including newly qualified, specialist and advanced practitioners. Consideration of the introduction of consultant AHP roles is also recommended. The Career Pathway for the development of AHP advanced practitioners is set out in the DoH Advanced AHP Practice Framework.[26] This defines the core competencies required for advanced AHP practice.

[26] https://www.health-ni.gov.uk/publications/advanced-ahp-practice-framework

The education and training required to underpin the successful development of advanced practice AHP roles across neurology services needs to be identified, resourced and developed.

For most people with a neurological condition, primary care is a critical part of the pathway. GPs will diagnose and manage the majority of headache and migraine, the most common neurological presentation to primary care. A small proportion will be referred on. Onward referral is usually required for diagnosis and management of other neurological conditions, like epilepsy, Parkinson's disease and MS which present less frequently, but not uncommonly. GPs will share long-term management of these conditions. There is a need to provide stronger support for GPs, through methods such as Advice and Guidance, to identify when a referral is required for specialist investigation of neurological symptoms, also avoiding delays in referral or treatment of potentially serious or treatable neurological conditions. The development of comprehensive referral guidance in line with NICE guidelines will be important in ensuring that patients who require an outpatient appointment are seen within the appropriate timescales. Guidance could also be incorporated within the referral window to prompt GP referrers on the appropriate actions required in the management and referral of common presentations.

It is important to recognise that workforce development is not just about increasing overall numbers. While this is essential in terms of increasing the capacity required to meet the needs of the population, it is also about supporting, developing and expanding roles to ensure that people with neurological conditions receive the care and support they need. In this context, focusing attention on neurology training for Specialty and Specialist Doctor (SAS) roles could assist the expansion of the neurology workforce. SAS doctor posts usually focus on providing direct patient care both in routine and emergency settings. SAS doctors are also often involved in teaching, service development, research and management. The Southern Trust currently have three SAS doctors in general medicine who contribute to neurology one day per week to cover ward duties and day case procedures. Trusts should give consideration to how these roles could assist in creating capacity in the consultant workforce through the management of neurology patients in appropriate settings.

The Review has also identified the potential to build on the contribution of GPs within neurology. There are currently four GPs with Enhanced Roles working within neurology based in secondary care, with scope both to grow this number and to develop new primary-care based GPERs in the medium term.

Empowering GPs to develop Enhanced Roles can be achieved through expertise shared using Advice and Guidance or from collaborative educational programmes such as the tele-mentoring platform Project ECHO. Project ECHO, an online learning and support mechanism encourages sharing of specialist knowledge and best practice to create a community of practice across both professional boundaries and across acute and community settings. Preparatory work to establish a pilot Project ECHO platform for Neurology in NI has been completed, work is ongoing to identify a clinical lead to take this forward. GPs with Enhanced Roles could deliver intermediate care for common conditions prior to or instead of a consultant led hospital outpatient clinic.

In addition, the development of the Advanced Nurse Practitioner (ANP), specialist neurology nursing and advanced practice AHP roles are key to ensuring that patients are seen by the right person at the right time and in the right place, reducing lengthy waiting lists and increasing the capacity of the consultant workforce.

There is also a clear need to expand Psychology capacity within neurology. In line with national guidelines and best practice, it is recommended that 7 additional psychologists are needed within the team at the Regional Neurosciences Centre to ensure equitable service provision. In addition, hospital based local neurology services should include a minimum of 1 WTE consultant psychologist, 1 WTE specialist psychologist and 1 WTE associate psychologist per Trust area to ensure equitable access to specialist psychological care for people living with progressive and intermittent neurological conditions.

As outlined in the table below, Northern Ireland currently has the lowest number of Psychology training places per head of population.

Nation	Population figures (ONS est. 2021)	Places 2022 Entry	Training places per 100,000 population
Scotland	5,517,000	83	1.50
England	56,233,000	1065	1.89
Wales	3,170,000	36	1.13
N. Ireland	1,900,000	21	1.11

In order to support the growth in the workforce recommended in this report, and in the context of wider pressures emerging from additional service reviews and developments, it will be important to keep the number of available training places under review.

In this context and in light of the challenges and constraints our analysis has shown, we recommend that the following workforce programme should be taken forward. Failure to implement these recommendations will see waiting lists grow even further, adding further pressure to an already under resourced workforce and restricting improvements in services.

Recommendations

Medical workforce

2a) A regional approach to workforce management is required to support the growth of the neurology consultant workforce to 45 WTE. This should include increased exposure to neurology at early and middle grade level training and the development of research posts within neurology.

2b) Two additional WTE neurophysiologist posts are required to increase the workforce to six posts in line with guidance. This will ensure timely access to Neurophysiology services across all Trust areas.

2c) Timely access to neuroradiology must be available across all Trust areas.

2d) An additional WTE neuropathologist post is required to increase the workforce to two in line with guidance. Consideration needs to be given to the sustainability of the training programme to facilitate this.

2e) An Action Plan is urgently required to expand and sustain the Training Programmes within the neurology specialty.

2f) Trusts should consider the expansion of Specialty and Specialist Doctor (SAS) roles to create capacity in the neurology medical workforce.

2g) GPs with Enhanced Roles should be developed in neurology through the provision of Fellowships or Integrated Training Posts.

Nursing Workforce

2h) An additional 41 neurology nurses are required by 2028 increasing to 47 by 2035, including 12 ANP trainee posts.

2i) A Neurology Nursing Team should be established in each Trust area.

AHP Workforce

2j) An additional 38 WTE Neurology AHPs are required to support multi-disciplinary working and to create additional community capacity across the four core professions (physiotherapy, OT, dietitian, SLT). Future workforce planning will ensure access to other AHP professions such as orthoptists, podiatry, arts therapies. Growth in the AHP workforce should be underpinned by a skill mix of generic and advanced practice roles, including the development of consultant AHP roles

Psychology workforce

2k) Seven additional psychologists are needed within the team at the Regional Neurosciences Centre to ensure equitable service provision. In addition, the establishment of hospital based local neurology services requires a minimum of 1 WTE consultant psychologist, 1 WTE specialist psychologist and 1 WTE associate psychologist per Trust area.

Psychiatry workforce

2l) Four WTE consultants in neuropsychiatry are required as a minimum to meet current levels of need within neurology.

Pharmacy workforce

2m) Neuropharmacy capacity needs to be developed both at the Neurosciences Centre and across Trusts. In the immediate term, an additional nine pharmacists, two pharmacy technicians and one consultant pharmacist are required to meet demand.

Priority Three: Addressing gaps in current services

As additional capacity becomes available, we need to ensure it is directed to the areas of greatest need in order to improve equity of access across NI. The development of condition-specific pathways can underpin this by driving an equitable, joined-up approach to service delivery across NI.

Regarding inpatient services, our first priority is to ensure that patients admitted as a neurological emergency have access to a specialist assessment from a Neurologist. Accessing neurological expertise for the care of patients with acute neurological disorders results in benefits for patient care. These include improved diagnostic accuracy, provision of patient appropriate and disease specific treatment, reduced length of hospital stay, improved outcomes and improved patient satisfaction. Analysis conducted as part of this Review has identified that 23% of unscheduled neurological admissions in NI were to hospitals without a neurology presence. In addition, the case mix in terms of those patients who would likely benefit from expert neurology care is similar across all hospital sites. This analysis provides a clear indication that there is considerable scope for improvement in this area to ensure equitable access to specialist neurology opinion across the region. It is important to note that currently, where patients do access input from a neurology specialist, that activity is not routinely recorded or measured by Health Trusts, and this activity has not been formally commissioned.

We also need to ensure that our neurology inpatient beds are sufficient to meet the needs of the population and support equitable access to inpatient beds. It is also critical that we have the relevant staffing to support those beds. We have estimated this demand based on 2018/19 activity and, while there is potential for service developments to reduce this demand, we are also cognisant that this could be counterbalanced by demands arising from an ageing population.

Going forward we need to ensure that outpatient resources are appropriately organised. The broad range of neurological conditions will be managed in General Neurology Clinics, with Specialist Clinics available where required to meet the needs of the population. For the most common conditions, including epilepsy and MS, this should mean a specialist clinic in each Trust area.

Regional Specialist Clinics will be required for less common neurological conditions. These should oversee the use and implementation of novel treatments, as well as providing assessment for epilepsy surgery and advanced treatments for Parkinson's disease. Specialist Clinics will also provide specialist treatments such as; immunotherapies for multiple sclerosis and other immunologically mediated conditions; interventions for spasticity, dystonia or complex neuro-disability; the treatment of neuromuscular disorders and motor neurone disease; and botulinum toxin in chronic migraine and management of complex headache disorders (IIH/SIH/RCVS). These clinics should have formal multi-disciplinary links with colleagues in neurosurgery, neuroradiology, psychiatry, learning disability, old-age psychiatry, care of the elderly, stroke, psychology and chronic pain. They should also offer access to clinical trials and research studies.

We also need to develop the needs of those transitioning between services, in particular from paediatric to adult services. Effective transition of care is the planned, coordinated movement from a child and family environment of paediatrics to a patient-centred adult care setting. Transition from children's to adults' services should be individually tailored to the young person's needs. All Trusts should ensure that the paediatric and adult neurology multidisciplinary teams can jointly review the individual transitioning from paediatric to adult care, at a time appropriate to the individual's needs, taking a person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their care.

Effective management of some neurological conditions such as FND are particularly reliant on services which sit outside of neurology specialty including psychology, physiotherapy, mental health services and pain management services. During the course of the Review, we have identified barriers to accessing these services for patients with FND in particular. We need to be cognisant going forward that all Trusts ensure that patients living with FND are able to access the appropriate services to help manage their condition.

There is considerable scope to develop a Multi-Disciplinary approach to supporting people with neurological conditions in the community. To this end, a specification for Local Neurology Teams should be developed and implemented across Trusts.

The Review has developed condition-specific pathways relevant for NI for a broad range of neurological conditions. These have been informed by nationally recognised standards and by a review of best practice pathways developed by the National Neurosciences Advisory Group[27]. The Review considers that these are central to driving improvements in care and improving equity in accessing services across NI. The next step in the completion of these pathways is to engage with service users, carers and members of the neurology workforce alongside an assessment of the actions needed to enable the pathways to be implemented.

Further information on work undertaken in the development of the pathways is available at Appendix 4.

If the neurology workforce develops in line with the recommendations in this report, there will be opportunities to improve equity by developing services such as epilepsy surgery which are not currently available in NI. It is recognised, however, that due to the rarity of some neurological conditions and the relatively small population of Northern Ireland, it is not possible to provide access to all treatments in NI, and there will be an ongoing requirement to maintain close links with supra-regional services in Great Britain via the Extra Contractual Referral process.

Regardless of approach – local development or access to services in GB – the fundamental recommendation of this Review is that people living with neurological conditions in NI should be able to access treatments in line with those available elsewhere in GB.

[27] https://www.nnag.org.uk/optimum-clinical-pathways

Recommendations

3a) Access to specialist neurology opinion must be available at all acute hospitals receiving unscheduled admissions in line with ABN Standards. Trusts must identify the measures required to achieve the Standard. Options such as tele-neurology should be considered as an interim measure.

3b) Neurology inpatient beds must be managed as a regional resource and protected against non-neurology unscheduled care bed pressures. Capacity at the Neurosciences Centre should be doubled from 18 to 36 beds supported by a proportionate increase in the workforce to provide an equitable regional service. Variation in care based on Trust of Residence must be addressed.

3c) General Neurology Clinics, alongside Specialist Clinics for the most common conditions including epilepsy and MS, must be available in each Trust area. Regional Specialist Clinics must be further developed for less common conditions and to support complex interventions and treatments.

3d) Condition-specific pathways based on accepted best practice must be finalized within the first two years of implementation. Progress towards the delivery of the pathways and accompanying standards should be a key metric during the implementation of the review.

3e) A service specification for local neurology services focused on rehabilitation and symptom management is required. Local Neurology Teams must then be established in each Trust.

3f) Trusts must ensure that barriers to accessing general mental health services for neurology patients, regardless of diagnosis are addressed.

3g) The commissioning of highly specialised services should be aligned to NHS England commissioning decisions to ensure patients in NI have equitable access to highly specialised services.

Priority Four: Using Current Resources More Effectively

While the need to increase capacity within neurology services is clear, we have also identified a number of opportunities to make better use of current resources by ensuring that existing services and resources are targeted more effectively to meet needs. In many cases this is about applying learning and best practice across local Trusts as well as aligning future service developments with the standards and principles established by bodies such as the ABN and GIRFT.

Regarding inpatient services, there is potential to develop services which provide timely assessment and avoid unnecessary hospital admissions. Accessing timely neurological expertise for the care of patients with acute neurological disorders through Rapid Access Neurology Clinics (RANCs) or a similar pathway to urgent assessment results in benefits for the care of some patients as an alternative to hospital admission. A RANC exists in the Belfast Trust on the Royal Victoria Hospital site. A study carried out on the RANC service suggested that provision of this type of service can reduce unnecessary hospital admissions, improve the quality of patient care and lower costs. Due to staffing variation across NI, a dedicated RANC is unlikely to be feasible at each acute hospital site. The provision of dedicated slots at General Neurology Clinics at other sites is a pragmatic means of providing urgent opinion for those who may not require hospital admission.

In addition to appropriate access to a RANC for those people who do not require admission to hospital, for those people who are admitted, access to specialist neurology opinion is important in managing their ongoing care. Evidence would suggest that when patients who are admitted to hospital with a neurological condition receive the appropriate input from a member of the neurology team, their length of stay can be significantly reduced. A study carried out by the Neurology Team in the Southern Trust identified that, on average, bed days were reduced by 1 bed day for every patient who received input from the neurology team.

The effective management of referrals from primary care for outpatient appointments such as the South Eastern Trust's Neurology Advanced Referral Management System (NARMS) and consideration of better ways of managing patients through advice and guidance such as the Southern Trust's Non-Contact Specialist Advice (NCSA) service enables better targeting of outpatient resources.

Reviewing a person's needs throughout the lifetime of their condition is also a key step in the provision of effective care. The point at which reviews should occur should be informed by a person's condition and circumstances. Consideration should be given to how we could monitor 'stable' patients without the need for traditional reviews. For example, by using a patient reported outcome measure (PROMs) tool, there is the potential to develop artificial intelligence solutions as an alternative to routine consultant reviews. This would enable patients to have more control over management of their condition, including Patient Initiated Follow-ups with the aim of ensuring that capacity within the hospital setting can be used to its maximum efficiency. There is evidence to support the use of PROMs amongst epilepsy patients[28], a condition that traditionally generates a high rate of patient reviews. The potential of technology to improve frequency and access to review where clinically appropriate for epilepsy patients has been demonstrated. There are many examples of the successful use of this approach, including Nottingham[29], Manchester and in Wales[30].

More broadly, developing our understanding of how people with neurological conditions access current services will provide insight into how we develop our services to better meet patient needs. The risk stratification approach undertaken as part of this Review has already identified important links between those patients waiting to be seen on an outpatient waiting list, ED attendances and inpatient stays. Progression of work in this area will also help to better understand the level of need in the community and develop services around those needs to ensure that patients are seen by the right person, at the right time, and in the right place.

[28] The use of patient-reported measures in epilepsy care: the Calgary Comprehensive Epilepsy Program experience - PMC (nih.gov)
[29] Reducing unnecessary follow ups with Follow-up Management (drdoctor.co.uk)

[30] Reducing inappropriate referrals with Aneurin Bevan (drdoctor.co.uk)

The ultimate aim is to better direct resources and move away from reactive strategies to those that are proactive and preventative.

Current Hospital coding systems for acute care record diagnosis and admission consultant activity, but access to in patient neurology opinion is not consistently recorded. This means that crucial neurology liaison activity occurs but is not captured. Sound data collection of all inpatient activity including ward liaison as well as other activity such as the provision of advice and guidance will enable the capture of all activity. Establishing a robust data set on all consultant activity will help to inform improvements in future service delivery both for inpatient and outpatient services. This data will also be useful in informing the development of ambulatory pathways to reduce length of hospital stay. It will also be important to capitalise on the full potential for data analysis enabled by the roll out of Encompass.

Improved awareness and education in neurology for non-neurology hospital specialists in key areas and across the wider the HSC workforce is important in ensuring the appropriate identification of neurological symptoms and subsequent decisions about referral, assessment, management and treatment. Access to relevant training in neurology for HSC professionals outside of the neurology consultant workforce would ensure that professionals in the primary care, nursing and AHP workforce are knowledgeable in managing neurological conditions and are proficient in providing support to neurology patients throughout the course of their illness.

We also need to do more to make sure that our services are accessible and provided in suitable environments to meet the needs of people with a neurological condition. This includes space for comprehensive assessment sensitive discussions around diagnosis and treatment and effective rehabilitation.

Recommendations

4a) All Trusts must develop an approach to referral management for outpatient referrals.

4b) Strategies for best meeting the needs of patients requiring neurological review should be considered. These should include Patient Reported Outcome Measures and Patient Initiated Follow-ups. This approach will first be piloted for those with epilepsy.

4c) Trusts must ensure that Neurology Clinics include protected slots for patients at risk of hospital admission.

4d) There is a need to broaden and develop data capture within neurology and the use of that data across Trusts to inform service developments. This should extend to capturing the breadth of all clinical activity undertaken as well as coding of diagnoses and interventions. Data should be used by the Commissioners to support the further development of approaches to risk stratification and to compare performance across Trusts to identify opportunities for improvement.

4e) Effective partnership working between Trusts and the community and voluntary sector must be specifically addressed in service planning.

4f) Training in neurology is required for non-neurology hospital specialists and the wider HSC workforce to support the management of people with neurological conditions.

4g) Trusts should ensure that care environments are age appropriate and are aligned with the physical and cognitive needs of people with neurological conditions.

SECTION 5: NEXT STEPS

Neurology Model

There is a significant degree of variation in current neurology service provision across NI. Variation within neurology services is not, however, unique to NI – the same observation was made about services in England in the GIRFT Neurology report. That report identified a number of approaches to the organisation of services. These include hub and spoke, federation and small regions. Each reflects local circumstances, and it is the view of the Review Team that a tailored approach is needed in NI.

This Review provides an opportunity to consider how best services can be delivered going forward to better meet the needs of people in NI. It is the view of this Review that there should be an emphasis on local first. Services for the main neurological conditions should be available in each Trust area on an equitable basis, with Trusts responsible for developing services to meet local need.

It is not, however, feasible to provide all services at a local level, with more specialist services including dedicated inpatient beds for those requiring access to all of the specialisms provided in a Neurosciences Centre being in one location but serving all of NI.

In addition, there are also a range of services which are more appropriately provided on a UK or all Ireland basis because demand is not sufficient. Alongside access to highly specialised care services in Great Britain, there are potential future opportunities to work with services in the Republic of Ireland, where economies of scale would make such working arrangements viable. This would remove the need for long journeys, by rail and sea, to be made by patients and their families. Such arrangements have been shown to be possible, including those for paediatric cardiac surgery across the island of Ireland.

Local Services

- Outpatient appointments;
- General Neurology Clinics;
- Specilaist clinics for the most common conditions including Epilepsy and MS;
- FND services including community mental health and rehabilitation services;
- Support in the community;
- Inpatient ward liaison;
- Cohorted inpatient beds for those requiring inpatient care but not care in a Neurosciences Centre.

Regional Services

- Regional Neurology beds at RVH;
- Other sub-specialty clinics;
- Regional Inpatient Rehabilitation beds at MPH and THH;
- Specialist assessment.

Highly Specialist Services

- Improved working with specilaist services across GB and Ireland.

This report has identified the development of the neurology workforce as a key enabler to develop and improve current services. While a focus on the local delivery of services is the right way forward, it is recognised that workforce challenges present a particular difficulty when considered at a local level only. Successive attempts to recruit consultants to posts in particular localities have proved unsuccessful, restricting the potential for any service development within that area. It is clear that we must promote the opportunity to share learning and resources across our HSC Trusts.

It is also clear from the Regulation and Quality Improvement Authority Review of Governance of Outpatients Services in the Belfast HSC Trust and the Independent Neurology Inquiry report that there is considerable scope to improve governance within neurology and it will be crucial to ensure that this learning is incorporated into the implementation of the recommendations set out in this report.

Neurology Delivery Team

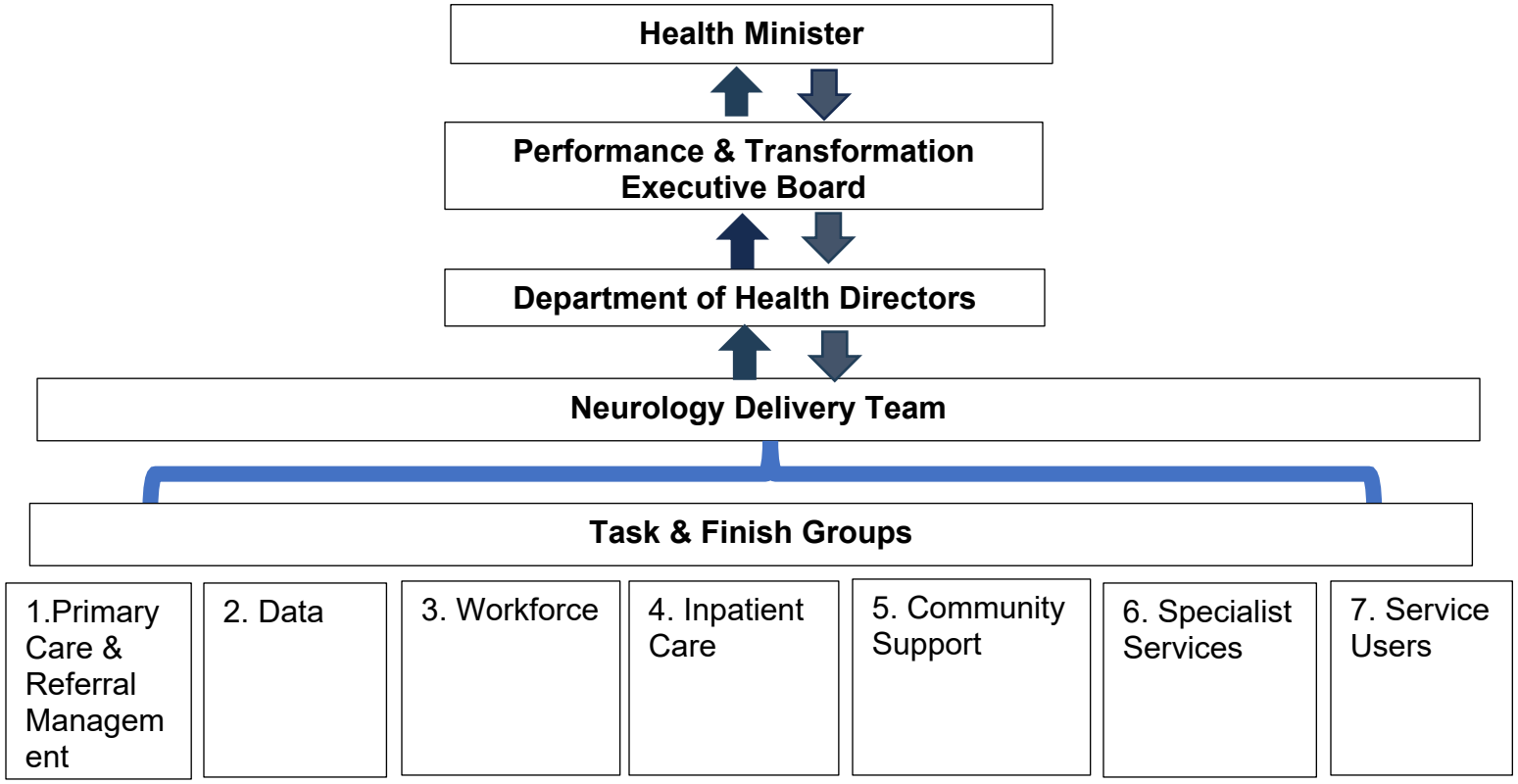
A Neurology Delivery Team (NDT) will be established to take forward the implementation of the recommendations of this Review.

The following section outlines a high-level assessment of the timescales associated with each of the recommendations. In order to drive implementation, the first task of the NDT will be to develop a more detailed action plan. The NDT will lead on those recommendations with a regional outlook, and will support and performance manage those recommendations led by other bodies. To support implementation, the NDT will also be tasked with:

- Promoting a joined-up, cross-Trust approach to the development of services within Primary and Secondary Care.
- Agreeing a regional approach to the management of the neurology workforce.
- Promoting the sharing of learning and best practice across the HSC driving ongoing service improvement.
- The development of key performance indicators.
- The development of mechanisms to ensure stakeholder engagement and user involvement.
- Ensuring standardisation of care and equity of access across the region.

The NDT will be chaired by Strategic Planning and Performance Group (SPPG), supported by a dedicated Clinical Lead and will include membership from Health and Social Care bodies including commissioners, providers of services, voluntary and community sector, professional bodies and service users. Membership will be kept under review.

The NDT will report to Directors in the Department of Health and SPPG, with regular reports provided to the Performance and Transformation Executive Board and Health Minister.


Health Minister
Performance & Transformation Executive Board
Department of Health Directors
Neurology Delivery Team
Task & Finish Groups
1.Primary Care & Referral Management
2. Data
3. Workforce
4. Inpatient Care
5. Community Support
6. Specialist Services
7. Service Users

Action Plan

Short Term: Years 1-2

Medium Term: Years 3-6

Long Term: Year 7 onwards

Priority	Recommendations	ST	MT	LT
1. A person-centred service	1a) Person centred care must be the focus of all patient-healthcare interactions for those with neurological conditions.			
	1b) Patients and their carers/families should be clear about their care and available supports, including the use of Patient Portals.			
	1c) Patients must have a designated point of contact as part of an effective care delivery network.			
2. Developing additional workforce capacity within Neurology	2a) A regional approach to workforce management is required to support the growth of the neurology consultant workforce to 45 WTE. This should include increased exposure to neurology at early and middle grade level training and the development of research posts within neurology.			
	2b) Two additional WTE neurophysiologist posts are required to increase the workforce to six posts in line with guidance. This will ensure timely access to neurophysiology services across all Trust areas.			
	2c) Timely access to neuroradiology must be available across all Trust areas			
	2d) An additional WTE neuropathologist post is required to increase the workforce to two in line with guidance. Consideration needs to be given to the sustainability of the training programme to facilitate this.			
	2e) An Action Plan is urgently required to expand and sustain the Training Programmes within the neurology specialty.			

	2f) Trusts should consider the expansion of Specialty and Specialist Doctor (SAS) roles to create capacity in the neurology medical workforce.			
	2g) GPs with Enhanced Roles should be developed in neurology through the provision of Fellowships or Integrated Training Posts.			
	2h) An additional 41 neurology nurses are required by 2028 increasing to 47 by 2035, including 12 ANP trainee posts.			
	2i) A Neurology Nursing Team should be established in each Trust area.			
	2j) An additional 38 WTE neurology AHPs are required to support multi-disciplinary working and to create additional community capacity across the four core professions (Physiotherapy, OT, Dietitian, SLT). Future workforce planning will ensure access to other AHP professions such as Orthoptists, Podiatry, Arts Therapies. Growth in the AHP workforce should be underpinned by a skill mix of generic and advanced practice roles, including the development of consultant AHP roles.			
	2k) Seven additional psychologists are needed within the team at the Regional Neurosciences Centre to ensure equitable service provision. In addition, the establishment of hospital based local neurology services requires a minimum of 1 WTE consultant psychologist, 1 WTE specialist psychologist and 1 WTE associate psychologist per Trust area.			
	2l) Four WTE consultants in neuropsychiatry are required as a minimum to meet current levels of need within neurology.			
	2m) Neuropharmacy capacity needs to be developed both at the Neurosciences Centre and across Trusts. In the immediate term, an additional nine pharmacists, two pharmacy technicians and one consultant pharmacist are required to meet demand.			

3. Addressing gaps in current services	3a) Access to specialist neurology opinion must be available at all acute hospitals receiving unscheduled admissions in line with ABN Standards. Trusts must identify the measures required to achieve the Standard. Options such as tele-neurology should be considered as an interim measure.			
	3b) Neurology inpatient beds must be managed as a regional resource and protected against non-neurology unscheduled care bed pressures. Capacity at the Neurosciences Centre should be doubled from 18 to 36 beds supported by a proportionate increase in the workforce to provide an equitable regional service. Variation in care based on Trust of Residence must be addressed.			
	3c) General Neurology Clinics, alongside Specialist Clinics for the most common conditions including epilepsy and MS, must be available in each Trust area. Regional Specialist Clinics must be further developed for less common conditions and to support complex interventions and treatments.			
	3d) Condition-specific pathways based on accepted best practice must be finalized within the first two years of implementation. Progress towards the delivery of the pathways and accompanying standards should be a key metric during the implementation of the Review.			
	3e) A service specification for local neurology services focused on rehabilitation and symptom management is required. Local Neurology Teams must then be established in each Trust.			
	3f) Trusts must ensure that barriers to accessing general mental health services for neurology patients, regardless of diagnosis are addressed.			
	3g) The commissioning of highly specialized services should be aligned to NHS England commissioning decisions to ensure patients in NI have equitable access to highly specialized services.			

4. Using current resources more effectively	4a) All Trusts must develop an approach to referral management for outpatient referrals.			
	4b) Strategies for best meeting the needs of patients requiring neurological review should be considered. These should include Patient Reported Outcome Measures and Patient Initiated Follow-ups. This approach will first be piloted for those with epilepsy.			
	4c) Trusts must ensure that Neurology Clinics include protected slots for patients at risk of hospital admission.			
	4d) There is a need to broaden and develop data capture within neurology and the use of that data across Trusts to inform service developments. This should extend to capturing the breadth of all clinical activity undertaken as well as coding of diagnoses and interventions. Data will be used by the Commissioners to support the further development of approaches to risk stratification and to compare performance across Trusts to identify opportunities for improvement.			
	4e) Effective partnership working between Trusts and the community and voluntary sector must be specifically addressed in service planning.			
	4f) Training in neurology is required for non-neurology hospital specialists and the wider HSC workforce to support the management of people with neurological conditions.			
	4g) Trusts should ensure that care environments are age appropriate and are aligned with the physical and cognitive needs of people with neurological conditions.			

Additional Investment

This report sets out a programme of work to drive improvements in neurology. This includes both a focus on what we can do better within existing resources and areas where additional investment will be required to facilitate and support workforce and service development.

An initial assessment of the investment needed to implement the recommendations which could be progressed in the short term is outlined in the table below:

	Additional Investment	Cumulative Additional Investment
Year 1	£4.6m	£4.6m
Year 2	£11.5m	£16.1m
Year 3	£13.6m	£29.7m
Year 4	£17.4m	£47.1m
Year 5	£18.3m	£65.4m

In seeking to identify the level of additional investment required beyond this period, it is important to recognise that a number of factors will have a direct impact on that estimate and there is currently a level of uncertainty with each:

- A significant number of recommendations require Trusts to develop action plans within year one and any financial requirements associated with those recommendations will not be known until that exercise is completed;
- Workforce development is essential to underpin improvements. However, such development is subject to a degree of uncertainty when taking into account variables such as the uptake of available training places and the retention rates of those completing training;
- Many of our recommendations are connected and implementation of some will be dependent on the successful, and timely, progression of others. For example, an increase in neurology inpatient beds will require the successful expansion of the consultant, nursing, AHP and psychology workforce.
- In addition, the number of additional beds may change as recommendations such as the availability of protected clinic slots in all

Trusts and more targeted community-based services may reduce admission levels;

- We have recommended several pilots in our recommendations. The costs of full implementation, if the pilots are successful, will not be known until post project evaluations are undertaken.

It is therefore expected that the level of investment required to implement all of the recommendations will evolve throughout the 10-15 year implementation period.

While the Review Team recognises the challenges associated with securing additional investment in the current financial context, the need to support improvements within neurology has been clearly identified in this report and if we are to avoid an ongoing deterioration in service despite the best efforts of staff, the need for additional investment is inescapable.

APPENDIX 1: NEUROLOGY REVIEW TERMS OF REFERENCE

Introduction/Background

The current neurology service model in NI has largely focused on outpatient delivery. There are approximately 11,000 referrals from GPs for outpatient neurology per annum and 7,000 referrals from other consultants. Current outpatient clinic capacity is for 11,535 patients per year to be seen. There is, therefore, a significant shortfall in outpatient capacity, which is compounded when the capacity required for planned reviews is taken into account.

Neurological disorders (including stroke) also account for about 15% of emergency department attendances and about 10% of emergency medical admissions (excluding stroke). The involvement of neurologists in unscheduled care, in addition to that provided from the Regional Neurology Unit in the Belfast Trust, is an area of increasing focus.

As currently configured, neurology therefore faces significant challenges in terms of waiting list size and length of wait. There are large waiting lists for patients waiting for a first consultant-led neurology outpatient appointment. At the beginning of June 2018 there were 17,987 people on the waiting list with 15,751 waiting more than 9 weeks, 14,168 people waiting more than 18 weeks and 9,325 people waiting more than one year.

On 1 May 2018, the Belfast Trust recalled 2,529 neurology patients following an internal Trust review of one consultant's patients and an external review carried out by the Royal College of Physicians (RCP) which raised a number of concerns.

On 31 July 2018, in the context of the commitment in Health and Wellbeing 2026: Delivering Together to undertake a programme of service configuration reviews, the Department announced a comprehensive regional review of neurology services covering all neurology specialties. While the review focuses on the neurology service for adults, consideration will be given to the challenges faced in the transition from paediatric to adult neurology services.

Following a workshop with stakeholders in September to help shape the review, work commenced in December 2018 with the aim of producing an initial report by early 2019.

Objectives

- Building on existing information from an earlier Neurology Service Needs Assessment, National guidance and benchmarking against

professional best practice, identify future demand for adult neurology services taking into account future demographic changes and the range of interlinking specialties/specialists;

- Review the existing policy framework and developments across the UK and, taking into account service user and carer views, consider how the future configuration of neurology services can adopt:
    - advancements in technology including the use of e-triage and virtual clinics;
    - new models for both scheduled and unscheduled care; and
    - integrated care pathways spanning primary and community, secondary and tertiary care.

- Building on the Neurology Medical Workforce Planning report for NI 2017-2024, which estimated consultant workforce requirements, identify the workforce and training needs of future service models having regard to:
    - extant professional, clinical and Departmental guidance;
    - new clinical roles, skill-mix, multi-disciplinary working and limits of professional competence;
    - building effective networks of care across the region;
    - ensuring region-wide service resilience with appropriate escalation arrangements.

- To consider the potential for:
    - joint initiatives nationally and internationally including on a cross-border basis; and
    - the development of research capacity including participation in clinical trials.

- Identify actions required to ensure services are underpinned by effective governance and quality assurance mechanisms, taking into account the findings of the RQIA review.

- Produce a strategic framework with accompanying implementation and investment plan setting out a resilient platform for neurological services that will:
    - ensure that patients across Northern Ireland receive timely access to neurological assessment, diagnosis, treatment, condition management support and rehabilitation; and
    - enhance primary and community service provision so that unnecessary admissions, excess bed days and length of stay are reduced.

Membership

The review will be chaired by Dr John Craig, Consultant Neurologist.

Membership of the project team will include:

- HSC Board – Commissioning;
- HSC Board – Data
- PHA Public Health Medicine;
- HSC Neurology X 2;
- PHA Nursing/AHP;
- niNCA;
- NIMDTA;
- Royal College GPs.

Membership will be kept under review to ensure suitable representation. The work of the Project Team will also be supported by workstreams as required.

Meetings
Meetings will take place at least every four weeks, with workstreams meeting more frequently as required.

Proposed Approach
The Review Team will produce an interim report by March 2019 with a final report by Summer 2019.

Outputs

- Identification of future demand and capacity;
- Engagement strategy;
- Identification of new/revised service pathways;
- Revised governance procedures; and
- Strategic framework with investment and implementation plan underpinned by a robust business case.

Outcome
Identification of optimal service configuration of neurology services for the next 10-15 years

APPENDIX 2: REVIEW OF TERMS OF REFERENCE

The Regional Review of Neurology Services was tasked with developing a strategic framework which would set out a resilient platform for neurology services. This report sets out that platform.

As outlined in the introduction to this report, workstreams were established in priority areas to undertake an analysis of current services and identify recommendations for improvement. These are outlined below:

- First Presenters, tasked with considering approaches to maximising the triage of outpatient referrals and supporting colleagues in Primary and Secondary care;
- Unscheduled Care, tasked with estimating the demand for inpatient neurological care, with a view to meeting available standards for best care and achieving the most efficient use of inpatient services;
- Community Neurology/Care Coordination, tasked with considering how best to support patients and carers to navigate the system, streamlining access to the right support alongside the promotion of self-care and management;
- Long Term and Complex Conditions, tasked with identifying gaps and constraints within the current system, identifying recommendations and standards to underpin future services and planning for person-centred care pathways specific to their conditions and needs;
- Nursing workforce, tasked with reviewing the current workforce and the potential for an expanded role for nursing within Neurology; and
- AHP workforce, tasked with reviewing the current workforce and the potential of developing and expanding the role of AHPs within Neurology.

Each workstream has produced individual reports which were agreed by the Neurology Review Team. Each report included an assessment of population level need, a review of best practice and guidelines and consideration of approaches undertaken elsewhere in the UK and Ireland. This final report reflects the key messages and recommendations from each.

As the Review progressed, the Independent Neurology Inquiry (INI) published its report, identifying 76 recommendations with patient safety at the core. Going forward, it will be crucial to ensure that the implementation of the Neurology Review and INI recommendations are aligned as far as possible in order to strengthen governance.

Below is a summary of actions undertaken and recommendations relevant to the Review's Terms of Reference.

Reviewing policy framework, best practice, national guidance

- Review of policy documents in Scotland, England, Wales and Republic of Ireland;
- Consideration of guidance from Association of British Neurologists and National Institute for Health and Care Excellence;
- Review of Getting It Right First Time Neurology report;
- Review of analyses undertaken by voluntary sector ('Neurology Now' (MS Society); 'The provision of care for people living with motor neurone disease in NI' (Motor Neurone Disease Association));
- Benchmarking undertaken for inpatient care and Nursing workforce;
- Review of service developments across UK and Ireland.

Identifying new models of care

- Recommendation for Trusts to establish e-triage service;
- Recommendations to strengthen and develop inpatient services;
- Recommendations to develop the use of Patient Portals and Patient Reported Outcome Measures;
- Recommendation to use data driven population planning to inform future commissioning.

Workforce

- Medical workforce – recommendation to increase exposure to Neurology training, increase in training places, recommendation to improve recording of activity to inform job plans;
- Nursing workforce review – recommendations for establishment of Neurology Nursing Teams and additional workforce requirement;
- AHP workforce – baseline analysis undertaken with recommendations for additional workforce requirement identify skill mix;
- Primary Care – consideration of potential for GPs with Extended Roles in Neurology;
- Recommendations for linked specialties.

Engagement with service users and carers

- Workshop July 2019;
- Meetings of the Neurology Engagement Platform;
- Workstream presentations to NI Neurological Charities Alliance;
- Care Opinion feedback.

Joint initiatives and Research

- Identification of potential future opportunities including All Island Epilepsy Centre and development of Deep Brain Stimulation service;
- Review of research progress to date with recommendation to develop capacity in academic neurology.

APPENDIX 3: NEUROLOGY STANDARDS

ABN Quality Standards

Scheduled Care

- **Statement 1** New patients referred to the general neurology service will be seen in a timely fashion: in keeping with NICE guidance where appropriate (e.g. first seizure, 2 weeks) and within NHS waiting time standards for N Ireland.
- **Statement 2** General practitioners will have access to advice from a neurologist by letter, phone or email. **(Advice and Guidance 24/7 access)**
- **Statement 3** All neurology patients should have a plan of care indicating the diagnosis, intended investigation pathway, treatment and where necessary the arrangement for follow-up. **(standards for review)** In most cases, hospital policy dictates that all clinic letters are copied to the patient, which provides the relevant information. Patients should be entitled to receive written information within 5 days following their appointment.
- **Statement 4** Patients will have appropriate access to follow up appointments with the neurology team, to discuss results or monitor progress, at the time interval stated in their care plan. Patients with long-term neurological conditions will have a named point of contact for re-accessing the service, in keeping with appropriate Quality Standard/NICE guidance) (e.g. Parkinson's disease, 2 weeks)
- **Statement 5** The service will be provided by appropriately trained and revalidated neurologists and members of the neurological care team, including specialist nurses, General Practitioners with a special interest (GPSI) and junior doctors, who will be appropriately trained and work within an appropriate framework of supervision and clinical governance.
- **Statement 6** Patients accessing the neurology service will have appropriate and timely access to neuro-imaging (MRI and CT), neurophysiology, neuropsychological testing, and ancillary investigations (serology and lumbar puncture), including inpatient assessment where indicated.
- **Statement 7** The service will have appropriate access to neurological rehabilitation including physiotherapy, occupational therapy, speech and language therapy, dietetics and neuro-psychology. Any patient discharged from hospital should have an appropriate handover to a 'named, accountable GP'.
- **Statement 8** The service will have clear referral pathways to neurosurgery and orthopaedic spinal surgery.

- **Statement 9** The service will provide, where appropriate, information facilitating access for patients to enrol in clinical trials.
- **Statement 10** The service will maintain expertise through training, audit, and continued professional development.

Unscheduled Care

- **Statement 1 –** Adults referred to hospital as a neurological emergency should have access to care in an appropriate inpatient setting without delay (no more than 2 hours after presentation to hospital).
- **Statement 2 –** Adults admitted as a neurological emergency should be able to receive advice on their management from a neurology specialist at all times.
- **Statement 3 –** Adults admitted as a neurological emergency should see a neurology specialist within 24 hours of admission to hospital.
- **Statement 4 –** Adults referred to hospital with an acute neurological problem should have access to care in appropriate inpatient setting within 4 hours after presentation to hospital.
- **Statement 5 –** Adults admitted to Acute Medical Units with an acute neurological problem should have access to daily consultation or advice from neurology specialists, if necessary by telemedicine.
- **Statement 6 –** Adults admitted to hospital with an acute neurological problem should have access to urgent inpatient imaging (CT and MRI) where indicated.
- **Statement 7 –** Lumbar Puncture, when indicated, should be available 24/7 to all patients admitted with an acute neurological problem
- **Statement 8 –** Rapid access pathways need to be established for adults referred from Emergency Departments and Acute Medical Units to neurology outpatient services on discharge. ***(RANC clinics)***
- **Statement 9 –** No patient should be discharged from a hospital setting without documentation of the neurological examination, including fundoscopy.
- **Statement 10 –** Immediate transfer of care information should be sent electronically to a named GP for all patients, as well as printed information for the patient.

Parkinson's Disease

- **Statement 1**: People with suspected Parkinson's disease should be referred untreated to a specialist with expertise in the differential diagnosis and treatment of the condition and seen within 13 weeks of referral.

- **Statement 2**: The diagnosis of Parkinson's disease should be reviewed at 6 to 12 month intervals and reconsidered if atypical clinical features develop.
- **Statement 3**: 123I-FP-CIT SPECT should be available to specialists with expertise in its use and interpretation for appropriately selected patients.
- **Statement 4**: People with Parkinson's disease should be reviewed regularly to monitor and treat the motor and non-motor features of the condition, including neuropsychiatric symptoms.
- **Statement 5**: People with advanced Parkinson's disease, where oral and transdermal therapies are insufficient to control the condition, should be considered for apomorphine infusion, deep brain stimulation surgery or levodopa carbidopa gel infusion.
- **Statement 6**: People with Parkinson's disease should have regular access to a multidisciplinary team comprised of at least a Parkinson's Disease Nurse Specialist, physiotherapist, occupational therapist, dietician, speech and language therapist and mental health team with experience in managing the neuropsychiatry of Parkinson's and related disorders.
- **Statement 7**: People with Parkinson's disease and their carers should be given the opportunity, at an appropriate stage, to discuss end-of-life issues with appropriate healthcare professionals.
- **Statement 8**: People with Parkinson's have a right to their prescribed medication at the right time specified by their prescription.
- **Statement 9**: End of life care includes health care professionals to be responsible to continue to administer medications in the patient's best interests

Additional Guidelines

- NG71: Parkinson's disease in adults (NICE)

Treatment of dystonia with botulinum toxin

- **Statement 1**: Patients with suspected dystonia should be referred to a specialist with expertise in the differential diagnosis and treatment of the condition.
- **Statement 2**: Botulinum toxin injections are the main treatment approach for patients with primary focal dystonia such as blepharospasm, cervical dystonia, upper limb dystonia and laryngeal dystonia.
- **Statement 3**: Adults, who require Botulinum toxin injections, have access to specialised Botulinum toxin services within 2 months of diagnosis.

- **Statement 4:** The Botulinum toxin service will be located within reasonable travelling distance from the patient's home address.
- **Statement 5**: The patients who benefit from Botulinum Toxin injections, are treated at intervals, adjusted to the duration of the therapeutic benefit of the treatment (usually 2 to 4 months, sometimes longer).
- **Statement 6**: Patients treated with Botulinum toxin can contact member of the medical team in case of side effects, discussed at the time of consultation.
- **Statement 7**: Patients who do not benefit from Botulinum toxin (non responders) are identified early and referred to a specialist centre with EMG and/or ultrasound facilities to review diagnosis, treatment and injection procedure.
- **Statement 8**: Each treatment centre records at the time of each injection, interval time, duration of benefit, response, side effects from last injection and brand of Botulinum toxin injected, dosage and sites of injection.
- **Statement 9**: Each treatment centre should audit outcome and safety.

Huntington's disease

- **Statement 1**: People with suspected or proven Huntington's disease should be referred to a specialist with expertise in the differential diagnosis and treatment of the condition and seen within 6 weeks of referral.
- **Statement 2**: All relevant investigations, in particular direct genetic testing, should be available to specialists with expertise in their use and interpretation.
- **Statement 3:** Clear local or regional referral guidelines and care pathways should be in place to ensure that people with Huntington's disease will be reviewed in a multidisciplinary setting with input from neurologists, psychiatrists, clinical geneticists and other relevant specialties.
- **Statement 4:** Management of Huntington's disease should focus on the priorities of the patient and their family with the aim of preventing avoidable complications and retaining function and autonomy. Their management should include both pharmacological therapy and non-pharmacological treatment options (e.g. physiotherapy, occupational therapy, speech and language therapy).
- **Statement 5:** Huntington's disease specialists should work closely together with Huntington's Disease Association (HAD)-regional care advisors to improve continuity of care.
- **Statement 6:** People with Huntington's disease and their carers should be given the opportunity, at an appropriate stage, to discuss advance

care planning/end-of-life issues with appropriate healthcare professionals.

Motor neurone disease

- **Statement 1:** Patients with symptoms suggestive of motor neurone disease (also called amyotrophic lateral sclerosis) should be assessed as soon as possible by an experienced neurologist. Early diagnosis should be pursued, and investigations, including neurophysiology, performed with a high priority.
- **Statement 2:** The patient should be informed of the diagnosis in a sensitive manner by a consultant with a good knowledge of the patient and the disease, in an appropriate private setting, with a relative or friend present if the patient wishes one to be. A follow-up appointment should be arranged to review the patient within 4 weeks.
- **Statement 3:** Following diagnosis, the patient and relatives/carers should receive regular support from a multidisciplinary care team, with a Single Point of Contact for all information, and review appointments every 3 months in typical cases, but tailored to individual needs.
- **Statement 4:** Medication with riluzole should be initiated as early as possible.
- **Statement 5:** Where available, patients should be managed according to accepted care pathways (e.g. NICE guidance on motor neurone disease, non-invasive ventilation, treatment with riluzole)
- **Statement 6:** Control of symptoms such as sialorrhoea, thick mucus, emotional lability, cramps, spasticity and pain should be attempted. Percutaneous endoscopic gastrostomy feeding improves nutrition and quality of life, and gastrostomy tubes should be placed before respiratory insufficiency develops. Non-invasive positive-pressure ventilation also improves survival and quality of life. Maintaining the patient's ability to communicate is essential.
- **Statement 7:** During the entire course of the disease, every effort should be made to maintain patient autonomy. Advance directives for palliative end-of-life care should be discussed early with the patient and carers, respecting the patient's social and cultural background.
- **Statement 8:** Patients should have access to research programmes, including involvement in clinical trials and other studies to determine the cause and management of this condition, for which there is no effective cure, and the cause remains largely unknown.
- **Statement 9:** There should be access to training and education for professionals involved in supporting and treating patients with motor neurone disease.

- **Statement 10:** The appropriate diagnosis and management of motor neurone disease includes a recognition of the overlap with frontotemporal dementia and access to specialist input to assess cognitive function.

Additional Guideline

- NG42: Motor neurone disease: assessment and management (NICE)

Neuromuscular disorders

- **Statement 1:** Each Region should provide a fully integrated multidisciplinary service for patients of all ages with neuromuscular disorders.
- **Statement 2:** Management of individual patients may be at a specialist centre, or through a shared-care protocol at a district hospital.
- **Statement 3:** Except for the rare curable neuromuscular disorders, specialist care should generally continue life-long.
- **Statement 4:** A regional Centre should provide advanced diagnostic facilities (e.g. specialist neurophysiology, muscle pathology) and collaboration with National reference services (e.g. NCG services).
- **Statement 5:** Prompt assessment (First appointment) should be available at the specialist centre for new referrals from primary or secondary care.
- **Statement 6:** Where available, patients should be managed according to accepted care pathways (e.g. Duchenne dystrophy).
- **Statement 7:** All patients should have ready access to a neuromuscular care advisor/specialist nurse. They should provide signposting to appropriate services including voluntary agencies and community groups.
- **Statement 8:** Patients should be made aware of national and international disease-specific registries that enhance development of treatment guidelines and standards of care, as well as enabling access to research studies for interested patients and families.
- **Statement 9:** Multidisciplinary care should include appropriately trained and experienced specialists in respiratory care (physicians and physiotherapists), non-invasive ventilation, cardiology, genetics, orthopaedics (spinal and tendon surgery), gastroenterology (PEG/RIG), physiotherapy, occupational therapy, speech therapy, dietetics, and orthotics.
- **Statement 10:** Specialist multidisciplinary transition clinics should be available for adolescents moving from paediatric to adult care.

- **Statement 11:** When appropriate, patients should have a personalised emergency care plan, for example with respect to managing respiratory and cardiac issues.
- **Statement 12:** There should be access to training and education for professionals involved in supporting and treating patients with neuromuscular disorders.
- **Statement 13:** Psychological support services should be available to help individuals at all stages of their journey, from initial diagnosis to end of life care, where appropriate.

Peripheral neuropathy

- **Statement 1**: Patients with symptoms suggestive of a peripheral neuropathy should be assessed within 13 weeks by an experienced neurologist. Early diagnosis should be pursued, and investigations, including neurophysiology, performed within 18 weeks of referral.
- **Statement 2**: Complex patients should be referred to a specialist peripheral nerve clinic, which should have access to advanced diagnostic facilities including neuropathology in collaboration with National reference services (e.g. NCG services)
- **Statement 3:** Each Region should provide a fully integrated multidisciplinary service for patients of all ages with neuromuscular disorders. Patients should have access to a neuromuscular care advisor/specialist nurse. They should provide signposting to appropriate services including voluntary agencies and community groups.
- **Statement 4:** Multidisciplinary care should include appropriately trained and experienced specialists in immunology, pain management, respiratory care, non-invasive ventilation, cardiology, genetics, orthopaedics (spinal and tendon surgery), physiotherapy, occupational therapy, speech therapy, dietetics, and orthotics.
- **Statement 5:** There should be access to training and education for professional involved in supporting and treating patients with neuromuscular disorders.
- **Statement 6:** Psychological support services should be available to help individuals at all stages of their journey, from initial diagnosis to end of life care, where appropriate.

Multiple Sclerosis

- **Statement 1:** MS patients must have access to a specialist neurological service providing an effective care pathway. It is the responsibility of the Commissioners to ensure that there is an

accessible and comprehensive service for patients with MS across England based on local population needs.

- **Statement 2:** Patients are entitled to a timely and ready access to a diagnostic service, seeing a neurologist within 2-4 weeks from the time of onset of suggestive symptoms who can offer a diagnosis of MS based on contemporary practice. MRI and other investigations (e.g., lumbar puncture, evoked potentials) should be undertaken, if required, within 2-4 weeks of seeing the neurologist. The results should be explained to patients and therapeutic options discussed within a further 2-4 weeks, preferably by a neurologist with specialist interest in MS.
- **Statement 3:** There should be an agreed pathway for consultant-to-consultant referral to specialised services in a regional neurosciences centre or to tertiary clinics for selected MS patients attending the local service. This may apply when there is a lack of diagnostic clarity for further clinical assessment, additional investigations and consideration of invasive procedures (e.g., diagnostic biopsy in rare cases); for specialised management of acute MS relapses (e.g., plasma exchange), for aggressive relapsing disease; for specialised treatments (e.g. botulinum toxin), for refractory chronic symptoms, or for access to specialist input (e.g. neurorehabilitation, neuropsychiatry).
- **Statement 4:** Patients receiving a diagnosis of MS should be provided with contact details of a local MS nurse specialist: unless declined by patient, the MS Nurse should establish contact within 5-10 working days of the diagnosis. Where appropriate, life-style issues should be discussed, and advice on employment and equality, access to physical rehabilitation, genetics, family and career planning, and access to counselling and/or psychological support offered.
- **Statement 5:** Patients with acutely relapsing episodes should be seen in a rapid access “relapse” clinic for appropriate assessment, investigations and advice. They should be supported by the multi-disciplinary team and seen within 2-5 working days of reporting a suspected relapse.
- **Statement 6:** Patients with relapsing MS are to be offered disease modifying therapy according to current ABN Treatment Guidelines – or an appropriate treatment switch, if disease activity continues on treatment.
- **Statement 7:** Patients with persistent problems require appropriate symptomatic management to improve quality of life and self-care abilities. For example, patients with urinary symptoms should have access to a continence nurse specialist or uroneurology service. Prevention of recurrent urinary tract infections should be considered a priority to reduce hospital visits or acute admissions.

- **Statement 8**: Patients with MS should have access to a review by an MS specialist service and multi-disciplinary team at least once a year; and the opportunity to self-refer to the clinic earlier if necessary.
- **Statement 9**: Patients with chronic MS who may be at risk of osteoporosis (post-menopausal women, patients with mobility impairment, frequent use of steroids and long-term use of anti-epileptic drugs like phenytoin or carbamazepine) should be considered for bone densitometry to prospectively identify and treat osteoporosis in order to reduce fracture-related hospital admissions.
- **Statement 10**: Patients with chronic disability from MS require needs assessment of long-term care support addressing key components of individual patients in terms of current health status and HRQoL. The care plan should identify community nursing, rehabilitative, psychological and social resources for continuation of support. There should be named care provider and home support teams for MS patients that must set out clear targets to meet patient's and family's educational, emotional, physical and cognitive needs.
- **Statement 11:** Participation in clinical research should become an expected standard of MS services as it offers the opportunity of linking with local academic clinical networks and national clinical trial units. MS patients should be made aware of research projects where they may volunteer and participate.

Additional Guideline

- NG220: Multiple sclerosis in adults: management (NICE)

Additional NICE Guidelines

Headache

- CG150: Headaches in over 12s: diagnosis and management (National Institute for Health and Care Excellence (NICE).

Epilepsy

- NG217: Epilepsies in children, young people and adults (NICE)

APPENDIX 4: CONDITION SPECIFIC PATHWAYS

Background

- Historically limited (or no) use of neurology patient pathways in NI;
- Little transparency for patients as to care they should expect (beyond all inclusive “mission statements”);
- Lack of direction for healthcare professionals as to what is effective;
- Well documented problems of co-ordinating care – primary, secondary, community, interdisciplinary, mental health, use of third sector etc

Problems with pathways

- “you can’t have a pathway for every patient or condition”
- “what about rare neurological disorders” (which in summation are actually relatively common)
- “a pathway is useless if it just leads to a cul de sac”
- “Trust XXXX has a Neurology pathway, the problem is that it takes 5 years to move through it to get a diagnosis”
- “that pathway is just unrealistic...we could never do/have the resources for that here”
- “just because you say it should happen, doesn’t make it so”

Value of pathways

- Encourage best practice;
- Facilitate equity of care across HSCTs/regionally/nationally;
- Provide a focus for service development;
- Help to identify barriers and bottlenecks;
- Drive quality improvement;
- Provide a basis for audit & a framework within which we can measure “success”;
- Challenges commissioners & policy makers, Government;
- Provides clarity & transparency to patients & families as to what they should expect.

The common & the really challenging

- Generic pathway;
- Epilepsy;
- Multiple sclerosis & other demyelinating disorders;
- Nerve & Muscle;
- Parkinson’s disease & other hypokinetic disorders;
- Functional Neurological Disorders;

- Huntington's disease;
- Motor Neurone Disease;
- Headache.

Process

- Draw on existing national standards of care (ABN);
- Utilise NICE/other guidelines where available;
- Seek pathways already in use or developed elsewhere;
- Consider documents previously published in NI;
- Keep the pathways as up to date as possible.

Considerations

- Make the pathways as locally relevant as possible:
  - Reflective of existing services (or lack of)
  - Take account of local expertise/areas of good practice
  - Geographical challenges
  - Regional isolation
- Incorporate learning from the pandemic;
- Consider issues arising both from the Neurology Recall and the INI report
  - Misdiagnosis
  - Team working/oversight
- Relevant to patients
  - Clinically relevant
  - Reflective of the patient journey & evolving needs

Sources

- ABN Standards documents;
- NICE guidelines (MS, epilepsy, Headache, PD);
- Local documents:
  - Service specifications
  - Needs assessments
- GB Regional pathways;
- Optimum pathway for MS

Optimal clinical pathways

- Under development by NNAG (National Neurosciences Advisory Group)
- Goal: To set out what good treatment, care & support look like.
- Scope: From 1st symptoms of a neurological condition right through to people who have lived with such conditions for a long time.

- Utility: To commission & improve local services to meet the needs of the local population & delivery efficiency savings through the system.
- Involvement: consultant neurologists, AHPs, patient groups & people affected by neurological conditions.

NNAG Pathways[31]

Completed

- Functional Neurological Disorder (Feb 2023)
- Headache & facial pain (Feb 2023)
- Movement disorders (Feb 2023)
- PD, Ataxia, HD, Tourette syndrome, Dystonia, MSA pathways
- Motor Neurone Disease (June 2023)

In development

- Neuromuscular conditions
- Multiple Sclerosis
- Neurological autoimmune disorders
- Epilepsy

Further details on the NNAG Optimal Clinical pathways can be found at https://www.nnag.org.uk/optimum-clinical-pathways

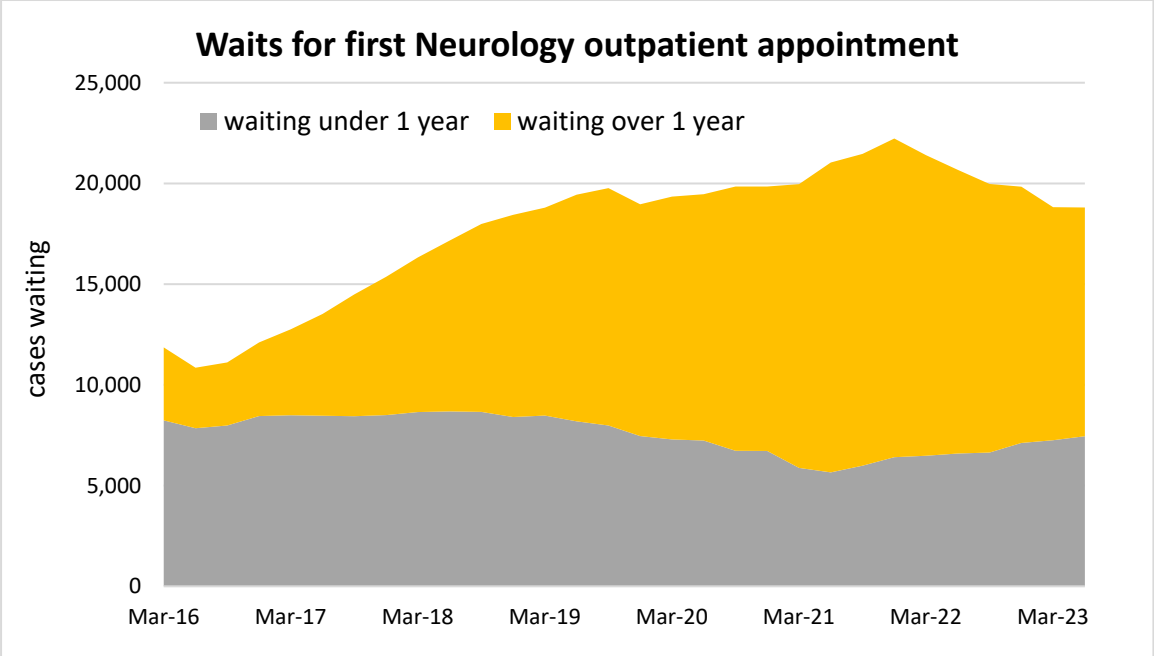
Review

- We have developed draft pathways for some of the most challenging LTNCs;
- Give direction on service planning & development;
- Outline some of the challenges we face in delivering modern, accessible, responsive services;
- Based on existing evidence re: best practice, incorporate existing pathways/guidance & reflect local issues & developments;
- Some of the draft pathways acknowledge the Pathway Development programme from NNAG;

[31] https://www.nnag.org.uk/optimum-clinical-pathways

APPENDIX 5: THE USE OF REFERRAL MANAGEMENT SERVICES IN NEUROLOGY

Most UK Neurology Services provide urgent or routine outpatient services for new referrals. With an annual capacity gap of approximately 3,000 appointments, waiting lists for a first outpatient appointment have grown significantly as illustrated below.



Other healthcare systems confronted with similar mis-matches between demand and supply have used referral management services. There is limited evidence on this process, although NICE have published specific guidance on Neurological Referrals (NG127) in 2019. The Association of British Neurologists (ABN) have published guidance on referral management in the light of the covid-19 pandemic which comments on processes for managing non-emergency care (ABN 2021). The Getting it Right First Time (GIRFT) Neurology report, published in September 2021, notes that advice and guidance and e-triage services are increasingly being introduced at many sites as a means of providing timely advice and avoiding the need for an outpatient referral. NHS England already fund Advice and Guidance Services where GPs can seek advice and guidance prior to or instead of a referral to outpatients.

Approaches

There are many different models for non-contact specialist assessment that have been tested in neurology services in the UK, Ireland, Canada and New Zealand. A summary of approaches is outlined at Annex A.

The development of an Advice and Guidance and referral management service in NI for new outpatient appointments will help to ensure that patients requiring a first outpatient appointment are seen in line with the timescales set out in NICE guidance where appropriate, for example within 2 weeks for a first seizure. The development of comprehensive referral guidance for e-triage services in line with NICE referral guidelines will be essential in ensuring that patients who require an outpatient appointment are seen within these timescales. Referral guidance will assist non-specialist healthcare professionals to identify those people who should be offered referral for specialist investigation. Referral guidance should have a specific focus on advice for those most common presentations along with those which cause uncertainty among non-specialists.

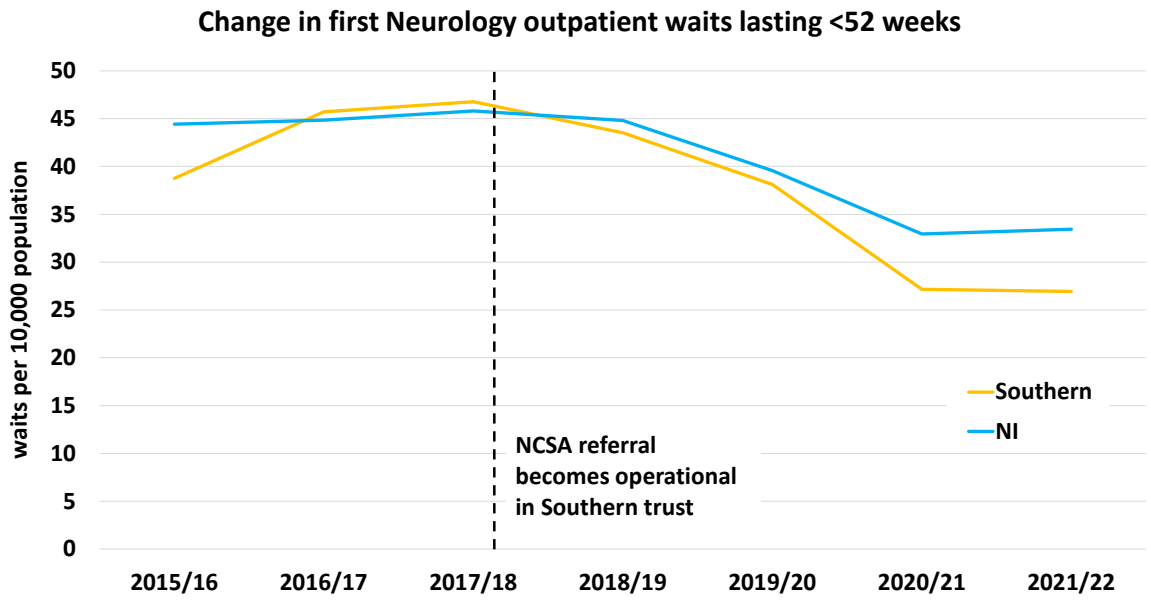
For many people with neurological symptoms, a referral for an outpatient appointment with a hospital consultant will continue to be the most appropriate course of action.

Advice and Guidance

The simplest model is the one funded by NHS England called 'Advice and Guidance'. Advice and Guidance is an electronic service that allows General Practitioners to ask for advice and guidance on case management. The premise is that the GP would feel confident managing the patient if the Advice provided by the consultant does not recommend outpatient referral.

A GP Advice and Guidance service, Non-Contact Specialist Assessment (NCSA), has been in operation in the Southern Trust for a number of years. GPs in the Southern Trust can request advice and guidance on the management of suitable patients via the existing Clinical Commissioning Gateway (CCG) system. The GP then takes on the shared responsibility of implementing the advice and treatment plan agreed with the consultant Neurologist.

A large majority of patients that are referred via NCSA are managed by their GP in a primary care setting with specialist advice as opposed to a lengthy wait on an outpatient waiting list. The Southern Trust model estimates around 10 advice requests per 100,000 population are received per week with 7% of initial requests triaged to outpatients and a further 7% triaged to outpatients following receipt of test results done after initial contact. When referrals for Advice and Guidance have been taken into account, Southern Trust residents appear to be less reliant on neurology outpatient attendances than other HSC Trusts. This supports a hypothesis that Advice and Guidance may reduce demand on hospital outpatients.

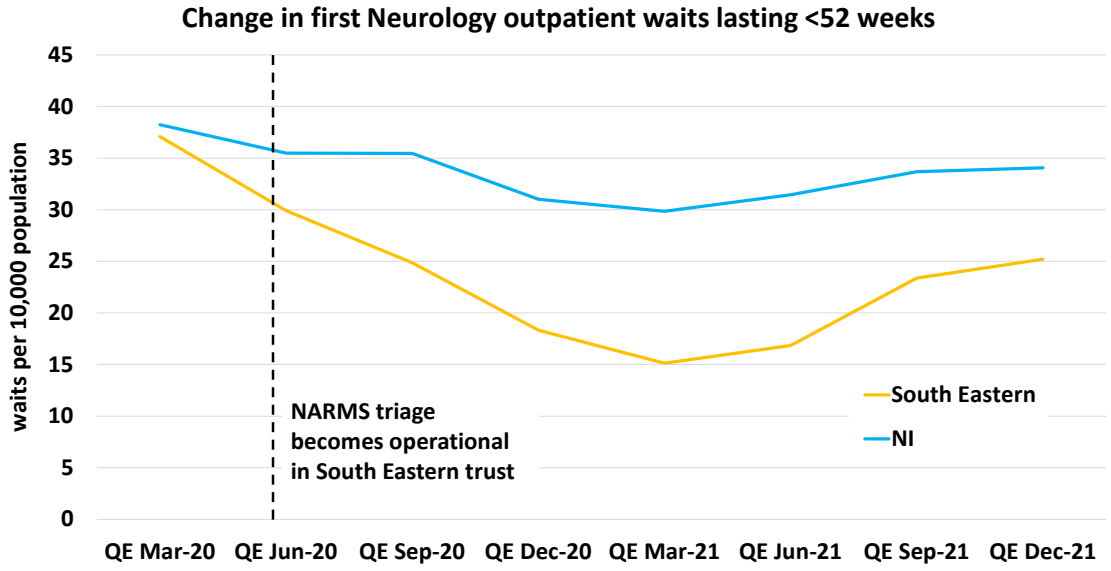


Source - https://www.health-ni.gov.uk/publications/northern-ireland-waiting-time-statistics-outpatient-waiting-times-march-2023

Neurology Advanced Referral Management System

An electronic triage service, Neurology Advanced Referral Management System (NARMS), currently being piloted in the South-Eastern Trust, was introduced to enable effective triage of new referrals from GPs to identify those patients who could be better managed as an alternative to face-to-face assessment in response to the Covid Pandemic.

Using the Trust's existing electronic systems, referrals from GPs are received by email and triaged to either advice or investigations or a face-to-face clinic. The neurologist responds directly to the GP to advise on any investigations required; to discharge those who can be managed in primary care with advice only; and to recommend an outpatient appointment either by telephone or face to face for those who require one.



Source - https://www.health-ni.gov.uk/publications/northern-ireland-waiting-time-statistics-outpatient-waiting-times-march-2023

Results of a survey conducted over a 6 month period from June to December 2020 indicate that 27% of patients referred by their GP were managed with advice only and discharged from the clinic, 17% of referrals were managed by telephone follow up; 23% were referred for investigations and 33% of all patients referred required a face to face consultation. The study did not identify a rise in the number of patients on the neurology waiting list which may indicate a positive impact on the capacity of the workforce.

Implementation

A referral management service is not a panacea and cannot replace outpatient services. However, there is evidence to suggest that such services can reduce reliance on neurology outpatient attendances.

Any Neurology Department undertaking a new referral management service would need to have this factored in as new work or would have to displace existing face-to-face work. Any referral management service has an opportunity cost if not commissioned as a new service with additional workforce.

The availability of training and support to Primary Care is also a critical factor, with increased capacity for shared care between Neurology Departments and Primary Care.

Annex A

Summary of referral management services for Neurology

System,Year, Author	Country (N)	Descriptor	Comments
Neurolink, Williams et al 2012	Ireland (710 referrals 2006-2011)	Web based form completed by PCP, replied to by specialist median of 19 hours (range 3 minutes to 18 days)	19% referrals managed with advice only 20% advice for headache, 15% epilepsy/seizure 18/18 GPs preferred Neurolink, 12/18 GPs felt more comfortable with neurological conditions. Investigations not organised as part of the service.
NCSA, 2012 Cariga et al	New Zealand (1107 referrals, 222 triaged to non-contact specialist assessment, 6 month follow-up)	Referrals to Neurology are graded and actioned by neurologist. Advice back to GP and investigations can be ordered by the neurologist prior to outpatient attendance	222/1107 managed without initial contact and followed up for 6 months. Of these 222, 16% re-referral rate. One significant delayed diagnosis occurred – a CT reported as normal showed a meningioma that was present on MRI. CT images were not available to assessing Neurologist. 22/222 (10%) NCSA cases had investigations organised by Neurology if not available directly to referrer.
Email Triage, Patterson 2004	Northern Ireland (N=76, 2004)	GPs advised to send in email instead of making traditional OP Referral. Neurologist replied to email and requested investigations on behalf of GP	68/76 replied to within 48 hours. 34/76 (45%) managed by advice alone. 23/76 (30%) had investigations performed. 9/23 investigated cases did not need to attend OPC. 9/76 (12%) investigations and advice, 33/76 (43%) required clinic appointments. Headache 26/76 (34%), Sensory 16/76 (21%), tLOC 7/76 (10%). 8/8 GPs said it made their job as a GP easier. 5/76 required hospital admission on advice of Neurologist.

System,Year, Author	Country (N)	Descriptor	Comments
			8/76 saw other specialists but no significant diagnostic changes occurred. Imaging rate 23/76 (30%) – mostly CT in 2004, organised by Neurology.
eConsult Bradi et al 2018	Ottawa, Canada N = 387, 2011-2015	Electronic Advice and Guidance Service	Headache 17%, Incidental Imaging findings 11%, Sensory 11%, Seizure 9% and cerebrovascular disease 9%. 23% of eConsults were for medication advice. 88% took <10 minutes, 80% answered within a day. 34% consults avoided OPC attendance. 3% econsults led to OPC when referrer thought none required. 54% had a new course of action for patient. Imaging was available to primary care referrers, not organised by Neurology.
Advice and Guidance, NHS England CQUIN 2017	England	Electronic Referral system where GPs ask for advice instead of making a referral. GPs responsible for requesting investigations and taking action on results including making referral for OP consultation.	Is now recommended means of accessing non-urgent outpatient care in NHS England and a 2017-9 Care Quality Indicator. In non-neurology specialities areas where GPs accessed advice and guidance outpatient referral rates were 23% when GPs received advice, but 74% when advice was requested but none received. One local audit in a Neurology Service in England (Kipps et al) found that Advice and Guidance increased referrals to Neurology by 12% i.e. detected unmet need. Investigations organised by Primary Care Referrers. No investigation rates published.

System,Year, Author	Country (N)	Descriptor	Comments
Virtual Clinic, Forbes 2015	Northern Ireland (N = 515, 2012)	Triage of OP referrals to diagnostic tests. Tests requested by consultant Neurologist who actions results.	199/515 consecutive referrals triaged to Non-contact specialist assessment. Of the 199, 95 (49%) advice only, 3 (2%) referred to other specialist, 1 admitted. Of the 515, 143 referred for diagnostic tests (28%), 3 chose private sector appointments. Of 143 for tests, 57 needed OPC assessment, and 85 were discharged back to GP. 11/85 were re-referred – most common reason was chronic headache. 1/85 was re-referred and had a diagnosis of idiopathic PD – the only instance of delayed diagnosis in this cohort.
CCG Advice Request, Campbell and Forbes 2018	Northern Ireland (N = 3571 since Jan 2014, analysis based on 1675 between 2017-2018 – Campbell and Forbes)	Dedicated advice only service using secure electronic advice system.	76% of advice is on new patients and 24% on known neurology patients. Headache 16%, LOC/epilepsy 10%, Sensory 9%. Service provided by 2 consultants – no difference in imaging rates (40% v 36%) or rates of advice to attend OPC (8.7% v 8.5%). Overall 76/1675 advised urgent OPC assessment and 67 for urgent OPC after investigations - 15% of advice requests lead to OPC with a further 6% being re-referred within 18 month – total 20% Advice Requests lead to OPC within 18 months. 4.3% attended ED in the following 18m and 0.7% sought private appointments. Of the 42 ED presentations, 16 were for epilepsy, 10 for headache and 3 were functional.

System,Year, Author	Country (N)	Descriptor	Comments
			Imaging rates were c38% of all referrals.

APPENDIX 6: EMERGENCY AND ELECTIVE INPATIENT CARE ANALYSIS

Introduction

Neurology Inpatient care in Northern Ireland

Similar to most Neurosciences regions neurology services in Northern Ireland (NI) were historically organised using a 'hub and spoke' model with Neurologists appointed to a central Neurosciences Centre with outreach services for other sites. Where necessary, patients were transferred to the Neurosciences Centre for specialist care under neurology according to clinical need. Postgraduate medical training programmes in neurology have traditionally been located in the Neuroscience Centre[1].

More recently, neurologists have also been appointed to hospitals outside the Neurosciences centre, predominantly to provide local access for outpatient care and some inpatient ward liaison work[2]. However, admissions under the care of a neurologist are currently only possible within the Neurosciences Centre.

The quota of regional inpatient beds for neurology in NI is 16 (plus 2 beds for Video EEG monitoring). This represents an increase of one inpatient bed for the NI population compared to over one hundred years ago[4] . Total bed space for inpatient neurology has fluctuated over time with a 70% reduction compared to 1977[4], which includes a 30% reduction in beds in 2010[5].

Neurology remains an under-resourced specialty in NI, relative to other developed countries. The UK and Ireland have the fewest number of Neurologists per head of population in Western Europe[6] . In 2011, the Royal College of Physicians (RCP) and Association of British Neurologists (ABN) recommended at least one consultant neurologist per 70,000 population for comprehensive local neurology services based at District General Hospitals, as well as recommending an increased focus on acute unscheduled care rather than only scheduled care[7]. Workforce requirements for tertiary level neurology care are not included in this proposed ratio.

This report includes analysis of the current burden of work due to patients with acute neurological disorders attending via unscheduled pathways, outline of the evidence-base supporting neurology involvement in acute care and recommendations on provision of care to patients presenting via unscheduled pathways.

Activity Analysis

Getting It Right First Time (GIRFT) is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking and presenting a data-driven evidence base to support change. GIRFT Neurology, published in September 2021, demonstrated variation between neurosciences regions in NHS England including for unscheduled care[9]. As part of the Neurology Review, an analysis of care for patients admitted acutely with neurological disorders in NI was undertaken using the same methods covering the same time period (2018/19) as GIRFT. This permits a comparison of neurology care in NI with that of NHS England.

Individual hospital sites were classified according to the level of neurology service available based on the service available in 2018/19. The table below outlines the classifications and identifies the hospitals in NI falling within each category.

Classification	NI Hospitals
N1 – Neuroscience Centre with Neurology inpatients and Neurosurgery;	Royal Victoria Hospital (RVH)
N2 – Neurology Centre with Neurology inpatient beds, but no Neurosurgery	
N3 – District General Hospital (DGH) where Neurologists are based but without Neurology inpatient beds	Altnagelvin, Craigavon, Ulster, Antrim
N4 – Site with visiting Neurologists only	
N5 – Site without access to visiting Neurologists	Daisy Hill, South West Acute, Causeway, Mater, Lagan Valley, Downe

Inpatient beds for neurology are solely located at the Royal Victoria Hospital (RVH) site within Belfast Trust (BHSCT) (an N1 centre). There are no inpatient neurology beds elsewhere in NI.

Trainees in Neurology

Six specialist trainee doctors in neurology were located in the BHSCT during the study period.

Aims

1. To measure the volume and location of hospital admissions for patients with acute neurological conditions regionally.
2. To document the proportion of acute neurological conditions who receive care from, or admission under, neurology.
3. To examine for variation in access to neurology for patients with acute neurological conditions across the region.
4. To review local evidence and examples of best practice nationally/internationally to provide recommendations on acute unscheduled care for neurology in NI.

Diagnostic categories for benefit from Neurology input

GIRFT classified different ICD-10 (International Classification of Diseases-10) diagnostic codes using the probability for benefit if that admission was under the care of a Neurologist. Four broad categories of potential benefit were assigned: *Definitely, Probably, Possibly and Rarely,* based on expert opinion and approved by the ABN [9]. Examples are as follows:

Definitely: Myasthenia Gravis, Encephalitis, Multiple sclerosis;

Probably: Parkinson's disease, motor neurone disease;

Possibly: Hydrocephalus, Tumour;

Rarely: Spina Bifida, Cerebral Palsy.

There are some limitations to this approach. Challenging cases may require admission under neurology to facilitate a diagnosis, and neurologists may play an important role in a patient's journey even where the final diagnosis is not a primary neurological disorder. Subsequently, where a patient was admitted under the care of neurology, that episode was captured regardless of GIRFT category, as exclusion of such episodes would result in an underestimation of actual workload.

Inpatient care under neurology can be for either scheduled or unscheduled care. Within the Neurosciences Centre, elective and emergency admissions are typically co-located in the same ward, meaning elective admissions also require measurement to document the range of inpatient care.

Results

Unscheduled Admissions

Amount and Distribution

There were 6,595 acute neurological admissions from April 2018-March 2019. Figure 1 summarises the level of neurology care available at the sites where they were admitted, along with equivalent data for England. Most strikingly, 23% of unscheduled admissions in NI were to sites without even a neurology liaison service (N5), in contrast to 4% in England. Furthermore, in NI, only 3% were admitted to inpatient Neurology beds (N1 Neuro). In England, this figure was more than double at 6.7%.

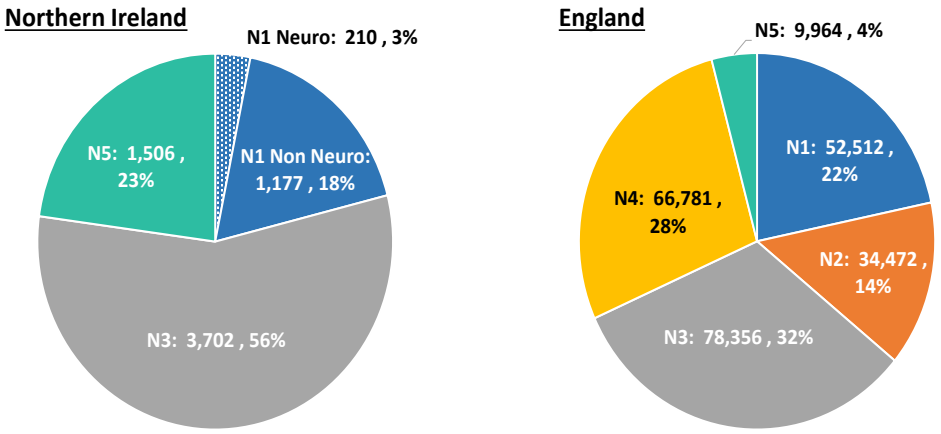


Figure 1. Unscheduled admissions for a neurological condition by site type.

Figure 2 shows that the case mix of admissions, in terms of likelihood to benefit from neurology care, is similar across hospital types, regardless of hospital size or which services are located at that hospital.

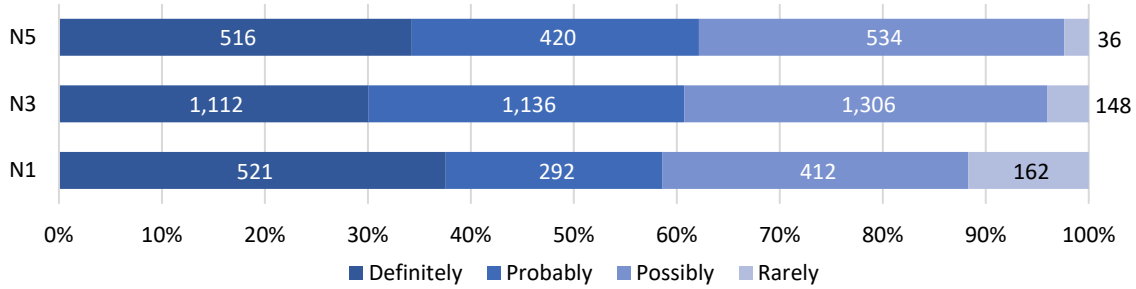


Figure 2. Unscheduled admissions per site type, classified by likely benefit from Neurological care.

Length of Stay

It is likely that neurological admissions with longer lengths of stay (>1 day) will benefit more from Neurologist input, whereas shorter stay admissions, typically under Emergency Medicine or Acute Medicine, may require less input.

There were 3,885 acute neurological admissions lasting longer than 1 day, constituting 59% of all admissions and 93% of bed usage.

Of these, only 5% were admitted under neurology, while 24% were admitted to hospitals with no neurology liaison service. As observed for all stay lengths, Figure 3 shows that the case mix of admissions lasting >1 day was similar at all sites regardless of the neurology services available.

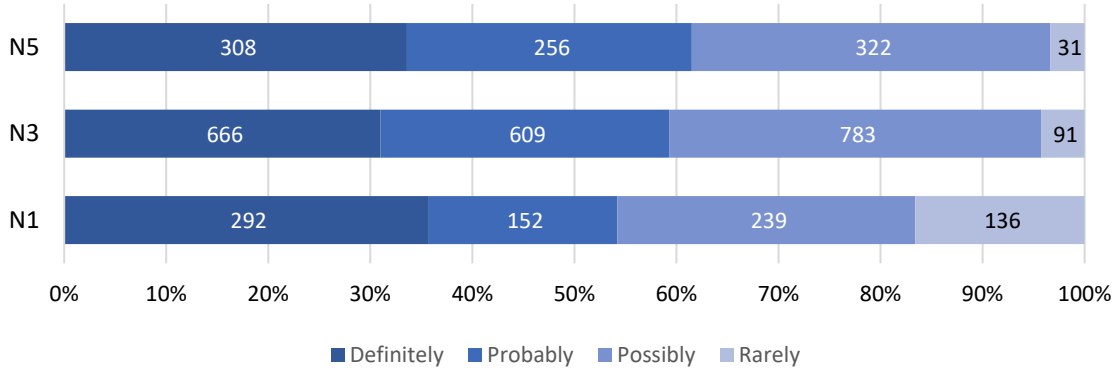


Figure 3. Distribution of long stay admissions (>1 day) according to site type and GIRFT likelihood to benefit classification.

Long Stay Admissions at Site with Neurology Inpatient Beds

A small proportion of long stay neurological admissions were under the care of a Neurologist. Even when admission occurred to a site where neurology inpatient beds are available, there were insufficient to accommodate all neurological long stay cases. Table 1 shows that clinical triage prioritised the more needy cases. However, more than half of those classified as *definitely* likely to benefit from neurology care, were admitted to other specialties because of the capacity shortfall. When all long stay cases were considered, this figure increased to 75%.

GIRFT likelihood to benefit classification	Total Admissions	Admissions Under Neurology	Admissions Under Neurology (%)
Definitely	292	137	47%
Probably	152	37	24%
Possibly	239	27	11%
Rarely	136	1	1%
Total	**819**	**202**	**25%**

Table 1. Unscheduled admissions to N1 centre with a neurological condition, classified by likely benefit from neurological care (admission length >1 day).

Long Stay Admissions: Distribution compared with GIRFT England

The distribution of admissions according to hospital type shows differences with data from NHS England published in GIRFT. Comparisons are not straightforward as GIRFT was a national programme comprising multiple neuroscience regions which were not identical and variation was evident between regions. Nonetheless, trends suggesting differences in how inpatient care is provided are evident.

When considering only those cases who would *definitely* benefit from admission under neurology (Figure 4a), a smaller proportion were admitted under neurology in NI (11%) than NHS England (11% at N1 + 5% at N2 = 16%). A higher proportion of *definite* and *probably* admissions were to hospitals without a neurology service on site in Northern Ireland compared with NHS England (Figures 4a & 4b).

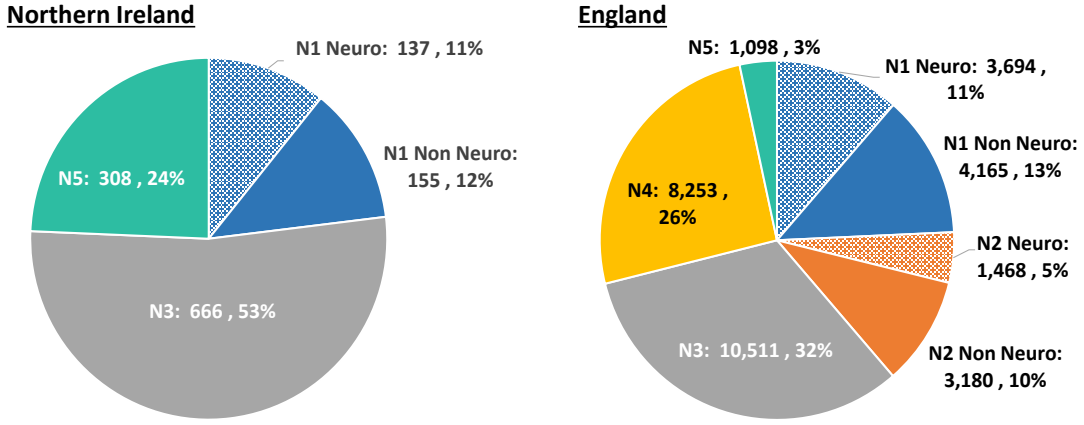


Figure 4a. Breakdown of admissions that definitely benefit from Neurology care.

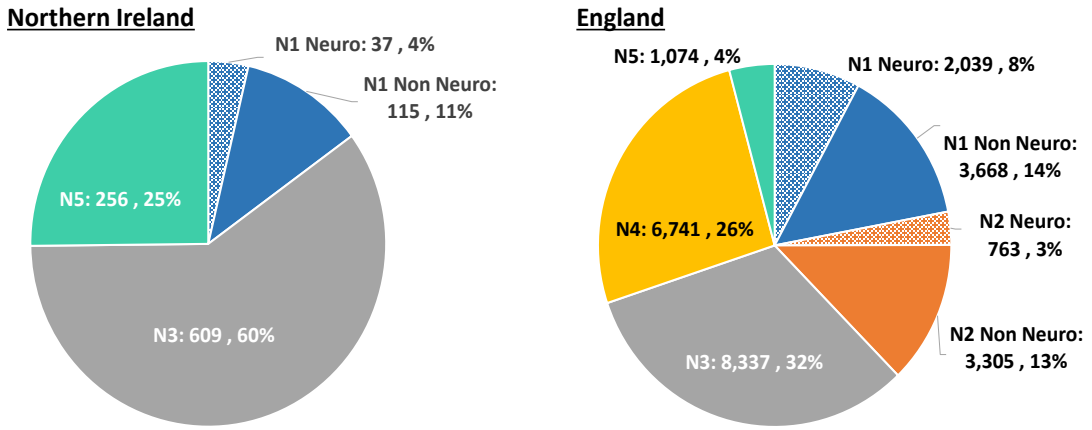


Figure 4b. Breakdown of admissions that probably benefit from Neurology care.

Long Stay Admissions: Diagnoses

Headache and epilepsy were the most common neurological reasons for unscheduled long stay admissions, in combination accounting for 49% of long stay admissions (Figure 5). As the range of neurological diagnoses is wide, diagnoses that are individually uncommon accounted for 17% of long stay admissions.

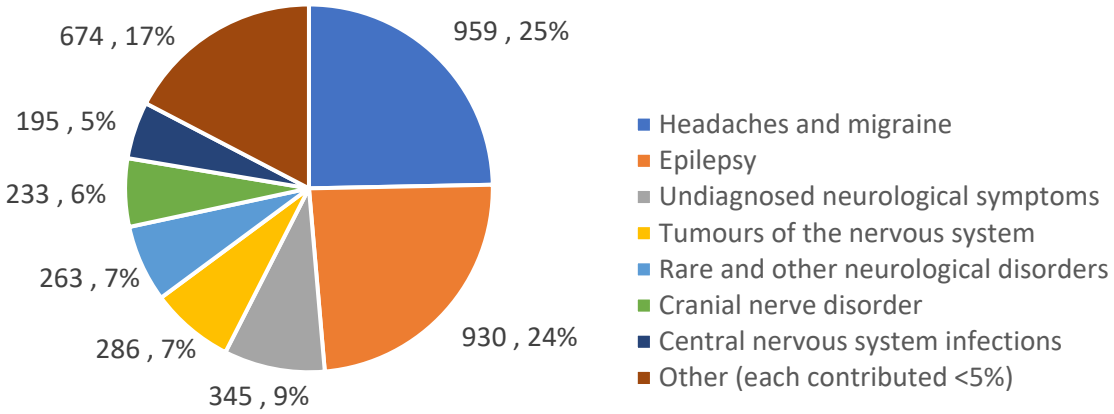


Figure 5. Breakdown of diagnosis for hospital stays lasting >1 day.

Long Stay Admissions under Neurology: Bed Usage v. Likelihood to Benefit

Beds under neurology in the Neurosciences Centre were not used exclusively by cases classified by GIRFT as having a neurological diagnosis. It is important to consider this additional bed usage as valid as, in practice, admission under neurology is likely to have been agreed to by a consultant Neurologist.

Figure 6 shows that most admissions (59%) were classified as *definitely* having benefit from neurology care, with the addition of *probably* benefitting cases increasing this figure to 73% of bed days under neurology.

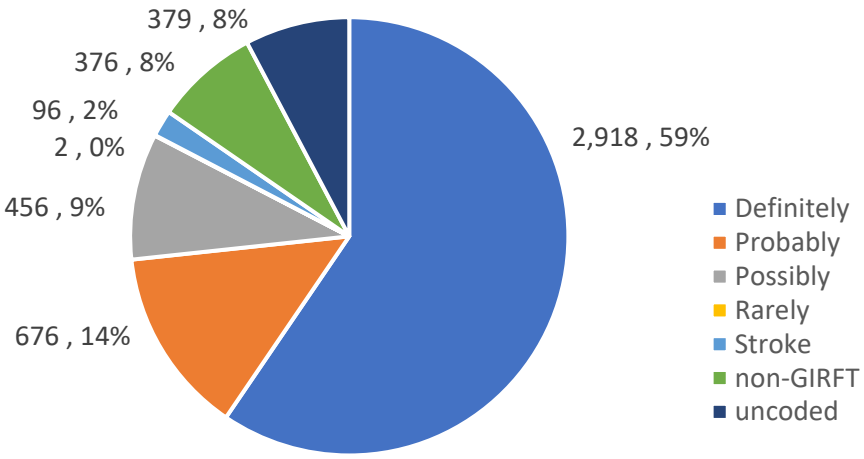


Figure 6. Bed days under Neurology according to GIRFT diagnostic category.

Long Stay Admissions under Neurology: Bed Usage v. Trust of Residence

The level of bed usage under neurology in the Neurosciences Centre varied in relation to the Trust area patients lived in, known as their Trust of Residence.

Calculation of the rate of bed day usage per 100K people from each Trust of Residence allows comparison between Trusts of residence taking into account their differing population sizes. Having adjusted for population, Figure 7 shows residents from BHSCT used the beds under neurology at the highest rate (400 bed days per 100,000 residents), with usage by Western Trust (WHSCT) and Southern (SHSCT) residents being at less than half that rate.

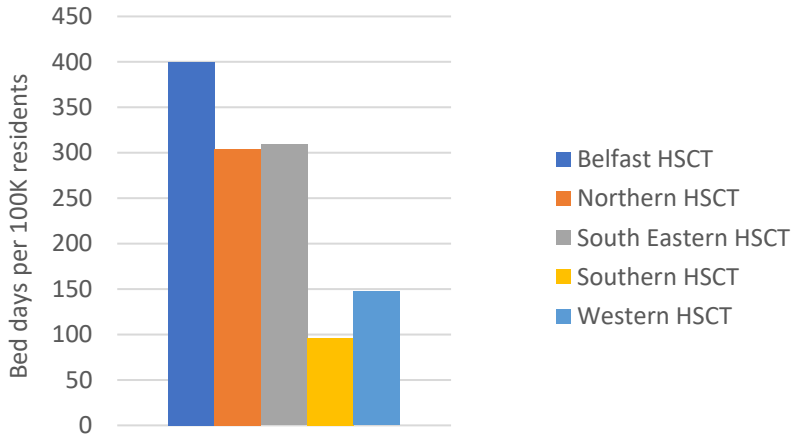


Figure 7. Bed usage rate under Neurology per Trust of Residence.

All Long Stay Admissions: Trust of Residence

Similar to the disparity between Trusts of Residence in the use of beds under neurology, Figure 8 illustrates variation in the proportion of admissions per Trust of Residence experiencing the different levels of neurology care: N1 Neuro=beds under neurology; N1 non-neuro/N3= neurology liaison service; N5=no local acute neurology presence.

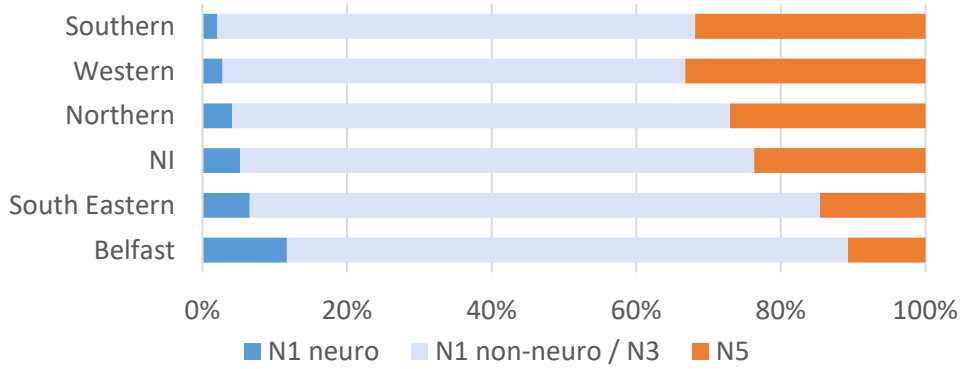


Figure 8. Proportion of admissions per Trust of Residence broken down by level of Neurology service provided. (NI = Northern Ireland average).

Adjusting for local populations, BHSCT residents admitted for neurological conditions were found to be more than twice as likely to be admitted under neurology as the Northern Ireland average, while SHSCT and WHSCT residents were admitted less than half as likely. Conversely, BHSCT residents were less than half as likely as the NI average to be admitted to an N5 hospital, while WHSCT, SHSCT and Northern Trust (NHSCT) residents had an above average risk for admission to N5 hospitals. It is doubtful that this variation in service provision can be explained by clinical need alone.

A map of admission frequency (for *definitely* and *probable* benefitting cases) according to area of residence is shown in Figure 9. As each area contains a similar number of people, darker colouring indicates a higher rate of admission for residents of that area. Map A shows that neurological admissions to hospital occur for residents of almost all areas. However, the white areas appearing in Map B, which excludes admissions to N5 sites, suggest that patients attend their local ED with neurological symptoms regardless of which services are available at that centre resulting in regional inequity.

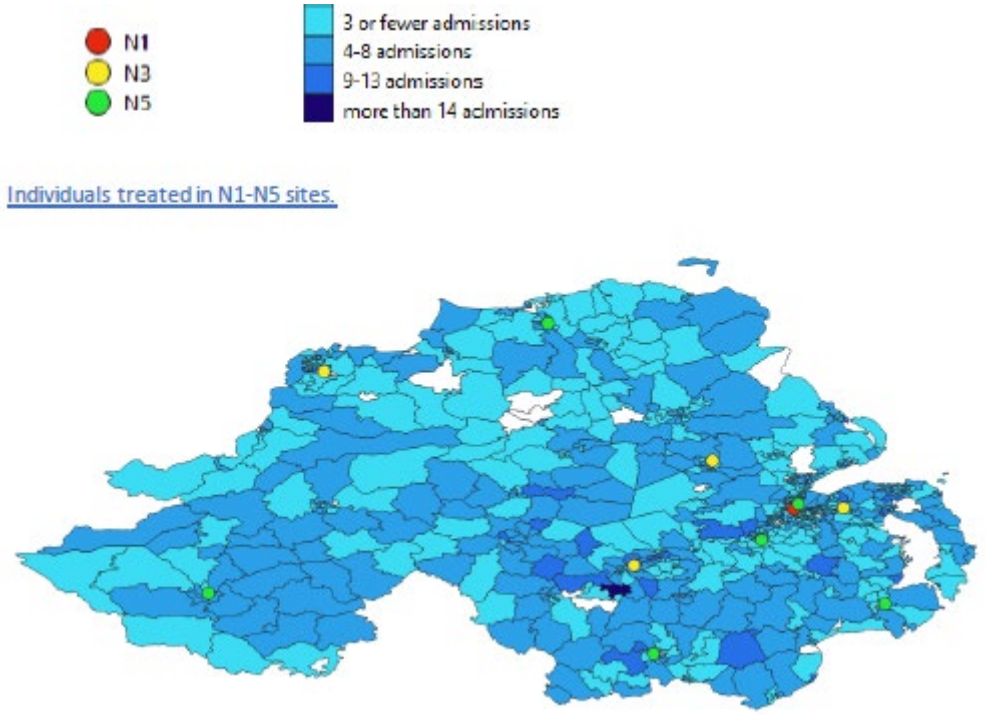


Figure 9 Map A. Individuals treated in N1, N3 or N5 sites.

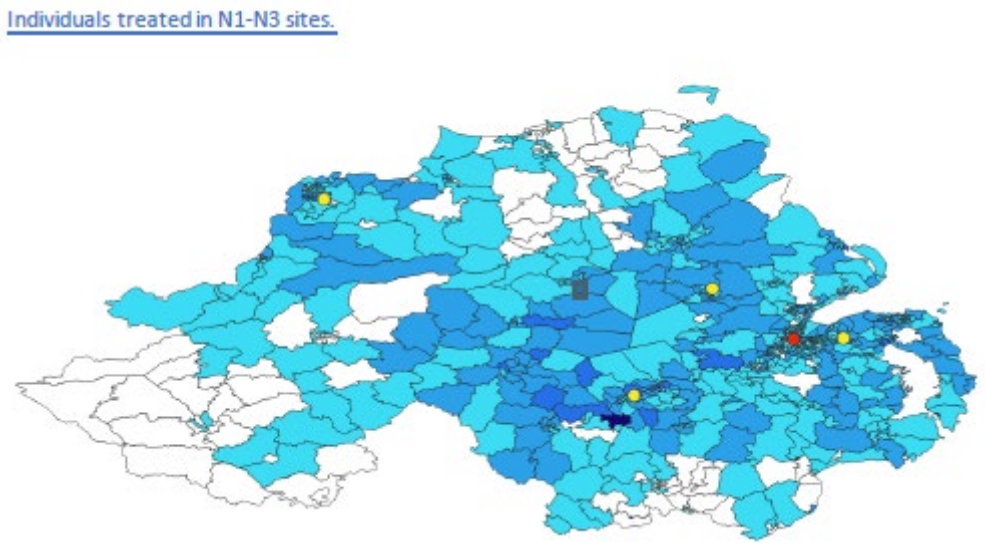


Figure 9 Map B. Individuals treated only in N1 or N3 sites.

Transfers for Care under Neurology

As most unscheduled long stay neurological admissions (GIRFT categories *definitely – rarely*) occur outside of the Neurosciences Centre, some patients admitted to other hospitals are subsequently transferred under the care of neurology at the Neurosciences Centre. In 2018/19, there were 42 such transfers accounting for 1.1 % of long stay neurological admissions.

Similar to NHS England, this suggests that neurological patients are typically cared for at the site to which they are admitted and it is relatively unusual for inpatients to be transferred between hospitals for treatment/care. As the case mix is similar across all hospitals, there appears to be an unwarranted variation in service provision given that consult services are not available at each site. While multiple factors likely contribute to this variation, a capacity gap for inpatient care under neurology is evident.

Elective Admissions under Neurology at Regional Neurosciences Centre

Inpatient neurology beds are required for both elective and unscheduled admissions. Complex neurological cases may require elective admission for investigation, diagnosis and treatment where outpatient investigation is less appropriate. Examples include motor neurone disease assessment, Video EEG monitoring, intrathecal baclofen therapy, Parkinson's disease assessment and diagnostic assessment for rare/genetic or undiagnosed neurological conditions.

During 2018/19, there were 284 elective long stay (>1 day) admissions under neurology, accounting for 2,050 bed days.

Long Stay Admissions under Neurology: Bed Usage v. Likelihood to Benefit

Elective long stay admissions had a range of diagnoses, with 54% of bed days being attributable to cases classified by GIRFT as neurological conditions *definitely* benefitting from neurology care (Figure 10). The addition of *probably* benefitting cases increase the bed usage to 85%.

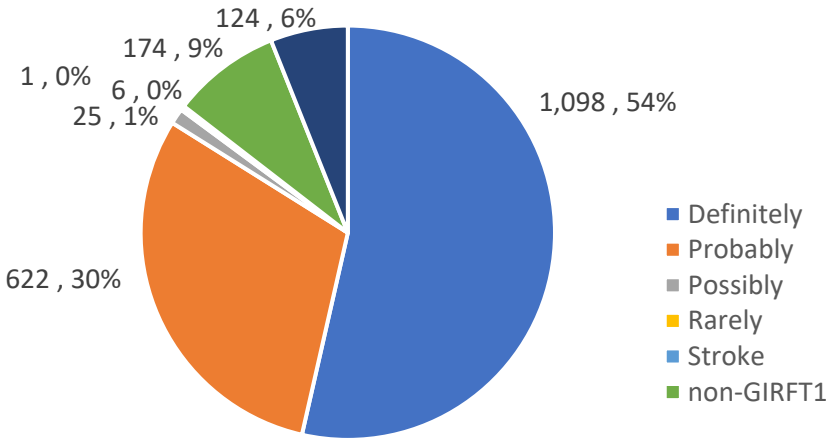


Figure 10. Bed day usage for elective admissions under Neurology according to GIRFT likelihood to benefit classification.

Long Stay Admissions under Neurology: Bed Usage v. Trust of Residence

As illustrated in Figure 11, the rate of bed day usage under neurology for elective care varied between Trusts of Residence.

Patients living in the BHSCT had the highest rate of bed usage (184 bed days per 100K local residents), while SHSCT and WHSCT residents had the lowest bed usage rates (41 & 65 bed days per 100K residents respectively).

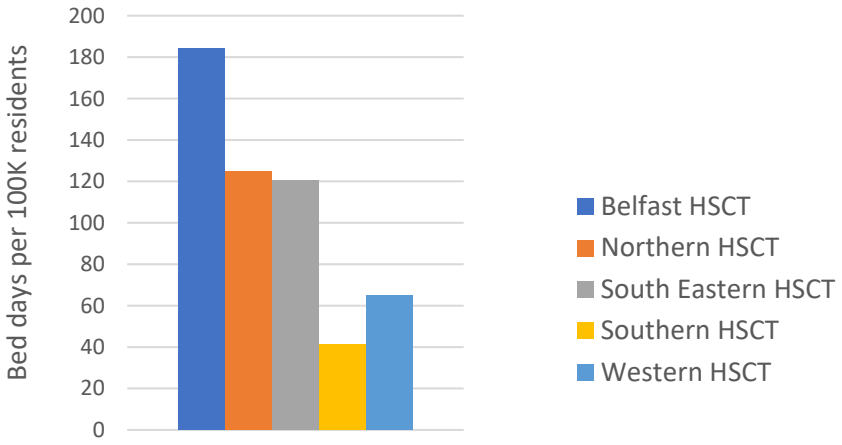


Figure 11. Bed occupancy rate per 100,000 residents according to Trust of Residence

Trainee exposure to acute neurology

The clinical and educational role of specialist trainees is necessarily wide. It includes outpatient training, inpatient case management, ward liaison, regional out-of-hours neurology advice as well as a point of contact for advice for specialist nurses, GPs and other inpatient settings regionally on a 24/7 basis**.** The small number of trainees necessitates concentration in a single site for shared training, education and maintaining an out-of-hours rota. However, 79% of neurological admissions regionally were to sites which did not have neurology trainees working at the time. Where trainees do provide input to acute referrals via ward liaison the activity is not consistently recorded by hospital systems, meaning access to neurology care is invisible.

Projections on Neurology inpatient bed requirements

Regional inpatient records for unscheduled long stay admissions (>1 day) belonging to GIRFT categories *definitely - rarely* demonstrate a number of points:

- Most admissions with neurological disorders are not admitted under the care of neurologist.
- A substantial proportion (24%) of neurological admissions are to N5 hospitals with no visiting service for inpatient ward liaison.
- Where patients are admitted to hospitals where Neurologists provide ward liaison, that activity is not captured by hospital systems.

- Variation in care is evident for elective and emergency care, with area of residence influencing the likelihood for admission under a Neurologist.
- The distribution of GIRFT categories being admitted appears similar between all hospitals, meaning variation in care is not explained by diagnosis alone.

There are currently 18 inpatient beds for neurology (including Video EEG) in NI catering for both unscheduled and elective activity.

Long stay (>1 day) inpatient activity recorded for 2018/19 was used to model potential options for neurology bed requirement to enable increased and equitable admission under neurology for unscheduled and elective care.

Option 1. Provide care under a Neurologist at site of admission.

Unscheduled Care

For illustrative purposes this model assumes that unscheduled admissions for patients with a neurological diagnosis could be admitted under the care of a neurologist in their Trust of Residence. Inpatient neurology services are contingent upon additional support services (including neurology trainees, sufficient consultants for an out-of-hours rota, neuroradiology & neurophysiology presence on site, and nursing staff for inpatient neurology), which are not projected as part of this analysis. Instead, it focuses only on bed requirements.

Based on 2018/19 bed usage for residents from each Trust area, Table 2 estimates the number of beds that would be needed to accommodate cases at an 83% bed occupancy rate.

Trust of Residence	*Definitely*	*Probably*	*Possibly*	*Rarely*	All
Belfast HSCT	7	4	7	1	19
Northern HSCT	9	6	8	3	26
South Eastern HSCT	8	7	9	2	26
Southern HSCT	6	6	6	2	20
Western HSCT	7	4	9	2	21
Unknown / non-NI	0	0	0	0	1
Total	**38**	**26**	**39**	**10**	**113**

Table 2. Range of projected bed requirements per Trust (83% bed occupancy).

As 18% of 2018/19 unscheduled long stay admissions under neurology are either un-coded, or not accounted for within GIRFT diagnostic categories

(Figure 6), relying on GIRFT categories alone to model projected bed days will result in an underestimation of necessary inpatient capacity. Projection for total bed requirements, taking this underestimation into account, could potentially be as high as 137 inpatient beds regionally for unscheduled care alone. Delayed discharges comprise approximately 7% of bed days in total, meaning even if delayed discharges were eliminated from calculations, total bed requirements could still be as high as approximately 127 to admit cases under neurology.

Elective Care

Elective care will continue to be provided at the Regional Neurosciences Centre, with capacity expanded to enable equal access to all Trusts of Residence as illustrated in Table 3.

Triage level	*Beds*
Only *definitely/probably* benefitting cases	9
2018/19 level	11

Table 3. Projected elective care bed requirements if all Trusts of Residence had the same admission rate under Neurology as BHSCT.

Option 2. Expand current service at Regional Neurosciences Centre and enhance service outside the Centre

Unscheduled Care

Figure 7 above demonstrated that triage occurs at the N1 site where inpatient beds are located. This triage reflects clinical need on a case-by-case basis, with patients more likely to benefit from admission under neurology receiving this care.

If the same triage occurred at all acute sites and the rate for admission to the Neuroscience Centre was the same regardless of Trust of Residence, more neurology beds would be needed at the Regional Neurosciences Centre. Patients not triaged to the Neurosciences Centre would then remain where they were admitted, but experience an enhanced local service expanded to provide neurology liaison.

Again, using 2018/19 inpatient activity as a basis for modelling, Table 4 estimates the number of beds required to accommodate unscheduled cases triaged to the Regional Neurosciences Centre at 83% bed occupancy. Two levels of coverage are illustrated: only cases *definitely* or *probably* likely to benefit; full 2018/19 triage level. The latter estimate is more likely to be appropriate as it is based on real-time clinical opinion rather than on diagnosis codes which are not assigned until after the admission has ended.

Triage level	*Beds*
Only *definitely/probably* benefitting cases	18
2018/19 level	25

Table 4. Projected unscheduled care bed requirements if all trusts of resident had the same admission rate under Neurology as BHSCT.

Elective Care

Projected elective care bed requirements are as described in Table 3 for Option 1.

Discussion of Proposed Models

Option 1 vs Option 2.

To provide inpatient care equally under neurology in each Trust at the site of emergency attendance (Option 1), at least 4 dedicated inpatient neurology services along with an expansion of neurology inpatient capacity of more than 700% from current levels would be required. As several Trusts have more than one acute site, the number of inpatient centres could theoretically be as high as 8.

For a relatively small population of 1.9 million people, it is unrealistic that such an expansion to inpatient neurology at acute sites would be achievable in the foreseeable future and more pragmatic approaches to providing quality and equitable care are required.

If Option 2 was implemented, projected bed needs for elective and unscheduled activity would require a minimum of 36 neurology beds located at the Regional Neurosciences Centre. This represents an increase of at least 100%.

Despite increasing inpatient capacity, this figure would not permit all neurological cases to be directly admitted under neurology. However, it is a more pragmatic option to provide equitable access to inpatient care regionally, based on clinical need and avoiding barriers based on Trust boundary. Importantly, such a model is contingent upon an enhanced provision of ward liaison service at all acute hospitals in addition to strong agreements on pathways for transfer and repatriation between Trusts for those cases deemed to need inpatient care under neurology. Such an expansion in service would require regional oversight to avoid unwarranted variation in care as well as agreed clinical criteria for inpatient care/transfer.

In 2011, the RCP and ABN working party highlighted that neurological disorders, although very common, are managed under services which are poorly planned and organised [7]. Acute neurology was an area of specific concern for the ABN/RCP as such services were rarely provided by neurologists, resulting in potential adverse outcomes. Among the

recommendations was expansion and improvement in *local* services with a shift in emphasis from scheduled to acute care with more equitable distribution[7].

Improving Access to Neurology outside the Regional Neurosciences Centre

Effective models of neurology care provided outside Regional Neurosciences Centres have been demonstrated using an acute Neurology Team to respond to unscheduled admissions. Members of the acute Neurology Team include consultant neurologists, supported by acute neurology nurse specialists and epilepsy nurse specialists. Importantly, this model permits flexibility regarding make-up of the team, where liaison services could be undertaken by specialty doctors, subspecialty nurses, trainee doctors and potentially physician assistants. In this model, initial consultation, either after proactive in-reach to the acute medical unit, or upon receipt of referral from the medical team, is with the acute neurology nurse/specialty doctor/trainee, with supervision and follow up by the consultant neurologist.

Provision of liaison neurology services in such settings increases the access patients can have to neurology (for appropriate cases)[13]. Proactive liaison services reduce the time taken to access appropriate clinical opinion and are associated with reduced length of stay, without increasing use of investigation.[14] Liaison Neurology permits more accurate clinical diagnosis, improves patient management and reduces the cost of inpatient care[15] . Despite the benefits for patients and healthcare systems, access to neurology for inpatients is variable and poorly recorded. An audit for the ABN in 2017 revealed significant variation in provision of acute neurology across the UK with 20% of acute hospitals having access to a neurologist on 3 days or fewer per week[8].

Data from NI is even more striking, with 24% of neurological admissions occurring at hospitals without access to ward liaison services.

Outside of the Regional Neurosciences Centre, where dedicated neurology beds are currently not available, individual Trusts should cohort patients with neurological conditions and consider providing admission under neurology where local volumes and staffing levels make this possible.

Rapid Access Clinics

Rapid Access Neurology Clinics have evolved alongside acute neurology service expansion in Neurosciences Centres as a means of providing acute Neurology opinion in selected cases, without the need for hospital admission. Most cases are discharged after a single appointment and not all referrals require further investigation[22]

A Rapid Access Neurology Clinic (RANC) exists in the BHSCT with an aim to provide access to neurology specialists in an urgent clinic rather than via admission to hospital. 406 patients were seen at the RANC in 2018-19

following referral from ED in BHSCT. At the same time, 644 short stay admissions to BHSCT hospitals were recorded. Data from the RANC suggests that the RANC appointments are equivalent to approximately 60% of short stay admissions at BHSCT hospitals. This suggests that some short stay admissions may benefit from neurology follow-up on a case-by-case basis, but that unscheduled admissions (e.g. self-limiting headaches, alcohol-related seizures, syncope) will not always require care under neurology.

A dedicated rapid access clinic is unlikely to be feasible at each acute hospital site. However, as the case mix at each hospital is similar, each will inevitably care for cases which are suitable for rapid access slots and may benefit from an ambulatory pathway. Provision of dedicated slots at a General Neurology Clinic outside the Regional Neurosciences Centre are a pragmatic means of providing urgent opinions for those who may not require hospital admission.

APPENDIX 7: GAP AND CONSTRAINTS ANALYSIS

Introduction

The management of long term and complex neurological conditions lies at the very heart of neurology services. Many neurological conditions are such that once diagnosed, a patient will live with that condition for life. Treatment options vary from condition to condition and the effective support and care of people living with a neurological condition requires the expertise of many different professionals working in medical, nursing, mental health, social care and the allied health professions. That care and support extends from primary and community care to hospital based services including acute care. Many people living with a neurological condition also benefit from the support offered by relevant community and voluntary organisations. The needs of people living with a neurological condition are wide ranging, impacting upon many aspects of everyday life and so our response needs to be holistic, multi-faceted, informed and comprehensive.

Within the Long Term and Complex Neurological Conditions (LTCNC) workstream, we have sought to identify the specific challenges facing neurology services here through engaging with relevant medical, nursing and AHP staff but also seeking and making recommendations for service development. It is important to reflect that despite issues of resources, frustrations around co-ordination of care and the more recent challenges of the pandemic, many healthcare professionals working in neurology have been extremely committed and innovative in approach, producing important quality improvements in recent years.

Approach

The LTCNC workstream drew on expertise across the range of common neurological conditions with medical colleagues who have subspecialist expertise in epilepsy, headache, nerve & muscle diseases, movement disorders, Huntington's disease, functional neurological disorders, motor neurone disease, MS/demyelinating disorders, psychiatry and psychology. Care of patients with such conditions is however complex and necessarily multidisciplinary in nature. It was therefore crucial to have input from the wider team and the workstream therefore benefited from colleagues in specialist nursing and with relevant specialist expertise in occupational therapy, physiotherapy, speech & language therapy, dietetics and social work. Workstream members actively engaged with colleagues in each of their subspecialist areas, testing opinion, data gathering and taking feedback on suggested improvement measures, pathways and obtaining wider perspectives, particularly from those in other HSCTs.

To obtain the broadest possible snapshot of the neurology service for LTCNCs in NI, workstream members were asked to complete a “capture” document. This specifically requested information on the following;

1. **Current service constraints**: a lack of resource in a service or an obstacle to neurology patients accessing an otherwise available service.
2. **Gaps in current service**: the absence of an expected or necessary component of service delivery.
3. **Recommended improvement measures**: steps to address constraints or gaps and enhance service delivery or the patient experience.

In the completion of the document, workstream members considered how existing services measure against recognised quality standards for specific conditions. The aspects of the patient journey to consider were;

1. Referral, neuro triage and investigation.
2. Diagnosis to specialist assessment.
3. Treatment.
4. Symptom management.
5. Advanced disease.
6. Specialist components of care not referenced elsewhere.

This approach was taken forward for the following conditions:

- Headache services;
- Multiple Sclerosis;
- Nerve & Muscle Disorders;
- Huntington’s Disease;
- Epilepsy;
- Parkinson’s Disease and other hypokinetic disorders;
- Motor Neurone Disease; and
- Functional Neurological Disorders.

In addition, a separate gap and constraints analysis was undertaken specifically in relation to the Allied Health Professions which informed the work of the dedicated AHP workstream.

Our Analysis

Whilst there are many challenges and considerations that are specific to certain specific conditions or closely associated disorders, we have also been struck by a pattern indicating that there are many problems facing patients, their families and healthcare professionals charged with their care, irrespective of neurological diagnosis. These recurring issues are explored below.

1. Waiting lists

   One of the key messages from our work is that waiting times experienced by neurology patients are unacceptable, not only with regard to first outpatient appointments but also with respect to a range of investigations and inputs required throughout their care journey. This ranges from backlog reviews of their condition, to delays in accessing AHP input, necessary housing adaptations, and barriers to receiving necessary equipment such as transfer aids, manual and powered wheelchairs, specialist seating and communication aids. The mechanisms to allow basic needs such as being able to move, communicate, safely swallow and socially interact are too slow and unresponsive to the urgency of patient need.

2. Inconsistency in the availability of services across Trusts

   Examples of services available in some, but not all Trusts, are identified below:

   - Access to NICE recommended treatments for migraine and other headache conditions;
   - Blood patch services for patients diagnosed with spontaneous intracranial hypotension.

   It is crucial going forward that people with a LTCNC have equitable access to the services required to meet their needs. We need to ensure that services are, as far as possible, available locally. Where this isn't feasible, services must be available regionally on an equitable basis.

3. Reliance on specialist services in GB

   Our analysis has identified a range of specialist services not currently available in NI where access for NI patients requires travel to GB. These include:

   - Deep Brain Stimulation for the treatment of Parkinson's disease;
   - Surgical expertise for epilepsy;

While it is recognised that some services will always require travel given the highly specialist nature of those services, consideration should be given to the development of those specialist services in NI which are sustainable in terms of cost and volume. Furthermore, where access to GB specialist services is required, the process of referral should be as smooth as possible so patients can access those services in line with their needs.

4. The coordination of services

   We have identified clear challenges regarding the coordination of the broad range of services required to support people with a neurological condition. For many patients, the need for improved coordination, underpinned by a joined-up approach to service delivery, is a key priority.

   This is also an issue for professionals working within services where referral routes can be unclear, resulting in duplication of effort and an expensive and inefficient use of staff time.

5. Commissioning issues

   Our analysis has identified a number of issues with the commissioning of current services in NI. We have identified areas where services have not been commissioned including services specifically to support patients with a functional neurological disorder. In addition, we have identified some services which are available within Trusts but are not specifically commissioned for people with neurological conditions which results in a lack of access. Examples include restricted access to splinting services within some Trusts.

   In the context of the Review's commitment to equity, it is clear that these issues need to be addressed going forward.

6. Mental Health support

   Unfortunately, it is commonly the case that a diagnosis of some neurological conditions such as Huntington's Disease (HD) delays, even prevents, access to necessary mental health services with HD viewed by some as a neurological illness and that psychiatric and/or behavioural issues should be managed by neurology or a HD care co-ordinator.

   Better access to mental health services and the removal of long-term internal barriers for neurology patients seeking to access support with mental health issues have to be addressed. Consideration should be given as to how counselling services offered by voluntary sector

organisations such as Epilepsy Action and the MS Society might be consistently woven into the patient pathway.

7. Workforce

   A key message is that the workloads currently faced by some consultant neurologists are too heavy and are unsustainable. This is particularly the case for the more senior members of the medical workforce and therefore closest to retirement. Direct replacements will not be able to take on these caseloads, a situation which has implications for timely, continuous and safe care of existing patients. It has also been a concern requiring urgent workforce planning and action for some time, forming the substance of the medical neurology workforce planning document from 2017.

   We believe that the targets outlined will be missed unless there is a detailed review of the postgraduate opportunities for trainees to experience working in neurology and related disciplines. The current gateways to a training post in neurology are too narrow and often come too late. There is a remarkable disconnection between the proportions of doctors at Foundation 1, Foundation 2 and Internal Medicine Training levels working in neurology and the scale of neurological presentations to Emergency Departments (ED), through the medical take and to GPs.

   The reliance of some services on individuals represents a risk to service sustainability in the event that the individual becomes unavailable. For example, the retirement of NI's only Neuropsychiatrist resulted in a loss of access to the service and while measures are being taken to address this, there has been a significant gap in access to this important service. It is important that lessons are learned to avoid such reliance going forward.

   Obviously, given the context we face, resolving workforce pressures would be a significant improvement in itself. However, there is also a need to improve education and training for doctors, including GPs, acute care physicians, ED doctors and other staff in relation to neurological conditions.

Condition specific issues

Many neurological conditions have specific pathways reflecting the diagnostic and treatment options available for that condition. These pathways outline what patients should expect across the scope of their journey from diagnosis to palliative phase management, including symptom control, multidisciplinary

care and self-management. For this Review we have developed draft local NI pathways for specific conditions such as Headache, MS, Parkinson's disease, Huntington's disease, motor neurone disease, functional neurological disorders, epilepsy and neuromuscular disorders. All of these lean heavily on existing national pathways and guidelines, in some instances updated in acknowledgement of changes in approach to patient care during the pandemic or amended in the context of existing and successful local services.

Areas of good practice

We have also identified many areas of existing good practice that merit wider extension across neurological healthcare services here.

Case Study - Co-ordinators in the multidisciplinary team

Welcome developments in MS therapeutics and increasing patient numbers have led to a substantial administrative burden in the safe management of MS patients.

Taking temporary advantage of a vacant MS consultant post, a pilot MS Co-ordinator role was established in early 2019 in BHSCT. This role, recently increased to 2 WTE staff, has helped to radically enhance the MS Service. The Co-ordinators arrange the separate monthly Regional DMT Panel and BHSCT Neuroinflammatory Imaging Meetings, liaising with medical, nursing and neuroradiology colleagues. Panel decisions, where required, are efficiently communicated to SPPG.

There is a significant contribution to quality improvement and audit, with collection of data outcomes from meetings and the creation of a regularly updated detailed patient database. Safety monitoring is a key element of the role including Progressive Multifocal Leucoencephalopathy (PM monitoring MRI in patients on natalizumab and skin surveillance messaging for patients treated with fingolimod. The co-ordinators facilitate scrutiny of and response to waiting lists, support the MS nursing team helpline and assist pharmacy colleagues with script generation. During COVID19, the Co-ordinators were crucial to communication with patients around vaccination and seeking feedback on the new virtual clinic format and new arrangements for infusional services.

In summary, this important administrative role supports patient access, care, safety, quality and effective communication within the MS Team. Such posts, appropriately scaled, should be available across all HSCTs and suitably adapted, would be of value in other subspecialist areas.

Case Study – Multidisciplinary Neuroinflammatory Imaging Meeting BCHSCT

Neuroradiology support is crucial to diagnostic and therapeutic decision making in neurology. This is particularly so in the interpretation of MRI. This can be challenging, differentiating between non-specific, age-related changes, artefact and potentially organic pathology, considering whether scans are stable or evolving, and assisting in differential diagnoses. Additional challenges arise from interpreting scans on different scanners with different sequences, access to private sector and international images, and reliance on reports from sources that may not have the same experience as a specialist Neuroradiologist.

In June 2018, the MS consultant team in BHSCT set up the Neuroinflammatory Imaging Meeting (NIM) in collaboration with some of the Neuroradiology team. The meeting now brings together a multidisciplinary team - MS consultants, clinical fellow, neuroradiology consultants, some MS nurses and an MS Co-ordinator.

The meeting occurs within a monthly afternoon session, with detailed discussion of the clinical cases at hand, coupled with review of recent and historic imaging. Outcomes from discussions are recorded and stored digitally. This includes data on any re-interpretation of images and subsequent outcomes for patients. Neuroradiology highlight the most significant variations in reports to the original reporting source in the interests of learning/education.

The meeting allows clinicians to bring forward cases with particular diagnostic uncertainty, or those in which imaging findings might play a crucial role in patient management. Up to June 2023, 1245 cases have been discussed at this meeting. In 31% of cases, significant changes have been made to the original reports following review. This has had very important implications for patient care, diagnosis and decision making. The benefits arising therefore have been;

1. Imaging review in complete parallel with the clinical context at hand.
2. Improved adherence to MS diagnostic criteria.
3. Detailed audit of key metrics, such as any revised imaging reports following specialist review, and subsequent changes in management with data presented at peer-reviewed national and international meetings.
4. Fostering of a positive, educational environment both directly and downstream, including clinicians, neuroradiologists, radiologists not specialist in neurology and any Fellows or junior neurology trainees who attend the meeting.
5. Improved interface with imaging acquired elsewhere, for example: the private sector, and other UK Trusts of previous patient residence.
6. Increased reliability of information on which treatment/diagnostic decisions are made.

Case Study – Disease Modifying Therapy (DMT) Panel for NI

The management of MS patients has undergone a significant transformation over the past 25 years with the advent of effective disease modifying therapies (DMTs). With this has come welcome developments in multidisciplinary care with increasing recognition that the best management requires a range of expertise across disciplines and specialties.

The developments in treatment have come with associated complexity and important considerations around safety and efficacy. Treatment options can also be expensive and they should be deployed appropriately and effectively. There is an expectation that modern medicine should deliver considered decision-making and transparent, rational processes that provide fair, efficient and equitable care to all patients irrespective of means and postcode.

During 2018 an MS DMT Panel for NI was established to provide a forum for consideration of patients suitable for those therapies with the most significant impact on relapse rates but usually with higher costs and important considerations around adverse events and safety monitoring. The medical team involved provide coverage to all of the 5 HSCTs in N Ireland. Every case is discussed, a standardized application process is used, the patient history is elaborated and a consultant neuroradiologist reviews relevant MR imaging. Following discussion a consensus is met about the reasonable treatment options moving forward taking cognizance of local and national guidelines. Outcomes from the Panel are subsequently communicated swiftly to GPs, MS Nursing teams across N Ireland and, where necessary, to Commissioners.

Over the past 3 years the panel has significantly evolved and expanded in response to new treatment options for patients with primary progressive MS, secondary progressive MS and those with refractory spasticity. We see a need for the Panel meeting to increase in frequency to allow adequate consideration of what is an increasing number of cases.

Outcomes in relation to patient treatment and care:

1. Clear focus and pathway for patients to access high efficacy DMTs. This has improved the speed with which treatments gain approval.
2. Decisions are taken after careful and expert reflection upon the available imaging.
3. Pharmacy input helps to highlight potential future pitfalls due to co-morbidities and co-existing treatments, again enhancing patient safety.
4. Equitable access to treatment.
5. Identification of issues in access to treatment and efforts to address these issues.

Recommendations

Drawing on this analysis, the following recommendations for improvement have been identified.

1. Multidisciplinary Team (MDT) working should be the accepted approach both in hospitals receiving and managing neurology patients and in the community through the establishment of Local Neurology Teams. Each MDT should include the most frequently required AHP inputs (SLT, OT, Dietetics and Physiotherapy) and be able to engage input from other allied and healthcare professions as necessary – podiatry, orthotics, specialist seating, communication advice centre, appliance office, pharmacy, social work, mental health nursing, psychology, neuropsychology, district nursing, palliative care and others.

2. The completion and implementation of the NI pathways developed as part of the Neurology Review should be prioritised and funded. In particular, the implementation of specific pathways for the management of headache should be prioritised, and Emergency Department (ED) teams and GPs provided with additional information on headache management and treatment.

3. Ensuring seamless and responsive access to UK commissioned specialist services should be prioritised. This is particularly pertinent but not limited to, nerve and muscle disorders.

4. A regional approach to the delivery of all neurology services should be established, to ensure equity of access to, and delivery of, high quality care irrespective of patient location/Trust of residence. This should be the key function of the Neurology Delivery Team.

5. The Medical Workforce Plan from 2017 should be realised. We believe that the targets outlined will be missed unless there is a detailed review of the postgraduate opportunities for trainees to experience working in neurology and related disciplines. The current gateways to a training post in neurology are too narrow and often come too late. There is a remarkable disconnection between the proportions of doctors at Foundation 1, Foundation 2 and Internal Medicine Training (IMT) levels working in neurology and the scale of neurological presentations to ED, through the medical take and to GPs. This should be urgently addressed.

6. The existing shortage in specialist nurses and AHPs, with excessive caseloads, should be addressed across all Trusts. This would support nurse led clinics, MDT clinics and home visits.

7. Investment in relevant diagnostics is a crucial area for development. Improved capacity for MRI and other diagnostic facilities would enable more efficient diagnosis and care. This is also important in contributing to patient safety. It is also crucial that sufficient dedicated inpatient beds are available to support diagnosis.

8. Self-management approaches need further development for patients with a LTCNC. There are opportunities to work closely with the voluntary sector in the development of online content that would support patient education and self-management. Patients would also benefit from a Helpline delivered by specialist nurses with the aim of supporting self-management and addressing immediate concerns.

9. Establishing a First Point of Contact (FPOC) for people with a LTCNC will facilitate early management of new symptoms or relapse. In addition, the use of Patient Portals would assist in providing a central repository of educational and self-help materials together with guidance on who to contact, how and where.

10. In the view of the workstream, provision of a Neurology PTU/DCU (Programmed Treatment Unit/Day Case Unit) would help ensure timely access to programmed investigations and treatments in an environment appropriate to the care of those with neurological disability.

11. Our analysis has identified particular needs for the development of services for people with FND, MND and those transitioning from children to adult services. The Neurology Delivery Team should prioritise the care and treatments available for these groups.

12. Better access to mental health services and the removal of long-term internal barriers to neurology patients seeking to access support with mental health issues have to be addressed. More widely, consideration should be given as to how counselling services offered by voluntary sector organisations such as Epilepsy Action and the MS Society might be consistently woven into the patient pathway.

13. Building on local resources and expertise and informed by recent local (QUB), UK and international collaborations, NI should aim to be an established research and clinical trials hub for MS within the timeframe for this Review. Appropriate support and investment (in this and other subspecialist areas) should be viewed as a means of attracting talent and expertise to Neurology, inspiring and nurturing clinicians and scientists and stimulating growth and professional expertise in the specialty. The ability to have patients in N Ireland participating in therapeutic trials is important and should be facilitated.

APPENDIX 8: RISK STRATIFICATION

In order to understand the problems regarding care co-ordination it is important to understand the needs of those trying to navigate the HSC system and how they interact with services. An important comment was made at the workshop in July 2019 that supports this point "how can we commission services if we don't have data." Studies have shown that as little as 5% of the population make up 50% of healthcare costs[32]. It would be useful if we were able to identify who that population group are and target specific interventions to help avoid Emergency Department attendances or admissions to hospital.

These studies have also shown that medium and low risk subpopulations are much larger with around 35% of the overall population classified as medium risk and 60% as low risk. An individual's risk is estimated based on information recorded during their interactions with the Health and Social Care system, such as hospital admissions or ED attendances. The identification of people classified on their respective risk estimates is referred to as risk stratification. Following risk stratification population segmentation can be performed. Segmentation can be performed based on general characteristics such as age, gender and specific diseases but also on morbidity and healthcare utilisation patterns.

Risk stratification means understanding the people within each segment who are at the greatest risk of having a significant health event of deterioration. It uses a population planning approach to segment the population so that patients receive the right level of care depending on their health and social care needs. Stratification analyses are often performed based routinely collected healthcare data. It can be used to support targeting of interventions and to align healthcare to individual health needs at an individual level. Predictions of health outcomes through risk stratification can be used to tailor proactive clinical care, to install preventive measures, to restructure healthcare, and to improve insight for healthcare professionals. In the long run, this approach will help improve the quality of care and reduce the costs[33]. The ultimate aim of this type of work is to better direct resources and move away from reactive strategies to those that are proactive and preventative.

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[32] Luo G, Stone BL, Sakaguchi F, et al. Using computational approaches to improve risk-stratified patient management: rationale and methods. JMIR Res Prot. 2015;4(4):e128.

[33] Haas LR, Takahashi PY, Shah ND, et al. Risk-stratification methods for identifying patients for care coordination. Am J Manag Care. 2013;19 (9):725-732.

Additionally, it is supportive of a Population Health Management approach in terms of trying to promote, prevent and protect, looking at the wider determinants of health and providing care at the right level as close to home as possible could help.

Risk Stratification Proof of Concept Project

The patient journey can be overwhelming as well as difficult for some patients to get answers to straightforward questions. Neurology patients will often suffer from more than one condition and their journey navigating the system can be complex. Figure 1 shows some of the different interactions neurology patients can have with the HSC system. Within HSC we collect data each time a patient interacts with the system; by extracting that information and carrying out analysis at a patient level we can better understand how patients use the system and how we can coordinate the care patients receive to meet their needs more effectively.

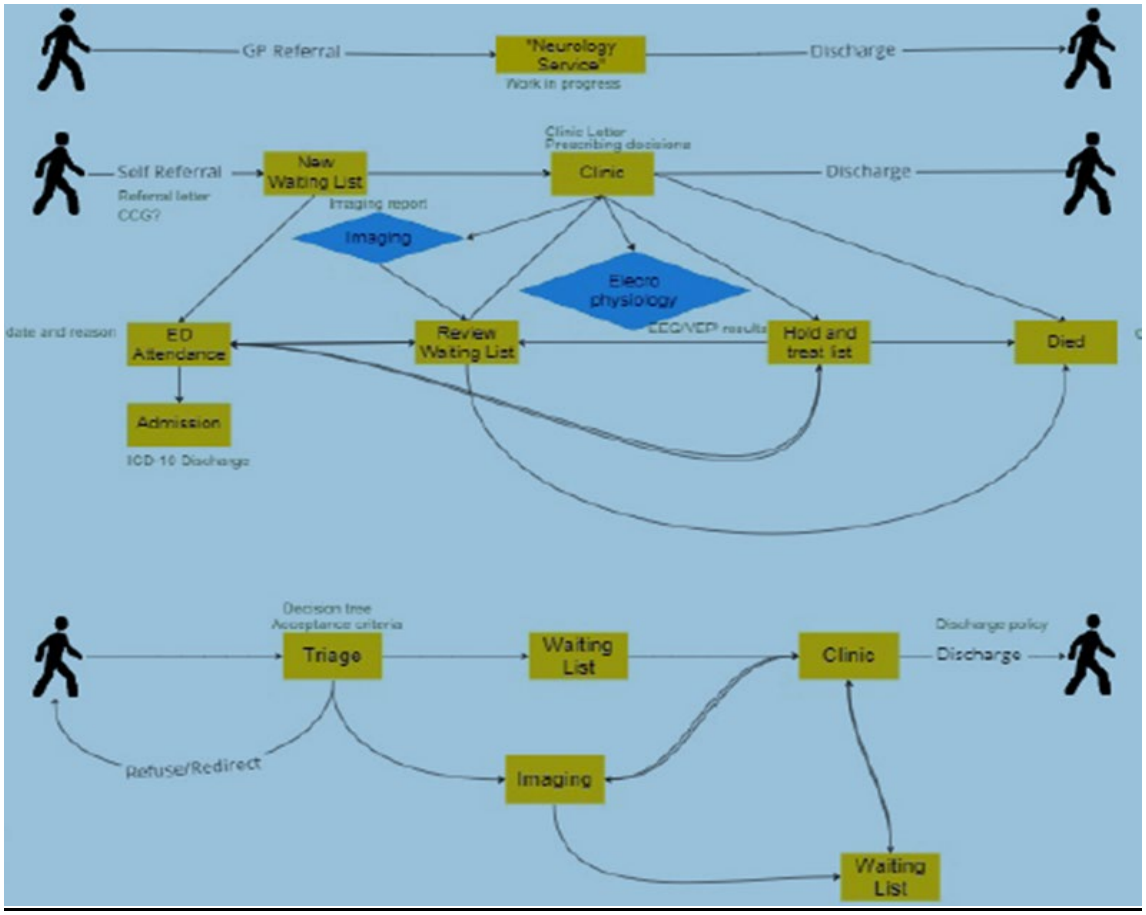

Figure 1: Complexity of Neurology patient's journey.

The care coordination workstream carried out a proof of concept project to explore how data associated with those on a neurology waiting list could be used to understand how patients interact with the system with a view to assessing their level of risk and therefore determine how patients can receive the right level of care depending on their health and social care needs, rather than the currently practiced “one-way traffic approach”.

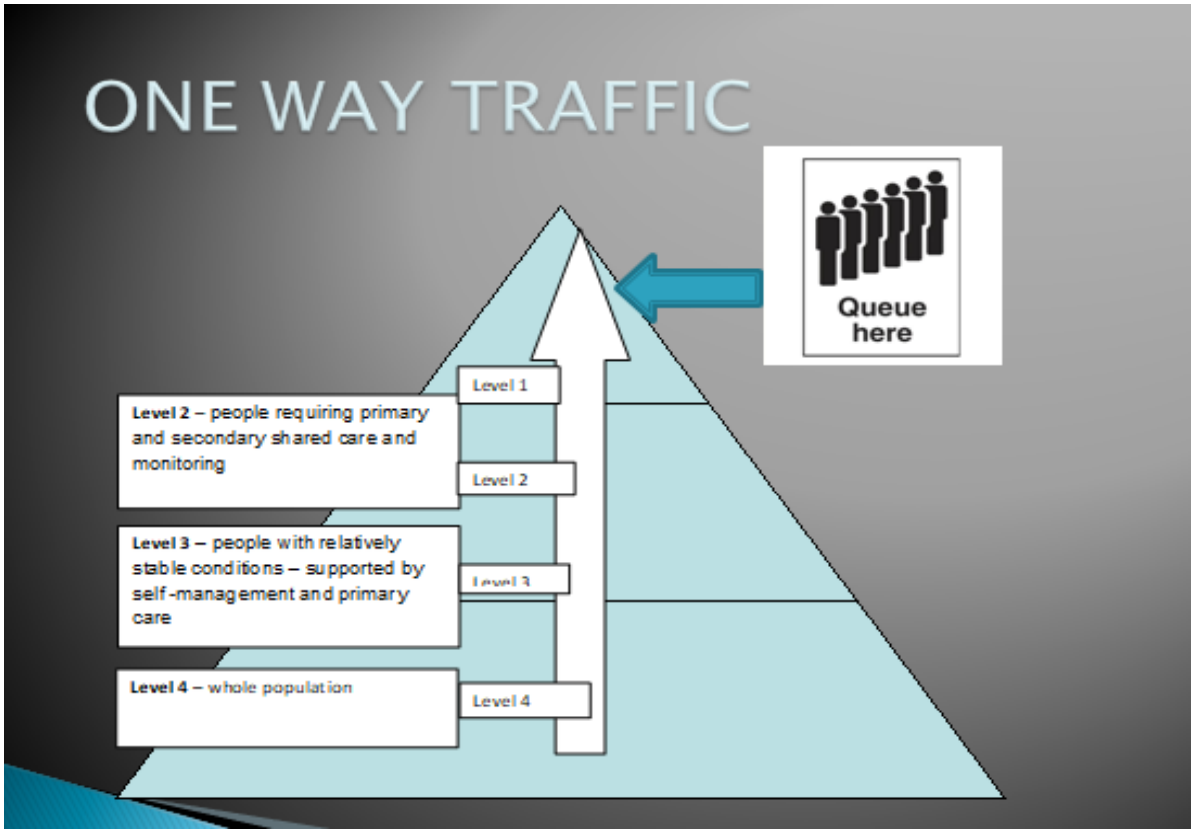

Figure 2: Current “one way traffic” approach

The “one-way traffic approach” in Figure 2 describes a pyramid of risk, where everyone is queuing to see a Neurologist yet patients have various levels of need; patient’s requiring specialist nurses in secondary care; patients that could be managed in primary care; patients with relatively stable conditions; and then our whole population where we look at preventative measures.

The current approach is unsustainable but a health intelligence risk stratification approach to providing care at the right level could offer a more effective and efficient alternative. The information that already exists on patients such as prescribing data, hospital admissions, hospital waiting lists, ED attendances and demographic information can help us understand their level of need. It should be noted however that this would be a tool to support clinical decision making and not to replace clinically-led processes.

The project centred on an expert team of people, with a comprehensive knowledge of the complexities of NI datasets, testing the potential development of a Neurology Longitudinal Dataset linking data from a range of HSC systems and sources. The team included clinicians, public health experts, commissioners, Honest Broker Service and Queens University machine learning experts, who have a great deal of understanding of the mathematics approach to using population healthcare datasets. The aims of the project were to –

1. Extract information from outpatient referral letters to supplement the Neurology Longitudinal Dataset and ideally mapping it to a diagnosis of condition.
2. Explore the potential for using the linked dataset in risk stratification.
3. Establish a robust process and governance structure to enable future linkage of additional datasets, e.g. imaging data, community data and GP data
4. Use the dataset to better understand patient journeys for those on Neurology outpatient waiting lists.

Identification of condition using outpatient letters

One of the major flaws within our system currently is that diagnosis is currently not indicated on outpatient datasets. This makes it difficult to identify condition-specific cohorts of patients. Alongside the risk stratification work, a piece of work was also undertaken to test the effectiveness in machine learning techniques to extract diagnosis information from outpatient letters with a view to targeting the needs of particular cohorts of patients at scale. The outcome of this exploratory piece was fed back at a risk stratification workshop in April 2023.

The process of information extraction and mapping was demonstrated using anonymous outpatient letters. A process was developed to test which information could be extracted from a batch of letters such as the patient health and care number (HCN) fabricated for test purposes, patient diagnosis and review information. The next stage involves mapping to an ICD diagnosis code following assessment of the accuracy of the information in the letters. Further work is intended to expand the range of information extracted from the letters, for example, to include patients' symptoms so providing more structured information for further study and linkage into the Longitudinal Neurology Dataset. By processing more outpatient letters we can build a more intelligent system for the machine learning technologies.

This work will facilitate the search for individual patients so we will know who is coming to clinic and for what condition. It could report on the burden or type of disease presenting in clinic such as epilepsy or headache and could input to the formation of condition-specific registers to help inform the decision making process and improve coordination of resources and care.

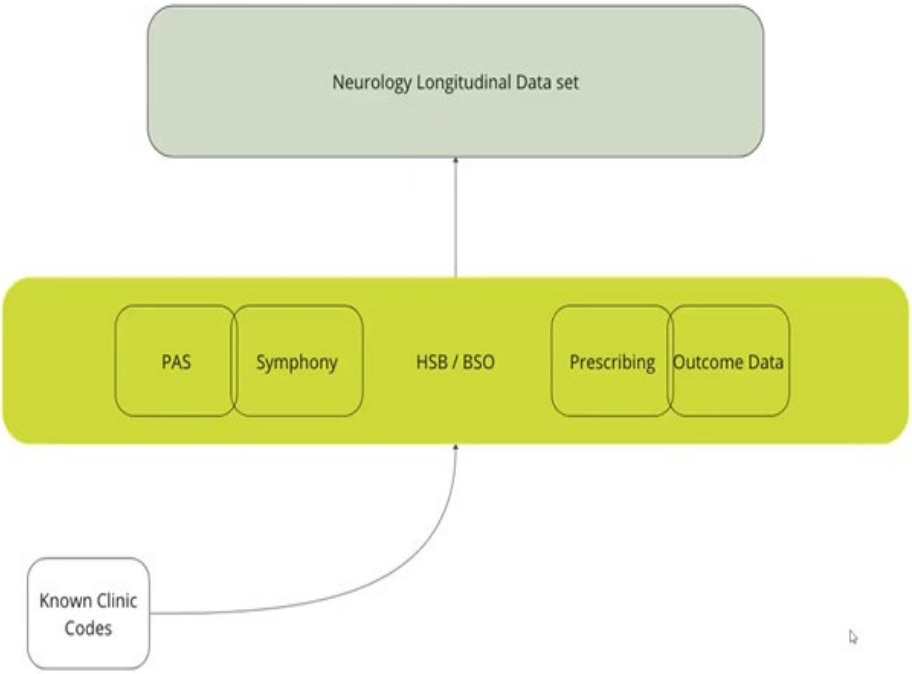

Figure 3: Using outpatient codes to inform datasets

Figure 3 provides a visual of how the machine learning technology can be used to link diagnosis, HCN and symptom information from outpatients to support the development of a Longitudinal Neurology Dataset.

Risk Stratification

The risk stratification proof of concept work has provided us with useful insights into the patient journey. One of the questions the proof of concept work sought to answer was; *is there a way to look at the patients on Neurology waiting lists in a more detailed way to help us understand how we can provide care in a way that better meets their needs*? Another question the proof of concept work examined was; '*is there a way we can use the data to start focusing more on outcomes, rather than activity*?' An outcomes focused approach is in line with the strategic direction set out by Department of Health in developing Integrated Care Systems within Northern Ireland.

This work also requires that we are 'disease-focused' rather than 'asset-focused'. The HSC tends to focus on individual interventions such as outpatient visits, investigations, inpatient bed days or therapies but often we need to focus on the progression of disease and how that impacts on how patients will use our services. The Long Term and Complex Conditions workstream have provided detailed information about disease progression, condition specific pathways and associated service need which will complement this concept.

This leads to consideration of questions such as; *Do all patients need a face to face outpatient appointment?; do you need a phone call or do you just need the ability to reach a clinician if condition deteriorates or relapses through patient-initiated follow-up (PIFU)?*

Consideration should also be given to how we could monitor 'stable' patients without the need for traditional reviews for example by using a patient reported outcome measure (PROM) tool. An aspect of the proof of concept work was exploring whether we would have the data intelligence and technology to support this. Figure 4 below demonstrates the complexities of the infrastructure that was created to do this work. This has now set the foundation for further expansion of this data intelligence approach and tested the infrastructure required to use technology to enhance service delivery. The proof of concept work allowed us to create a process and governance structure to link datasets to create a longitudinal neurology dataset and carry out detailed analysis to start answering some of the questions listed above.

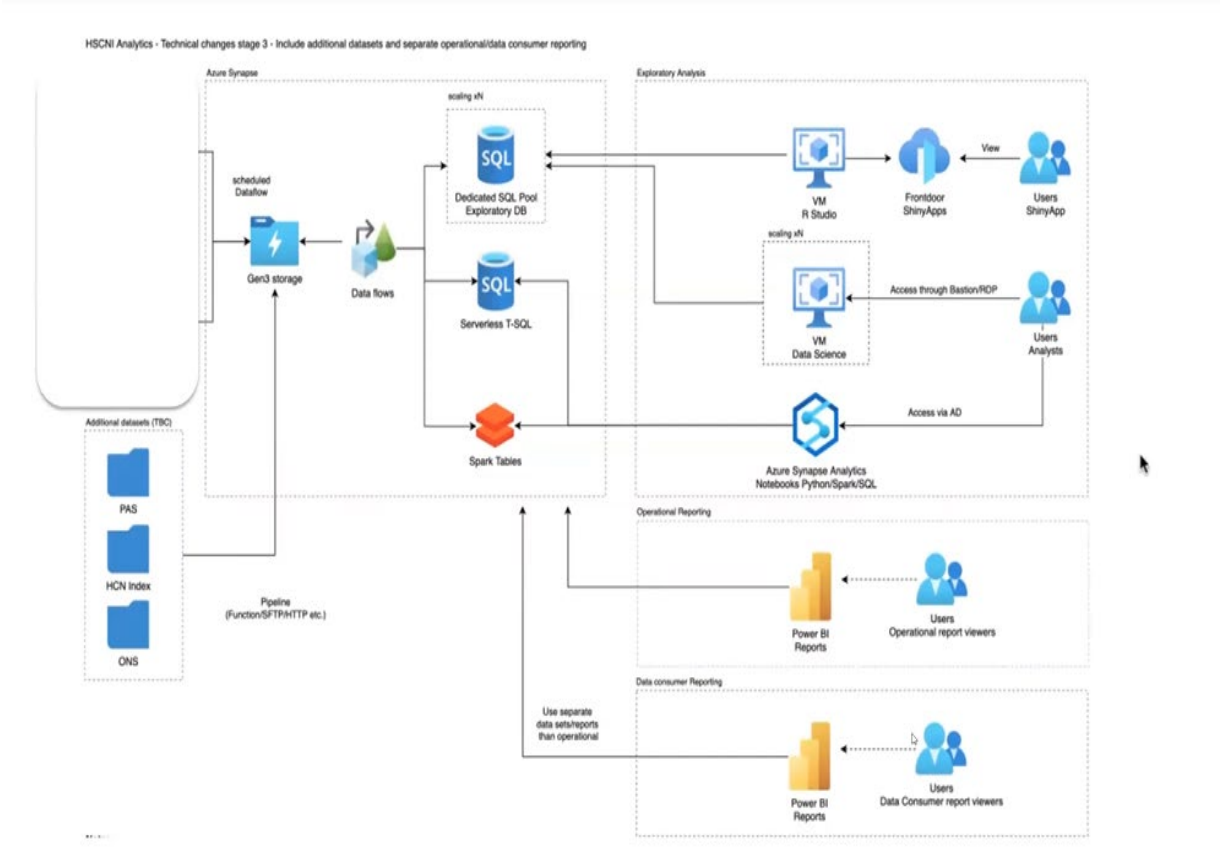

Figure 4: Process required to create datasets for analysis

Datasets

In order to understand how patients move through the system we need to be able to connect the data within the system. The proof of concept work joined the datasets outlined in table 1 below.
Table 1: Datasets used in proof of concept work.

Dataset	Information	Variables
Symphony	Emergency data - Belfast, Northern and Western trusts	Arrival, departure, incident type
NIRAES	Emergency data - Southern and South Western trusts	
Electronic Patient Data (EPD)	Prescription data	Issue/scan date, BNF information, prescribed drug Dmad code
Patient Administration System (PAS)	Inpatient data	Arrival, departure, hospital, length of stay, diagnosis (up to 15), method admission, discharge destination, internal management (day case, planned sequence overnight etc.)

Currently a dashboard is under development that will help us interrogate and understand this data further, but initial findings tell us that:

- 1 in 4 patients on a Neurology waiting list, also have attended ED at least once;
- 1 in 3 patients on a Neurology waiting list have also had an inpatient episode;
- 58% of Neurology waiting list patients are female;
- Average age of patient on a Neurology waiting list is 48 and median age 50.

As we start to understand the profile and service usage of neurology patients we can target services to better meet their needs. The concept of a neurology dashboard can be developed further to provide ‘real time’ information so that services can be proactive rather than reactive.

Data mining

The proof of concept work also investigated the feasibility of carrying out a data mining exercise to map the journeys of patients through the system. Figure 5 shows an example of the patient journey mapped by connecting neurology waiting list and inpatient datasets.

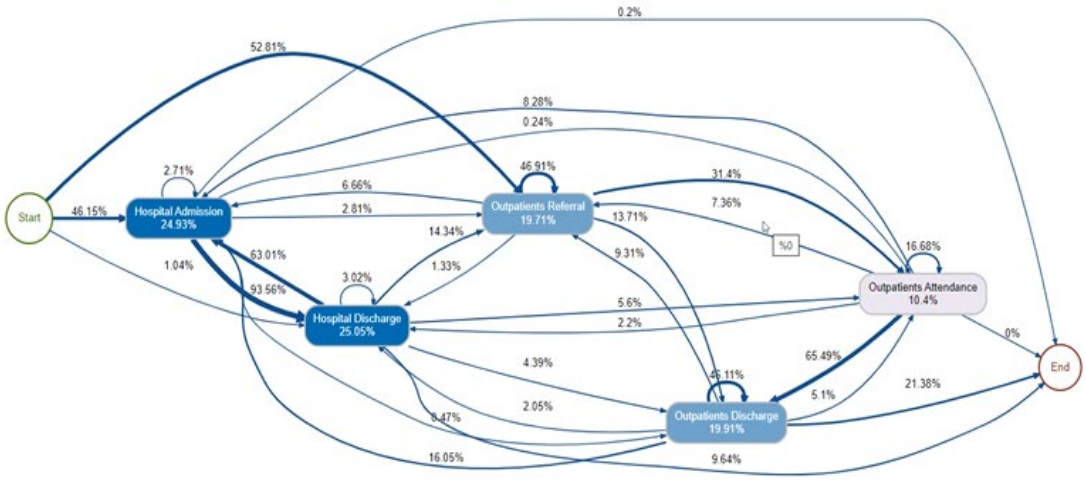

Figure 5: Patient journey process map

We can add additional datasets such as ED data and prescribing data to detail more elements of the patient journey. This approach could be used to work out statistical patterns, such as the probability of patients moving from one state of health to another, and so create a simulation of the patient journey. This tool could give us a synthetic population that simulates into the future how the population will behave.

This could be a valuable asset to assist in commissioning services that better meet patient need; for example, in relation to workforce, there is the potential to use this technology to work out how many consultant neurologist hours are needed to make the system behave in the way we want e.g. see patients within a defined timeframe. This could also be integrated into a dashboard that shows what activity is in the system every week or month and what the characteristics or outcomes were for those patients during that period.

Condition specific segmentation research

The machine learning process we tested in relation to diagnosis from outpatient letters should provide us with valuable condition specific insight for the neurology population in Northern Ireland. However, we can also draw on published data that will help our understanding of segmentation of neurology patients.

Evidence also shows that almost two thirds of referrals to a consultant neurologist can broadly be grouped into the following categories:

- Headache
- Seizure / Epilepsy
- Psychological / functional disorders
- Movement Disorders
- Neuromuscular

Research also shows that following a first outpatient appointment 52% of people referred to neurology outpatient services are offered at least one diagnostic test and 35% are offered a follow-up appointment. However, interrogation of data indicates that variation exists depending on the reason for referral, for example 73% of patients who attend a first appointment for epilepsy will receive a follow-up appointment compared with 11% for headache. Almost 90% of headache patients will be discharged after their first appointment[34]. If we consider the hierarchy of care we need to consider support that can be offered in the community for those patients, particularly those with long-term neurological conditions. We should also consider the option of remote monitoring, facilitated by technology where clinically appropriate such as PROMs.

The intelligence provided from this population health approach is vital to ensure we provide services in the right place that are accessible at the right time and will allow us to deliver a patient-centered approach.

Risk stratification work also identified areas for development of artificial intelligence solutions through the introduction of PROMs measures as an alternative to routine consultant reviews so that patients have more control over management of their condition and capacity within secondary care could be used more efficiently. Case study 1 below gives us an example of how this works.

Case study 1: Aneurin Bevan Health Board

- Value-based healthcare programme using technologically-driven methods in the pursuit of better patient outcomes and prudent use of resources;
- Invested in a digital platform (DrDoctor) to support the remote collection of patient-reported outcome measures (PROMs) with support from clinical teams;

[34] Biggin F, Howcroft T, Davies Q, et al. Variation in waiting times by diagnostic category: an observational study of 1,951 referrals to a neurology outpatient clinic. BMJ Neurology Open 2021;3:e000133. doi:10.1136/ bmjno-2021-000133

- By integrating PROMs data collection into this existing system, patients understand that responding is an integral part of their care. The data is used by clinicians to power patient care, enabling patient-led discussions around shared goals;
- Has enabled a move away from regular set review appointments to using PROMs and clinical data to arrange appointments based on patient need, ensuring the right patients are being seen at the right time e.g. speedier access for patients who become symptomatic;
- Other examples Nottingham and Manchester NHS foundation Trust.

There is evidence to support the use of PROMs amongst epilepsy patients[35],a condition that traditionally has a high rate of patient reviews. As described previously, technology could be used to improve frequency and access to review where clinically appropriate for epilepsy patients.

Tiered approach

The data evidences that not all neurology patients are the same and they all have various levels of need at different points in the patient journey. When discussing risk stratification above it is important to consider the levels of care and characteristics of patients at each level.

The vast majority of neurology conditions are such that once diagnosed, a patient will live with that condition for life. Treatment options vary from condition to condition and the effective support and care of people living with a neurological condition requires the expertise of many different professionals working in medical, nursing, mental health, social care and the allied health professions.

As figure 6 illustrates care and support extends from primary and community care to hospital-based services including acute care. Many people living with a neurological condition also benefit from the support offered by relevant community and voluntary organisations. The needs of people living with a neurological condition are wide ranging, impacting upon many aspects of everyday life and so our response needs to be holistic, multi-faceted, informed and comprehensive.

Each level of care illustrated in figure 6 can be considered in further detail and options considered for improvement in access and care coordination given the population health approach discussed above.

[35] The use of patient-reported measures in epilepsy care: the Calgary Comprehensive Epilepsy Program experience Delgado-Garcia et al. J Patient Rep Outcomes 2021, 5(Suppl 2):83)

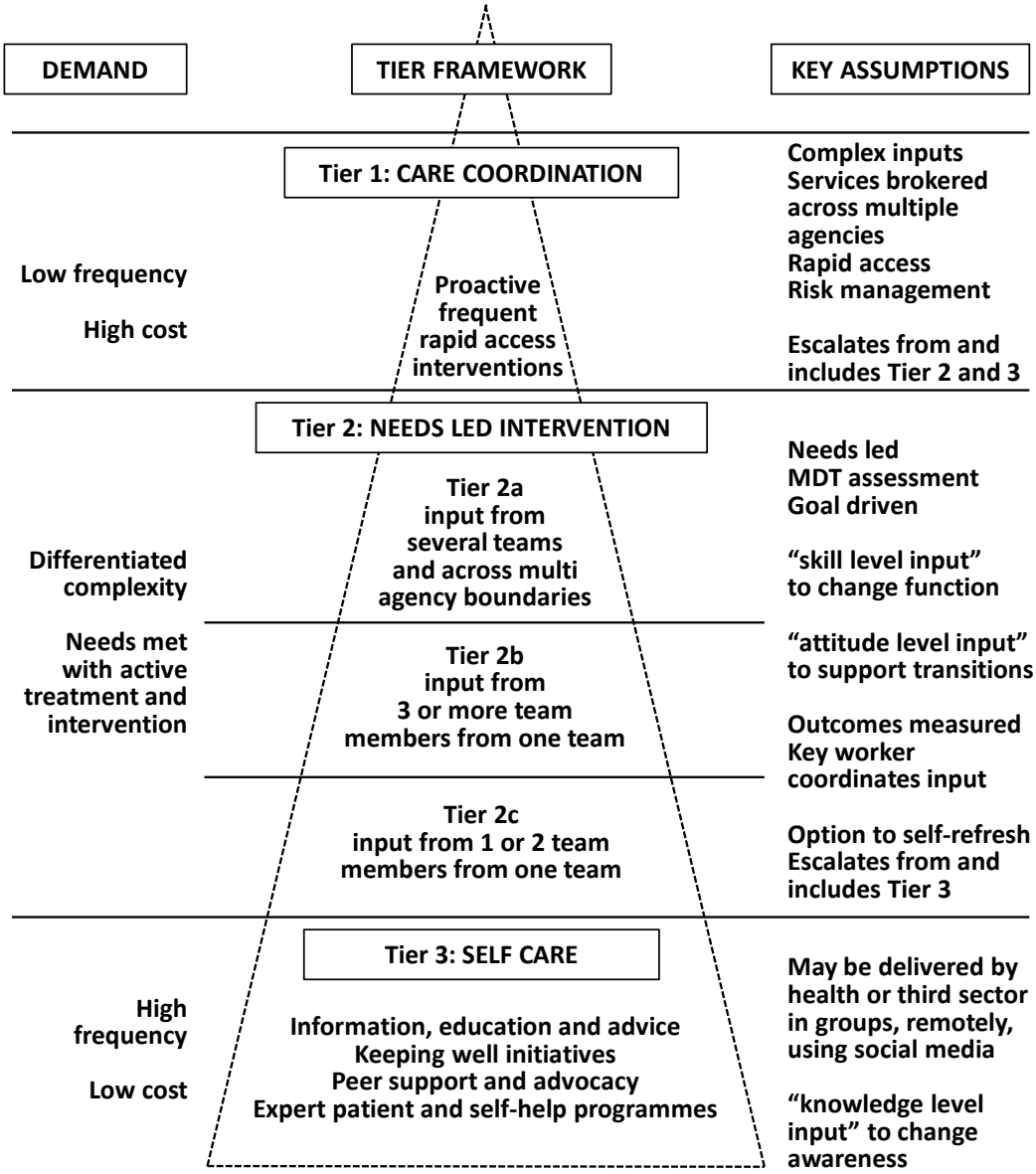

Figure 6: 3 tier model Thames Valley Strategic Clinical Network: Transforming Community Neurology

Each level of care illustrated in figure 6 above can be considered in further detail and options considered for improvement in access and care coordination given the population health approach discussed above.

Figure 7 shows the care for those with most acute and complex needs. Evidence would indicate that is 5% of those accessing neurology services. The Unscheduled Care workstream is assessing unscheduled care neurological admissions and where there are gaps in access to a consultant neurologist.

The No More Silos programme was developed to improve emergency and urgent care services in Northern Ireland[36] it aims to achieve the right care, first time for every patient. One of the mechanisms it hopes to use to achieve this is through rapid access assessment and treatment services which enable GPs to make direct appointments for patients to be seen rapidly by the right specialist (nurse, consultant or AHP professional) for assessments, tests and diagnosis without having to go through an emergency department. Rapid access clinics have been developed in neurology but access could be improved to ensure equity across the region.

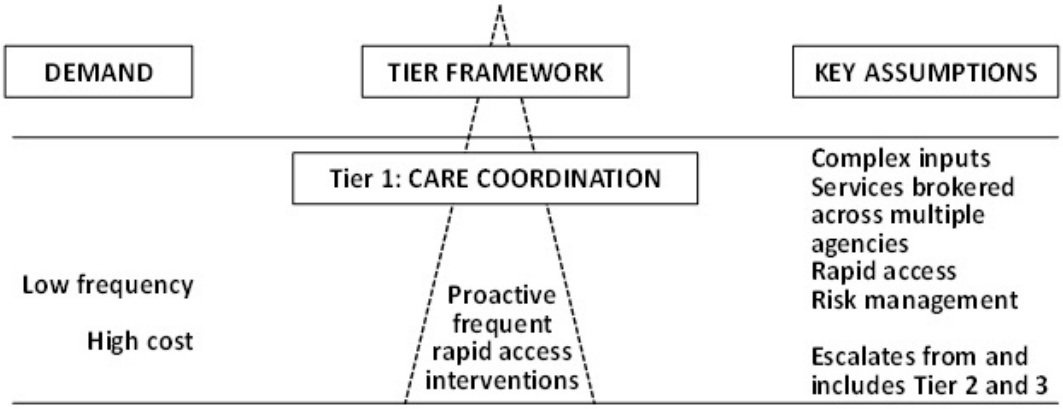

Figure 7: Acute and complex care

Case studies can provide examples of how integration between hospital and community care can avoid hospital admission and allow patients to be managed in their own home. A summary of case study two relating to Nottingham City Care Community Neurology Team Rapid response team for multiple sclerosis (MS) has been provided below.

Case Study 2: Nottingham City Care Community Neurology Team.Rapid response team for multiple sclerosis:
Provides hospital in-reach to outpatient clinics and ward visits, home visits and also community-based clinics across the city of Nottingham.
Added value:
The service highlighted the number of avoidable admissions for patients attending A&E with relapse which could have been managed at home;
A pathway was developed with A&E to provide structured assessment for people with MS presenting at A&E;
The pathway allows immediate issues to be addressed and patients discharged back to the community with follow-up to avoid further unnecessary admission;
The service was extended to out of hours A&E.

[36] No More Silos factsheet. July 2022

(Source NHS Thames Valley Strategic Network)
A service review highlighted a number of avoidable admissions, for patients attending A&E with relapse, which could have been managed at home with additional support from MS nurses. In collaboration with the A&E department, an MS pathway was created to provide a structured assessment for people with MS presenting to A&E.

The pathway now allows immediate issues to be addressed, then patients are discharged back to community with proactive nurse follow-up to prevent further unnecessary admission. The service was further extended to out-of-hours GPs so the same care could be followed without the person attending A&E.

The initiatives mentioned above and case study examples can help identify how we can improve access and provide care closer to a patient's home and create capacity within that top tier where we have high levels of clinical expertise and need to care for the most complex and acutely ill patients.

The key features of these examples are:

- Community neurology approach;
- Locally provided integrated care, organised around the patient;
- Links with tier 1 service to facilitate swifter discharge and perhaps admissions avoidance;
- Links with Acute Care At Home, community falls teams;
- Community MDT team;
- Patient centred careplan;
- Designated point of contact.

The Model for care coordination cited by Thames Valley Strategic Network for care coordination[37] provides a number of case studies in Tier 2. These include The Royal Free Hospital Neuro Rehab centre which covers the community of Barnet in London and provides community based neurological services to adults with long-term neurological conditions. Other examples include Colchester community rehab team and the Changing lives reintegration service in Tyneside. Figure 8 illustrates the level of care co-ordination required at tier 2.

[37] Thames Valley Strategic Network. June 2016 Transforming community neurology. What Commissioners Need to Know.

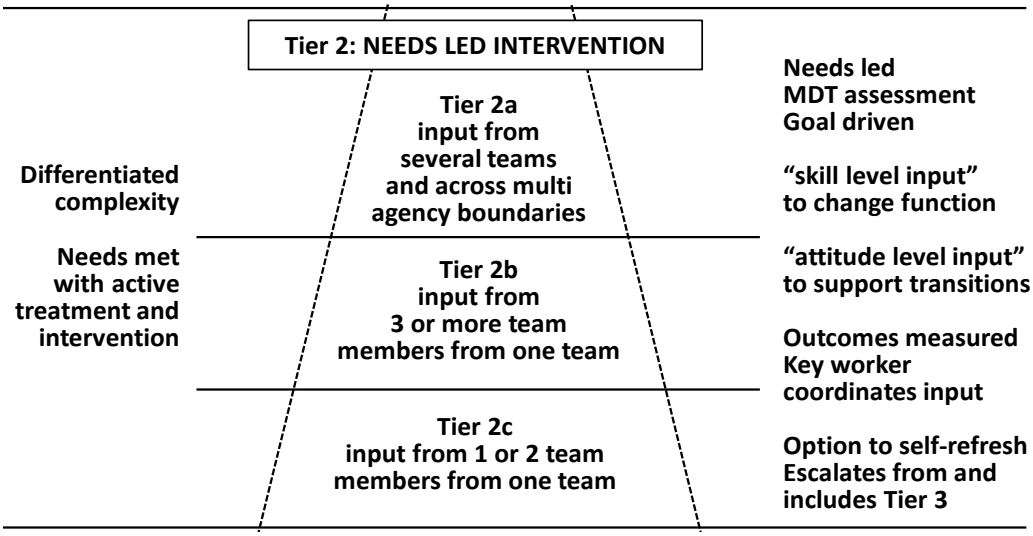

Figure 8: Tier 2 services

The key elements of these models are:

- Team assembled after needs of patient assessed;
- Skills-level input to support functional performance;
- Support adjustment and change, incl. mental health;
- Support carers and family to look after patient;
- Support to find or stay in work.

Support at this level involves a range of professionals such as:

- GP, neurologist, specialist nurses, psychologist, occupational therapist, psychotherapist, speech and language therapists, vocational rehab team and a Keyworker who acts as a Neuro-navigator.

Evidence suggests that patients spend just a few hours each year in contact with health care services and are self-managing their conditions 99% of the time. This makes it vital that the support available in tier 3, as illustrated in figure 9 helps empower patients to manage their condition as effectively as possible. Tools such as Patient Portals and resources available from community and voluntary (C&V) sector as well as health care providers are important to support self-care. Consideration should also be given to support that will help address some of the wider determinants of health in addition to condition specific support. According to research by the National Institute for Health[38]:

[38] Aspinal F, Bernard S, Spiers G, Parker G. Outcomes assessment for people with long term neurological conditions.

"*outcomes that go beyond the clinical and functioning aspects of health are likely to be equally, or more, important to people with long-term neurological conditions*".

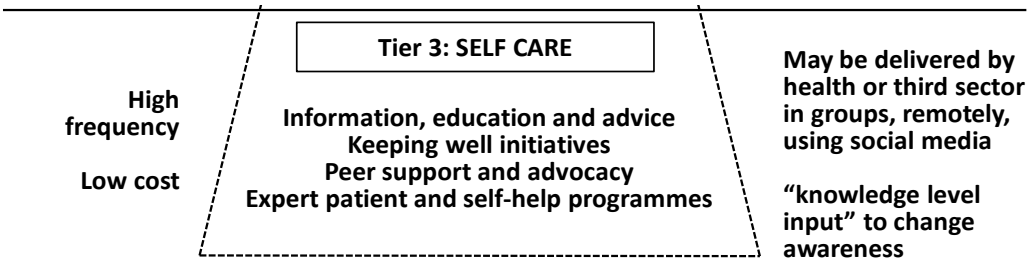

Figure 9: Tier 3 Services

The main elements of tier 3 are:

- Assets based approach;
- Added value from C&V sector;
- Education, funding, peer support, communication network;
- Use of networks to address wider detriments of health e.g. Community Planning Partnership;
- ICS approach;
- Care plan;
- Patient Portal.

APPENDIX 9: NURSING WORKFORCE

Neurology Specialist Nursing Workforce Planning Report

A Regional Neurology Specialist Nursing Workforce Planning Report for Northern Ireland (NI) was developed as part of the Regional Review of Neurology Services. Development of the Report was overseen by the Regional Neurology Review Nursing Subgroup, informed by an Expert Reference Group of Neurology Nurses representing all Health and Social care Trusts and a broad range of neurology specialist roles. The Report follows the Skills for Health Six- Step Methodology as detailed within the Regional HSC Workforce Planning Framework.

The Workforce Planning Report reflects the neurology nursing workforce planning requirements over the next 3-5 years in the first instance, with a recommendation to review the requirements for neurology nurses every 5 years going forward.
The following stages in the development of the Report were undertaken:

- A stocktake of the existing adult neurology nursing workforce across the five Health and Social Care Trusts in Northern Ireland.
- A desktop exercise to review existing evidence and literature relating to the neurology workforce.
- Identification of the projected population-based need, for Neurology Nursing services in NI and the potential requirement to meet that need initially from 2022-2028 and also the requirement at 2035.
- By identifying the number of neurology nurses required to meet the needs of the NI population over the next 5 years by considering the potential workforce impacts (where possible) to the reform and modernisation of the regional neurology service informed through the recommendations of the Regional Neurology Review.

A survey of the neurology nursing workforce in NI was undertaken from 31 January 2022 to 30 June 2022. This survey identified a total of 55 WTE adult specialist neurology nursing permanent posts with 1 temporary post. The majority of posts are currently based in acute hospital settings but many also outreach into the community also. 17% of specialist neurology nurses in NI are estimated to be eligible to retire from 2022- 2025.

Specialty	WTE
MS	17.4
Epilepsy	9.1
Parkinson's Disease	6.5
Acute Neurology Nurse	5 + 1 temporary
Learning Disability Epilepsy Nurse	5
Movement Disorder	3
MND	2
Neurovascular	2
Headache	2
Neuromuscular	1
Huntington's	1
Total	**55**

The current profile of Neurology Specialist Nurses in NI reflects the investment into specific neurology conditions over a number of years. Nurses working across neurological services in primarily specialist roles are specific to conditions such as epilepsy, multiple sclerosis and Parkinson's/movement disorder. There are a small number of nurses supporting people with less common neurological conditions such as Huntington's disease, motor neurone disease and neuromuscular conditions.

To inform the review, a literature search was conducted, incorporating specific neurological condition websites. This included a review of both population-based and caseload-based recommendations for staffing levels. The workstream agreed that the caseload approach should be used where available; if no caseload guidance was available, a population-based approach should be used. A summary of the approach taken is outlined in the table overleaf.

Speciality/Role	Approach	Recommended staffing
MS	Caseload: 315 clients per nurse	17.14
Parkinson's Disease/Movement Disorder	Caseload: 300 clients per nurse	13
Epilepsy	Population-based: 9 nurses per 500,000 population	34.2
Others	No guidance available on which to base a recommendation to increase the workforce. Recommendation based on current workforce levels.	8
Acute Neurology Nurse	Population-based: 3 nurses per 500,000 population	11.4
Advanced Nurse Practitioner		11.4

The table below summarises the total recommended Nursing workforce using the approaches outlined above.

Special Interest	**Current WTE**	**Recommended workforce**	
		2028	**2035**
MS	17.4	17.4	19
PD/MD	9.5	13	16
Epilepsy	14.1	34.2	34.92
Others	8	8	8
Acute	6	11.4	11.64
ANP	0	11.4	11.64
Total	55	95.4	101.2
Gap		**40.4**	**46.2**

It is projected that by 2028, 24,350 people in Northern Ireland will require access to Neurology Nursing services. In response to the projected increase in people and taking other conditions into account, the workforce review identified a need for 95.4 WTE neurology nurses, recommending an additional 40.4 WTE to meet the NI population need by 2028 increasing to 46.2 by 2035. These are further posts required in addition to backfilling posts left vacant from retirements and other leavers. While this reflects the neurology nursing workforce planning requirements

over the next 3-5 years in the first instance, it is also recommended that workforce requirements should be reviewed in 5 year cycles after this point.

The nurses' roles are multifaceted and include assessment, care delivery, prescribing and titrating medication, coordination, navigation and advocacy. They have a presence throughout the person's journey from diagnosis to end of life providing a person-centred approach which includes holistic assessment, establishing therapeutic relationships and often act as a designated point of contact.

Throughout all of their interventions, nurses will draw on their knowledge and expertise to plan, deliver and evaluate the appropriate care to meet the person's needs whilst upholding professional standards as outlined by the Nursing and Midwifery Code (NMC, 2018).

Whilst neurology nurses provide support to consultant neurologists they also work in multi-disciplinary teams and autonomously through nurse-led clinics where they devote time to reviewing care objectives, redefining interventions to improve outcomes and quality of life for that individual. A composite part of the nurse's role is providing clinical advice and support through telephone triage and helplines. Key to this level of intervention is the nurse's role in promoting self-management techniques to empower the individuals to live a full and meaningful life within the constraints of their condition. This method lends itself to effectively managing a population of clients rather than focusing on a specific caseload.

Nurses also have an educator role in relation to other health and social care colleagues, both within the specialty and core services. This covers colleagues working in acute hospitals, intermediate care, community services and the independent sector. The educator role extends to partners, families and carers of the people with neurological conditions. It is acknowledged that supporting family members and significant others of people with long-term conditions is a demanding but crucial aspect of nurses role as it contributes to achieving the self-management goals and maintaining a quality of life. In addition, establishing and maintaining networks with the Voluntary Sector who contribute to supporting individuals with neurological conditions is viewed as an important component of the service delivery model.

Whilst most current nursing roles are of a specialist nature, there are examples where skill mix has been introduced and reported to be a valuable asset. Examples of such roles include administrative roles that monitor calls to a helpline, provide clinic management support, support data collection for audit purposes and signpost clients to address enquiries in relation to social issues within a delegation protocol. We estimate that MS Nursing Teams in NI manage approximately 450 calls per week across the region.

In this context, the workforce review also makes a recommendation for a Neurology Nursing Team to be established in each HSC Trust. This Team approach will help improve the cohesion and professional support for neurology nurses, address challenges and capacity issues and reduce the risk of service disruption through unplanned absence of neurology specialist roles. The retention and recognition of the Neurology Specialist Nursing roles, particularly those with a particular interest in specific neurological conditions will be a key component of the Neurology Nursing Team. In addition, the recently established NI Neurology Nursing Forum will provide professional support and sharing of best practice throughout NI.

The review recommends incorporating a broad skill mix into the Nursing Team as outlined in the table below:

Role	**Main Duties**
Senior Nursing Assistant	Responsible for delegated activities including limited clinical or therapeutic interventions.
Staff Nurse	Newly Registered Nurse or a nurse with no/minimum experience in neurology. Duties in line with what a registered nurse is expected to know and be capable of doing safely and proficiently at the start of their career under the direction of the Neurology Nurse and/or the Neurology Specialist Nurses.
Neurology Nurse	Registered Nurse with a minimum of 2 years' experience working within neurology to include both experiential learning and educational programmes undertaken.
Neurology Specialist Nurse Acute AND Neurology Specialist Nurse with Specialist Interest	Registered Nurse with a Specialist Practice Qualification in Neurology; this may be in Acute Neurology or a Specialist Interest area. Leads the team and manages a caseload using collective leadership skills. Has specialist knowledge and competencies which enables them to work autonomously with patients who have a wide range of complex care needs, including palliative and end of life care.
Advanced Nurse Practitioner (ANP)	Registered Nurse who is highly experienced. Responsible for comprehensive health assessments and management of a range of illnesses and conditions that present in various settings, including acute illnesses, exacerbation of long-term neurology conditions, palliative and end of life care needs. Educates,

Role	Main Duties
	supervises and mentors nursing colleagues and other healthcare professionals within the Nursing Team.
Consultant Neurology Nurse	Registered Nurse at an advanced level in the delivery of high quality, safe and effective person and family centred care. Blends a significant proportion of direct, higher level clinical care with education, research, service development and evaluation activities. Works with multidisciplinary teams across organisational and professional boundaries. Leads and influences service policy development at a strategic level and drives improvements in population and public health and wellbeing outcomes across all services.

The Nursing Workforce Model Report proposes investment in new and higher levels of practice roles which may create opportunities for some of the experienced neurology nurses. This includes two types of Neurology Specialist Nurse roles. Some will be Neurology Specialist Nurse roles with special interest in specific neurology conditions and some will focus on acute presentation of people with neurology conditions who present in ED or at clinic or cared for in an inpatient bed that is not a neurology specialist bed. The model also recommends further investment in the Advanced Nurse Practitioner (ANP) role which has already been successfully introduced in NI.

The ANP in neurology is an experienced and expert practitioner in this area of practice who is accountable and responsible for an agreed caseload of patients. The ANP is educated to a master's degree level which includes a major clinical component relevant to neurology. The core components of the ANP role include autonomy in clinical practice, expert practice including non-medical prescribing, professional and clinical leadership and research. In addition, the ANP role includes practice that enhance the patient's journey and flow including seeing first presenters, ordering diagnostics, prescribing care/interventions and nurse led discharge.

The ANP is clinically accountable to the patients consultant neurologist. They are professionally accountable to the Director of Nursing in the Trust they work within. They will be responsible for the local delivery of high-quality care in the hospital and the community. They are also responsible for the safe, efficient and effective management of patient care. The advanced nurse practitioner provides clinical leadership, clinical supervision and support to clinical nurse specialist.

Of the additional 40.4 WTE increase in posts, it is recommended that these should comprise 11.4 WTE ANP trainee posts, equating to 2 WTE in each Health and Social Care Trust to facilitate the development of new and higher-level nursing roles. As

Neurology Nursing Teams are developed, consideration will be given to the consultant neurology nurse role.

The role of the ANP has already been introduced in NI, with the first candidate in the South Eastern Trust completing their training in September 2023. The case study below outlines the benefits of this role within the neurology service.

Case Study: Advanced Nurse Practitioner Role – South Eastern Trust

The overarching theme of the role is to practice autonomously within an expanded scope of clinical practice, to include direct clinical care, leadership, education and research. The ANP training programme within neurology in the South Eastern Trust has enabled the nurse practitioner to perform an advanced assessment on all neurology patients, in relation to detailed history taking, clinical examination and provision of a management plan. This plan includes a diagnosis, to consider the differentials, request investigations, prescribe appropriately, review patients and referral to specialists as required.

At present the role is an acute role, currently focusing on neurology patients presenting to the emergency department and admitted within unscheduled care requiring neurology input. Such conditions include headache, seizure, functional neurological disorder, multiple sclerosis, Parkinson's disease and neurological emergencies such as Guillan Barre and Myasthenia Gravis.

The role also includes providing support at general neurology clinics and the assessment of in patient referrals, in addition to an educational role in supporting the provision of teaching for Foundation Year 1 doctors.

Most recently, the role has expanded to include the triage and management of neurology patients referred from Primary Care via the Neurology Advice and Referral Management System (NARMS). This also involves running NARMS clinics and performing any service development work in relation to NARMS.

Career Pathway

To support the development of the Nursing Team, a specific Neurology Nursing Career Pathway has also been developed using the NI Practice and Education Council (NIPEC) Guidance Framework to Support the Development of Nursing and Midwifery Career Pathways. The Neurology Nursing Career Pathway is designed to facilitate a consistent approach in the development of nursing roles. It identifies the range of key nursing roles that support the delivery of high quality, safe, effective, person and family centred care and will help clarify and strengthen the important contribution of nursing in supporting the required transformation within neurology services.

The Pathway comprises key roles with associated core competencies, education requirements and job descriptions. This will enable a standardised approach to the continued development of the roles identified during the development process within Neurology Nursing, including the role of Senior Nursing Assistant. This will support nurses in taking on a range of extended roles and responsibilities supporting the neurology service. It is also intended to help attract and retain nurses within the neurology service, supporting stability and driving innovation through enhanced expertise and experience. A microsite for Neurology Nursing will be populated on the NIPEC website to aid those nurses engaging in a Neurology Nursing Career Pathway.

The nursing and support roles that have been agreed as core to neurology nursing in Northern Ireland are as follows:

- Senior Nursing Assistant;
- Registered Nurse (new or inexperienced registrant entering the service);
- Neurology Nurse (experienced registered nurse commencing a specialist practice journey in neurology services);
- Neurology Specialist Nurse Acute AND Neurology Specialist Nurse Special Interest;
- Advanced Nurse Practitioner Neurology;
- Consultant Nurse Neurology.

Senior Nursing Assistant Role

The senior nursing assistant works as a member of the Neurology Nursing Team and assists in the provision of safe, effective, person and family centred care under the direction of a registered nurse. Senior nursing assistants must have the relevant education and supervision before undertaking clinical care. They take responsibility for delegated activities including limited clinical or therapeutic interventions in line with the Delegation Framework (NIPEC 2019). Senior nursing assistants may also consider the option to progress to become a registered nurse.

Staff Nurse Role
The staff nurse is a newly registered nurse or a nurse with no/minimum experience in neurology. They work in line with the Nursing and Midwifery Council Code (NMC 2023) and the Future Nurse Standards of proficiency for registered nurses (NMC 2018). These proficiencies are grouped under seven platforms, followed by two annexes. Together, these reflect what a newly registered nurse is expected to know and be capable of doing safely and proficiently at the start of their career. This approach provides clarity to the public and the professions about the core knowledge and skills that they can expect each registrant to demonstrate. These proficiencies provide new nurse graduates with the knowledge and skills they need at the point of registration.

The platforms are:
1. Being an accountable professional
2. Promoting health and preventing ill health
3. Assessing needs and planning care
4. Providing and evaluating care
5. Leading and managing nursing care and working in teams
6. Improving safety and quality of care
7. Coordinating care

The staff nurse is a member of the Neurology Nursing Team working under the direction of the neurology nurse and/or the neurology specialist nurses to provide care and support to individuals who have a neurological condition and their families. The staff nurse promotes self-care and independence, mental and physical health and well-being and prevention of ill health and will support and participate in quality improvement activities within the team as appropriate.

Neurology Nurse
The neurology nurse is a registered nurse and member of the Neurology Nursing Team with a minimum of 2 years' experience working within neurology. The requirements for this role remain the same as for the newly registered nurse, however at this level the registered nurse will no longer be a novice in the field of neurology nursing practice and will have developed specific knowledge and skills relating to the field of practice. This will be underpinned by both experiential learning and educational programmes undertaken by the registrant which will consist of modules and /or short courses in the field of neurology nursing. It may also include programmes of study which are designed for the totality of the multidisciplinary team operating within the neurology field of practice.

Neurology Specialist Nurse Acute AND Neurology Specialist Nurse with Specialist Interest
The neurology specialist nurse is a registered nurse with a Specialist Practice Qualification in Neurology; this may be in Acute Neurology or a Specialist Interest

area e.g Parkinson's, multiple sclerosis, epilepsy, motor neurone disease etc. Within epilepsy services, there will be learning disability specialist nurses. The neurology specialist nurse may lead a team and manages a caseload using collective leadership skills. They will assist patients to make autonomous decisions about their care by co-ordinating and delivering person and family centred care. Neurology specialist nurses use a population health-based approach and proactively works with all members of the Multi-disciplinary Team, as well as patients, families, carers, community and voluntary agencies. The neurology specialist nurse has specialist knowledge and competencies which enable them to work autonomously with patients who have a wide range of complex care needs, including palliative and end of life care. They enable patients to be cared for safely in all settings and where possible reduce unnecessary hospital attendances or admissions. The Neurology specialist nurse also promotes self-care and independence, mental and physical health and well-being and prevention of ill health. They work in a Neurology Nursing Team using collective leadership skills and will support and proactively lead quality improvement activities within the team.

Advanced Nurse Practitioner Neurology

The Advanced Nurse Practitioner (ANP) is a registered nurse and is a highly experienced, expert member of the Neurology Nursing Team who practises autonomously within his/her expanded scope of clinical practice, guided by the NMC Code (2023). Professional standards of practice and behaviour for nurses and midwives (Nursing and Midwifery Council (NMC) 2018). They demonstrate highly developed assessment, diagnostic, analytical and clinical judgement skills. They are accountable for the total episode of care for people with undifferentiated and undiagnosed needs. They undertake comprehensive health assessments and manage a range of illnesses and conditions that present in various settings, including acute illnesses, exacerbation of long-term neurology conditions, palliative and end of life care needs. They educate, supervise and mentor nursing colleagues and other healthcare professionals. The ANP contributes to and undertakes activities including research, quality improvement and monitoring the effectiveness of practice.

Consultant Nurse Neurology

The consultant neurology nurse is a registered nurse and practices autonomously at an advanced level in the delivery of high quality, safe and effective person and family centred care. The consultant neurology nurse's role blends a significant proportion of direct, higher level clinical care with education, research, service development and evaluation activities. The consultant neurology nurse works with multidisciplinary teams across organisational and professional boundaries.

They lead and influence service policy development at a strategic level while continuing to provide a strong clinical commitment and expert advice. They drive improvements in population and public health and wellbeing outcomes across all services.

Core competencies have been developed for each of the 6 roles identified within the Neurology Career Pathway. The core competencies have been organised around four domains for each of the roles:

- Clinical Practice;
- Education and Learning;
- Research and Evidence-Based Practice;
- Leadership and Management .

It is anticipated that this Career Pathway for Neurology Nursing will play an important role in the transformation and re-design of neurology services across NI. Supporting the development of a highly skilled and competent nursing work force will support nurses in taking on a range of extended roles and responsibilities supporting the neurology service in meeting the evolving needs of patients and delivering high quality, person-centred care. In addition to improving patient care, creating a clear career pathway will help attract and retain nurses within the Neurology service supporting stability and driving innovation through enhanced expertise and experience.

The Career Pathway will be further strengthened by a Neurology Learning and Development Pathway, which will be taken forward out-with the remit of the Regional Neurology Review.

APPENDIX 10: AHP WORKFORCE

An AHP workforce paper 2022 – 2027 was developed as part of the Regional Review of Neurology Services. The report was overseen by the Regional AHP representation across the Neurology Review workstreams and the PHA - Trust AHP Leads forum. The current Department of Health Workforce Planning: AHP Workforce Review Reports run from 2019 – 2029[39] covering the next 3-5 years and aligning against the proposed lifetime of this AHP workforce review. It is therefore pertinent that this work informs the implementation of those workforce reports and is connected into the DoH mechanisms to do so and any workforce planning in the subsequent years.

The AHP Workforce Report was developed following the Skills for Health Six- Step Methodology as detailed within the Regional HSC Workforce Planning Framework, March 2015, Department of Health Northern Ireland[40]. This is consistent with the aforementioned current Department of Health Workforce Planning: AHP Workforce Review Reports. The workforce report outlines AHP workforce recommendations to ensure the neurology AHP workforce is appropriate to meet the population needs in Northern Ireland.

The development of the AHP workforce report included the following actions:

- A stocktake of the existing commissioned adult neurology AHP workforce across the five Health and Social Care Trusts in Northern Ireland (Baseline Collection December 2022.)

- Consideration of the projected population-based need for neurology AHP services in Northern Ireland and the potential requirement to meet that need in from 2022-2027. Further consideration will be required in the context of the lifespan of the implementation of the Neurology Review.

AHPs are a diverse group of clinicians who deliver high quality care to patients and clients across a wide range of care pathways and in a variety of different settings. AHPs are vital in the delivery of high-quality care for people living with Neurological conditions. AHPs play an important role in modern Health and Social Care services. Practical interventions from AHPs are often significant in enabling people to recover movement and mobility, psychological wellbeing, overcome visual problems, improve nutritional status, swallowing/ dysphagia management, develop communication strategies, achieve independence and everyday living skills including return to vocation/leisure, thus allowing them to sustain and enjoy quality of life even when faced with life-limiting conditions.

[39] https://www.health-ni.gov.uk/articles/workforce-planning-workforce-review-reports

[40] https://www.health-ni.gov.uk/publications/regional-hsc-workforce-planning-framework

A scoping exercise of commissioned permanent staff working as neurology AHPs in NI was undertaken in December 2022. The results of this exercise indicates that there are a total of 36.34 WTE neurology AHPs broken down by Profession below. It should be noted that there are a number of Professions not currently employed within neurology services including Podiatrists, Orthotics, Prosthetists, Paramedics and Music, Art and Drama Therapists. It was also noted that there were no joint appointments between Universities and HSCTs.

Profession	**Inpatient**	**Outpatient/ Community**	**WTE**
Physiotherapist	8.54	10.85	19.39
OT	8.5	1	9.5
Dietitian	3.15	1.5	4.65
SLT	2.7		2.7
Orthoptics	0.1		0.1
Art Therapists			0
Dramatherapists			0
Music Therapists			0
Podiatrists			0
Paramedics			0
Prosthetists			0
Orthotists			0

A high percentage of these posts (63%) are currently based in inpatient hospital settings, with a small number based in outpatient, community and specialist services. In addition, variance in provision and pathways across Trusts was identified along with challenges regarding multiple referral sources; repatriation from regional centres; training needs of core staff; and limited specialist AHP neurology staff.

AHPs are an essential part of the MDT providing inpatient care to neurology patients either via the emergency department, general core AHP teams or within specialist neurology teams. Although the majority of commissioned posts outlined in the table above are based in inpatient settings, this still falls below accepted standards. A comprehensive review of the in-patient neurology AHP workforce is required to outline the number of AHPs required to support in-patient care to neurology patients in both the specialist regional unit as well as in the district general hospitals.

The scoping exercise also outlined that there is a very small compliment of commissioned AHP services across the region for the provision of specialist neurology

care and rehabilitation in the community. With the recommended development of Local Neurology Teams in each Trust it is vital that AHPs are resourced adequately to provide input. In the context of recognised guidelines, it is recommended that an additional 38 WTE neurology AHPs across the four core professions (Physiotherapy, OT, Dietitian, SLT) are required as a minimum to support multi-disciplinary working and create additional community capacity.

Role	Per million population	NI estimate	Current Community Workforce	Additional Workforce Required
Physiotherapists	6	11.4	1.5	9.9
Occupational therapists	10	19	1.0	18.0
Speech and language therapists	4	7.6	0	7.6
Dietitian	2	3.8	1.5	2.3
Total requirement		**41.8**	**13.35**	**37.8**

In addition, further consideration will be required in future workforce planning to ensure access to other AHP professions which provide support and interventions to patients with neurological conditions e.g. Orthoptists, Podiatry, Arts Therapies. Growth in the AHP workforce should be underpinned by a skill mix of generic and advanced practice roles, including the development of consultant AHP roles.

The scoping exercise did not determine the workforce percentage estimated to be eligible for retirement from 2022- 2027 however this has been considered in the DoH AHP Workforce Reviews 2019 – 2029. Recognised workforce standards, some of which are population based, were identified, however further work will be required to reach consensus across the various parts of the neurology pathway.
There are also many common competencies across AHPs working with progressive neurological conditions.[41]

[41] (2021) Allied Health Professionals' competency framework for progressive neurological conditions. [Online]. Available at: https://www.mndassociation.org/app/uploads/2020/09/Allied-Health-Professionals-Competencies-Neuro-Conditions.pdf

Currently AHPs are underutilised within neurology outpatient services across NI. However, models have been introduced in other specialties where AHPs, working within a wider Multi Disciplinary Team can support specialist service outpatient clinics to increase capacity. Examples include orthopaedics where an enhanced MDT has delivered assessment clinics for new and review patients.

In this context, the AHP Workforce Paper also recommends the development of a skill mix of generic and advanced practice AHP roles. An appropriate skill mix of AHP staff will provide a range of newly qualified, specialist, advanced practitioners (Level 1 & 2) including more autonomous practitioners as points of first contact and as multi - disciplinary managers and leaders across the pathways in which neurology patients present. That skill mix will also drive continuing professional development within teams and clinical excellence. Consultant AHP roles should also be considered in line with the vision outlined for such roles in the NI DoH Advance Practice Framework[42]. Integrating advanced practitioners into MDTs provides clinical leadership and enables collaboration across the MDT through complex decision making and managing risk.

This robust MDT workforce model provides a flexible workforce to meet changing population, patient, and service delivery needs and helps to address current workforce challenges of recruitment and retention across all professional groups. Advanced practitioners help to improve clinical continuity and provide high-quality care for patients enabling provision of a wider range of advanced clinical care by a varied range of multi-professional clinicians rather than focusing on medical doctors as the sole providers of advanced clinical care. Consideration of the introduction of consultant AHP roles is also recommended.

The Career Pathway for the development of AHP advanced practitioners is set out in the DoH Advanced AHP Practice Framework[43] which sets out the core competencies required for advanced AHP practice. The education and training needs required to underpin the successful development of advanced practice AHP roles across neurology services needs to be identified.

[42] https://www.health-ni.gov.uk/publications/advanced-ahp-practice-framework

[43] https://www.health-ni.gov.uk/publications/advanced-ahp-practice-framework

Case Study: AHP services, Belfast Trust

The Belfast Trust has created a new Band 8A physio post in neurology with a specialist in movement disorders. The implementation of this new role enabled the introduction of:

- Physio led clinics for newly diagnosed patients;
- Review clinics for those whose meds have been implemented and reviewed with outcome measures by physiotherapist;
- Review of physical activity /mobility/movement strategies
- Support of information and educational needs and;
- Education of neurology /core service physiotherapists.

The Band 8 Physio has also formed a network of physios interested in management of Parkinson's disease to discuss management of patients, education and support general networking across NI to provide support to other AHP colleagues.

APPENDIX 11: PSYCHOLOGY WORKFORCE

Psychologists working within neurology services are experts in psychological and neuropsychological assessment, management and interventions, as applied in the context of people living with brain diseases and neurological conditions. An integrated psychological workforce plays a key role in delivering clinically effective neurological care, helping to deliver better outcomes and cost effectiveness.

Brain diseases present as one of most complex and unique challenges in healthcare. Patients not only experience physical neurological symptoms and neuro-disability, but frequently experience changes in neurocognitive status, as well as personality, behaviour and emotional functioning as a direct consequence of physical neurological disease processes and dysfunction. Psychological and neuropsychology services are therefore fundamental to providing high quality, holistic and effective care for neurology patients. As the numbers of people living with long-term neurological conditions increases, treatments advance, and associated costs grow (Public Accounts Committee, 2012), this is an important area to prioritise in commissioning.

As many neurological disorders are chronic, progressive and incurable, requiring active and lifelong management, the additional personal, familial and social impacts are high. This results in additional personal and healthcare burden, with exceptionally high prevalence of co-morbid mental health disorders in neurology populations. Almost half of new referrals to UK General Neurology Clinics have been found to be patients who meet criteria for diagnosis of at least one co-morbid anxiety or depressive disorder (Carson et al., 2000). Mental health difficulties in neurology populations result in very significant implications for wellbeing, and for medical management. They are associated with poorer quality of life, lower response to treatments associated with issues of concordance and tolerance, and higher treatment regime change based on emotional factors regardless of clinical efficacy. Neurology patients with unmanaged mental health difficulties have higher service utilisation and wastage (e.g. DNAs), lower care satisfaction, and difficulties utilising self-management information (Alsaadi et al, 2019; Barsky et al, 2001).

Alongside advances in medical investigation techniques (e.g. neuro-imaging), neuropsychological assessments continue to have a key role in multidisciplinary neuro-diagnostics. Neuropsychological services help to establish and monitor correlations between neurological damage or lesions in the brain, and relatively specific functions in psychological behaviour and cognitive function. This plays an important role in enhancing neurological differential diagnostic and treatment processes, including being required elements in candidacy selection and safety for advanced medical treatments (e.g. Deep Brain Stimulation (DBS) in Parkinson's Disease, epilepsy surgery).

Neuropsychological assessment also assists with detecting and monitoring more subtle but significant neurocognitive changes associated with neurological diseases (e.g. cognitive changes in people living with Relapse Remitting M.S.). Such assessments are fundamental to supporting people living with neurological conditions and their families, helping them to understand their condition, benefit from rehabilitation approaches, enable optimal self-manage, and empower patients to making informed choices in their lives.

On the basis of neuropsychological assessment, a diagnosis, prognosis and recommendations for treatment and support will frequently address the following areas:

- **Cognitive dysfunction** e.g. disorders of memory, concentration, perception, language, loss of insight or awareness, planning and problem-solving, speed of thinking, intellectual dysfunction
- **Mood & Neuropsychological disorders** e.g. anxiety, depression, emotional dysregulation, apathy, co-morbid functional neurological disorders, and emotional adjustment disorders.
- **Behavioural disorders** e.g. aggression, hyper-sexuality, sleep disorders, obsessional behaviours, substance misuse.
- **Neural localisation and reorganisation** e.g. using functional MRI, WADA, and invasive monitoring are used to identify eloquent cortex such as the brain regions responsible for language that should be spared in neurosurgery.

The integration of psychology within neurology improves the effectiveness and efficiency of multidisciplinary teams. It maximises the neurology service options for patient treatment and assessment. Integrated neuropsychological care can also support appropriate involvement and co-ordination of other services in complex cases and contributes to wellbeing of staff as well as patients.

Neuropsychological intervention can secure the following clinical outcomes:

- Maintaining optimal cognitive function and behaviour for patients over time, thereby reducing distress and risk of other health related problems (Cicerone et al., 2004).
- Early identification of neuropsychological deficit to trigger timely interventions and treatment (Coewtzer & Rushe, 2005).
- Early identification of neuropsychological deficit to inform differential diagnosis and prevent unnecessary on-going investigations and associated distress.
- Effective collaboration with neurosurgery to assist with diagnosis, monitor progress and improve surgical outcomes eg deep brain stimulation for Parkinson's disease.
- Enhancing clinical outcomes of neuro-rehabilitation teams, through appropriate early rehabilitation therapy to reduce long-term disability, or prevent further disability (Coetzer & Rushe, 2005; Ponsford et al., 2006).

These benefits are also likely to result in improved patient-reported outcome measures and patient satisfaction levels.

The importance of commissioning a good neuropsychology service across the wide range of neurological conditions is clearly evidenced in commissioning guidelines, Condition-specific NICE guidelines and NHS Service Frameworks as well as the growing research evidence base as noted above. (Ref Clinical Neuropsychology Services – delivering value for the NHS 2015. British Psychological Society).

Emergent Additional Demands: Functional Neurological Disorders

There is growing recognition that an extremely high proportion of neurology patients present with specific and disabling neurological symptoms, such as weakness, tremor, seizures, or paralysis, that cannot be explained "medically", and are not directly related to any "typical" neurological disease processes. This group of patients suffer from functional neurological disorder (FND), historically known as "Conversion Disorder". It is now widely recognised to be one of the commonest causes of neurological symptoms and neuro-disability, disproportionally impacting on younger adults of working age (particularly women), and with a prevalence greater than that of Parkinson's disease. It causes disability and impaired quality of life similar to that of M.S.

FND is one of the commonest reasons Neurology seek Psychology service referral, and yet this area has never received any workforce investment, with no commissioned psychology staffing anywhere in Northern Ireland, at any level. Health and social care costs are exceptionally high (within people of working age in the UK, "medically unexplained symptoms" of which FND forms a major part, are estimated at £18bn per year, more than the cost of dementia care).

The diagnosis of FND was made in 16% of almost 4000 consecutively surveyed new patients referred to neurology outpatient clinics in Scotland (Stone et al., 2010). This makes FND amongst the commonest diagnoses made in all of neurology outpatients. Gargalas et al. (2017) showed that 8.4% of patients admitted to a hyperacute stroke unit had FND (replicated in South Tees; Jason Price, personal communication). A Cambridge based observational study, showed that the number of frequent attenders to ED increased from 2.59 to 4.12% over 8 years. A case note review was conducted of 100 consecutive frequent attenders, and 45% of these had 'medically unexplained syndromes', most with FND (Jacob et al., 2016). Prospective data collection of emergency admissions at St Georges University Hospital for 1 year (2016/17) found 335 admissions for people with FND per annum (270 patients). 42% spend more than 100 hours as in-patients (unpublished audit data, currently being prepared for publication).

50% of patients admitted as emergencies in apparent status epilepticus have FND-seizures (Stone et al., 2009) and have a significant risk of iatrogenic harm and death (Reuber et al., 2004), which could be prevented by better management, particularly in the early stages.

The UK has led the way internationally over the past 10 years in raising the profile of FND both clinically and in medical research. If untreated, FND has chronic, poor prognosis with extremely high associated cost when looked at within primary care, outpatient care, inpatient care, emergency care, and these costs continue to rise in people with long-term symptoms from FND.

Strong evidence now exists to guide best practice in diagnosis, diagnostic explanation, triage into appropriate treatment, and specific treatment techniques. Interventions, including neuropsychologically informed diagnostic explanation and self-management approaches, can produce long-term benefit in symptoms, reduce health care use and is associated with reduction in health care expenditure.
FND patients understandably feel disillusioned and angry with current healthcare services (Stone et al, 2009). This leads to complaints, repeat attendance at ED, and repeat attendance for the same symptoms, and attendance of multiple specialists (Crimlisk et al., 2000).

An audit at St George's University Hospital based on the National Service Framework (NSF) for Long Term Conditions shows patients with FND receive poorer levels of health and social care compared with people attending a specialist clinic for MS, with standards of care falling short of those set out by the NSF. Although FND patients have more disability than MS patients (based on scores on the quality of life measure EQ5D) they report significantly longer time to diagnosis, worse communication of diagnosis, worse patient centred care, poorer access to services (e.g. no specialist nurse or psychology support, lower rates of referral into physical and mental health therapy services) with worse relationships with Health and Social Care professionals.

Alongside the poor patient experience and outcomes, the lack of services has significant economic and budgetary impact. Patients with medically unexplained syndromes in general, have twice the outpatient and inpatient medical care utilisation and twice the annual medical care costs of other patients (Barsky *et al*., 2005).
FND in Scotland cost £1.3 million per year for out-patients, £6 million for in-patients and £4.01 million for primary care (Carson *et al*., 2011). A study from the Republic of Ireland evaluated the economic cost and the treatment costs of FND-seizure (Magee et al.,2014) and estimated the national annual cost as over 27 million euros.
It is also important to highlight that specific conclusions of the Neurology Inquiry (Lockhart, 2022), include a note that a marked reluctance in some cases to diagnose FND was a contributory factor in the Neurology Recall.

Current Workforce

Current staffing and access to psychological and neuropsychological services in Northern Ireland for neurology patients is extremely limited as a result of decades of chronic under-investment. The core Neuropsychology Service, RVH, has been in place since the 1980's with staffing of 1.0 WTE consultant clinical psychologist. The service received no additional investment for approximately 35 years, until 2018 – the additional investment and current available staffing is detailed below.

The current psychology workforce within neurology provides specialist neuro-cognitive and neuropsychological adjustment services for people living with progressive brain diseases, such as multiple sclerosis, motor neuron disease, atypical and young onset dementia, Huntington's Disease, Parkinson's disease and related disorders. In addition, services are provided for intermittent or episodic neurological conditions, including highly prevalent conditions in neurology, such as epilepsy and complex headache disorders, as well as functional neurological disorders co-morbid to neurological disease.

Psychological Services for neurology in Northern Ireland are provided solely from within the Adult Acute Neuropsychology Services Team, BHSCT. This is in contrast to local developments for other populations of brain disorders, such as Dementia in Older Adults, Stroke and Post-Acute Stable Brain Injury populations. These populations typically have access to community MDT services, usually with integrated psychological services, and located across each Trust area with specific remits only for these presentations.

In 2010 to 2015 a review of regional brain injury services, workforce and pathways for people living with non-degenerative Brain Injury was completed. Brain injury is estimated to impact approximately 2000 people regionally per year.

Services to the brain injury population have always included access to Adult Acute Neuropsychology within the Neurosciences Ward, RVH. Developments in this area have included post-acute inpatient and outpatient services via the Regional Acquired Brain Injury Unit in Musgrave Park with MDT staffing, currently including 2.0 WTE consultant clinical psychology posts. At community level, each Trust provides a community MDT service, which at the time of the ABI Review included a regional total of 13.4 WTE psychologists and additional assistant psychology staffing, embedded in community MDTs across each Trust and integrated with an additional workforce of dedicated occupational therapy, physiotherapy, social work, and speech and language therapy in each Trust.

In stark contrast, neurology patients with progressive and intermittent neurological disease/condition had access to 1.0 WTE consultant clinical psychologist within acute services, RVH, BHSCT only. At community level, provision for psychological workforce for progressive and intermittent neurological disease and condition was

0.0 WTE, across the five Trust areas. This remains the current level of provision today within the community, while the expansion of specialist provision has had small increase, not as yet fully commissioned, as noted above.

The lack of provision for community/local level psychology services for neurology patients in Northern Ireland, and lack of outpatient or inpatient provision outside of BHSCT, places severe demand and pressures on BHSCT Adult Acute Neuropsychological Services. This team is required to provide psychological services to local Belfast community neurology populations, outpatient and inpatient tertiary regional neurology populations, and assist in support for wider community services who lack access to psychology in all local HSC Trusts. In addition, it should be noted that the RVH general Neuropsychological Team Services are commissioned to provide service across all neurosciences tertiary specialisms, including both neurology and neurosurgery outpatients and inpatients.

As can be seen below, most neurology sub-specialisms and MDTs have no dedicated psychology provision, even at acute level, meaning the only access is via the general Neuropsychology RVH Team. This results in severe issues with capacity/demand leading to extensive waiting lists, and lack of integrated psychological care for conditions such as epilepsy, M.S., MND, and HD. This is unsuitable to meet the needs of people living with progressive degenerative disorders, reduced life span, difficult end of life decisions and often relapse/remitting or rapidly evolving complex presentations. Patients living outside the BHSCT with significant neuro-disability also must travel in order to access aspects of service which could be delivered locally.

Current Workforce Breakdown

RVH TEAM The remit of this service is to provide general adult neuropsychology services providing specialist cognitive assessments and neurological health adjustment psychological therapies services to people with progressive and intermittent brain diseases. There is no funded provision for FND.		
Consultant Clinical Psychologist B8c	1.0wte	Clinical Lead & General Neuropsychology Inpatient: Neurology & Neurosurgery
Highly Specialist Clinical Psychologist B8b	1.0wte	General Outpatients: Neurology: Cognitive Disorders
Specialist Clinical Psychologist B8a	1.0wte	General Outpatients: Neurology: Cognitive & Adjustment Disorders
Specialist Clinical Psychologist B8a	0.6wte - reconfiguration of 1.0wte B5 post to better meet profile of service demand – appointed	General Outpatients: Neurology: Cognitive & Adjustment Disorders
Associate Psychologist B5	1.0 wte In recruitment	General Outpatients Neurology & Neurosurgery
CONDITION SPECIFIC / MDT (currently recruited at risk to BHSCT Neurology services)		
Specialist Clinical Psychologist B8a	1.0 wte	Regional Movement Disorders MDT – Parkinson's disease & related disorders
Specialist Clinical Psychologist B8a	1.0 wte	Regional Headaches Disorder MDT
REGIONAL REHAB		
Regional Inpatient Neuro-rehabilitation	Neurology Unit MPH	Specialist Clinical Psychologist 1.0wte B8a

Required workforce

In 2016, a scoping exercise by the Division of Neuropsychology (DoN, BPS) provided a benchmark for the best resourced (at that time) acute Neuroscience Centres in NHS England at that time, with one qualified psychologist per 150,000 population (equivalent of ~12.5 WTE in NI). This was with acknowledged ongoing gaps in service availability and delivery By comparison, in 2016, the sole Regional Neurosciences Centre in Northern Ireland, employed 1 WTE per 1.8 million with access only being via Belfast Trust consultants. Subsequent modest increases in investment in psychology workforce in NI have been noted above.

This scoping and benchmarking refers to Neurosciences Centre for typical neurological disease population only. More complex and advanced services (e.g. dedicated advance treatments services for Deep Brain Stimulation in Parkinson's Disease, epilepsy surgery, and Awake Craniotomy services are not specifically addressed in this paper. Any new service developments should have clear psychology input and any psychological needs be indicated and funded as part of any new service proposals. Additional beds should also have linked increases in psychological workforce – the current workforce projected needs are in keeping with the current inpatient beds (n=64).

Equally this scoping and benchmarking does not take account of additional workforce in community level specialist teams, such as an FND MDT service (currently 0.0 WTE in NI). Examples of best practice, such as NHS England Devon Trust's development of a dedicated FND service, employed an additional 1.6 wte Band 8 psychologists for a population of 378,000, alongside MDT support (e.g. dedicated physiotherapy).

All neuroscience centres should have a dedicated Department of Clinical Neuropsychology led, by at least, one whole time equivalent consultant grade psychologist. This is currently in place.

Provision for Psychology within Neurology Services

Regional Neuroscience Centre

- **based on 2016 DoN,BPS benchmarking paper**

REQUIRED: 12.6 wte core Psychologists for Neurosciences Centre NI (1:150,000 population)

Current core Acute Neuropsychology Workforce (3.6 WTE)

- 1.0wte B8C Consultant Psychologist – Service Lead & RVH Inpatient Lead – RVH Regional Neurosciences Centre – currently in post
- 1.0wte B8b Highly Specialist Psychologist – General Neurocognitive Assessment Lead- RVH Regional Neurosciences Centre – currently in post
- 1.6 B8a Specialist Psychologist – Neuro-Adjustment & Cognitive Service - RVH Regional Neurosciences Centre –appointed

Current specialist Acute Neuropsychology Workforce (2.0 WTE)

- 1.0wte B8a Highly Specialist – Movement Disorders – in post; at risk – need commissioned funding
- 1.0wte B8a Highly Specialist – Headache Service – in post; at risk – need commissioned funding

Additional Workforce Required (7 WTE Psychologists)

- 1.0 wte B8b – Specialist Psychologist, Neuroscience Inpatients including inpatient FND support within neurology ward
- 1.0 wte B8b – Highly Specialist Psychologist – Complex Epilepsy MDT sub-specialism
- 1.0 8a – Specialist Psychologist – Epilepsy
- 1.0 wte B8b - Highly Specialist Psychologist – M.S. MDT sub-specialism
- 1.0 wte B8b Highly Specialist Psychologist – MND (including Palliative supports) MDT sub-specialism
- 1.0 wte B8b - Highly Specialist Psychologist -Huntington's Disease & related hyperkinetic disorders MDT sub-specialism
- 1.0 B8a – Specialist Psychologist- Neurocognitive Disorders MDT sub-specialism

***Psychological Services management time and administrative provision will also need commissioned to support this growth in service delivery.

Regional Neuro-rehabilitation Unit. Musgrave Park

- **1.0 B8a Specialist Psychologist in post (Neuro-rehab bed support)**

Supervision, support and governance is provided via the RVH consultant post – this is seen as an extension of inpatient support. Thus the RCP and British Society of Rehabilitation Medicine guidelines (2003) of a consultant psychologist for the first 10 beds can be seen to be met via this role.

RCP and British Society of Rehabilitation Medicine guidelines (2003) give recommendations on minimum staffing levels in in-patient and out-patient rehabilitation teams. An in-patient rehabilitation service focusing on cognitive and behavioural rehabilitation following brain injury/illness will need a minimum of one full time psychologist per eight to 10 beds (this is in post). Further expansion of psychology roles into neuro-palliative and respite beds would require additional investment at a minimum of 1 psychologist per 10 beds
This post is the lead for psychology delivery within the Unit. In order to ensure retention and better reflect the specialist role and leadership aspects of the job on a second inpatient site, **this post should be uplifted to a B8b Highly Specialist Psychologist.**

Community Level Psychology for Neurological presentations across Northern Ireland

Local Neurology HUB Model with local MDTs

In line with examples of best practice for other local neuro-disability service areas, such as Non-Progressive Brain Injury and Stroke, a model of locality based provision within community HUB MDTs for neurology patients is recommended for each local Trust, with dedicated Psychology provision.

RCP and British Society of Rehabilitation Medicine guidelines (2003) give recommendations on minimum staffing levels in in-patient and out-patient rehabilitation teams. Based on these multi-disciplinary recommendations, adequate provision for a community/local team serving a population of up to 500,000 should have at least two whole time equivalent psychologists.
We advise beginning with the following staffing and putting into place regular outcome reviews including accessibility and outcome data monitoring. The wider MDT needs will be addressed within their own workforce submissions.

Each local HUB should on average have minimum staffing of:

- **1.0wte Consultant Psychologist (B8c)**
- **1.0wte Specialist Psychologist (B8a)**

- **1.0wte Associate Psychologist (B5)**

This would provide equitable access for people living with progressive and intermittent brain diseases to MDT services with integrated specialist psychological care. Neurology HUBs would be offer input for all patients and their families, tackling significant health inequalities for neurology patients, including the FND population.

Given the significant numbers of neurology patients, including FND presentations, within each Trust area, and the services provided to a high percentage of patients by local Neurologists, the local HUB should function as a secondary care service, accepting referrals from locally based Neurologists and teams. It would not be appropriate for this to be a Primary Care facing HUB, although it will be important to build relationships and act as a resource to Primary Care in terms of information and support.

Psychologists within the local Neurology MDT Hubs will have close links with regards to training and supervision from the regional Neuroscience Centre psychology staff.

APPENDIX 12: PHARMACY WORKFORCE

Pharmacists and pharmacy support teams are an essential part of the Multi-Disciplinary Team (MDT) providing care to patients across Trust services whether with or without dedicated neurology pharmacy service provision. The pharmacy workforce requires suitably skilled and resourced service provision in neurology. The gap in this speciality is through lack of dedicated pharmacy funding and the need is exacerbated by the complex medications used to treat the many conditions that neurology teams care for. We need to significantly increase the pharmacy workforce to meet current and projected demand of neurology services. There would also be an expectation to deliver relevant neurology education to Trust staff and other stakeholders. In addition, the pharmacist should identify gaps in neurology medicines management, safety and optimisation, and address these using innovative service development, guideline development, Quality Improvement (QI), and research approaches.

Pharmacists have a well-defined expert role in the medicines management of complex patients and can also offer support to other multi professional team members working in neurology services. Outside of dedicated neurology wards, consultant neurologists provide support to patients with neurological conditions admitted across specialities on inpatient wards. Specialist clinical pharmacists in neurology would provide in-reach support for inpatients with complex neurology needs. Dedicated neurology pharmacists working across inpatient and outpatient services would be able to further support GP practices in the safe, long-term management of conditions managed with complex medicines across the interfaces of care. When pharmacists are members of the multi professional teams, published evidence shows a reduction in medication errors and improved outcomes for patients by individualisation of patients' medications and cost reduction by optimisation of medicines.

Critical and complex medicines are key treatments in many of the most prevalent conditions such as epilepsy, Parkinson's and MS. Strategies to improve and increase prescribing and access to medicines across N.I. requires planned resourcing for pharmacy to manage these medicines. Prescribing is the most common patient level intervention in the NHS and is the second highest areas of spending after staffing costs. Between 30-50% of medicines prescribed for long-term conditions are not taken as intended. Pharmacy teams contribute to system wide approaches on key medication safety improvements for example the regulatory changes to safer use of sodium valproate. The Interface Pharmacist Network for Specialist Medicines team of pharmacists and technicians currently provide a key role in supporting the safe prescribing and supply of these medicines from secondary care services though levels of clinical pharmacy services that can further support these teams varies across the region.

The DOH pharmacy workforce review 2020 details the varying roles of a modern day pharmacy service in providing expert medicines management as well as extended roles such as prescribing pharmacists and advanced pharmacy practitioner roles right through to consultant pharmacist roles[44]. Established workforce models in other specialities should be applied to the neurology pharmacy workforce.

Pharmacists and pharmacy support teams have the appropriate skill mix to support the neurology workforce in supporting people with neurological conditions in the right way in the right place must be at the centre of our approach to workforce development. Inpatient clinical pharmacists may be present in Trusts as general ward based pharmacists, however none of these posts are directly linked with neurology teams or working as specialist neurology pharmacists. Through the provision of dedicated neurology pharmacists, these pharmacists would be based in outpatient or ambulatory hubs and provide in-reach support to inpatients under the care of neurology teams.

On review of the draft neurology workforce report, it has been highlighted that there is a need to include a comprehensive neurology pharmacy workforce model. This model will suitably detail and plan investment and growth in pharmacy services to neurology. The pharmacy workforce will need to be connected to the recommendations for the successful expansion of associated professions alongside the medical, nursing, AHP and psychology workforce.

Pharmacy teams can align to deliver the attainment of priority actions through use of a variety of their clinical skills including prescribing and advanced level practice such as the consultant pharmacist roles. As neurology services expand, it is important at the outset to give consideration to the increasing numbers of patients accessing these complex treatments, whether dispensed and delivered to the patient from the Trusts, the use of Homecare solutions, or support to GPs for shared care arrangements. Pharmacy teams will require infrastructure to support these growing needs. As pharmacy workforce is developed in neurology, consideration would be given to advanced practice prescribing roles. This would align with case studies provided in the GIRFT neurology report and a 10 year pharmacy workforce model needs to be established.

With respect to a baseline in neurology pharmacy services across NI, there are some pharmacists and pharmacy technicians working with neurology specialities within the interface specialist medicine teams but these teams are beyond capacity of any historical funding. There has been a lack of planned investment across the region for pharmacy services to neurology. In some Trusts pharmacy technicians are managing the dispensing of many high cost medicines and have an important role in optimising efficiencies and reducing medicines waste.

[44] https://www.health-ni.gov.uk/publications/guide-developing-role-consultant-pharmacists-northern-ireland

Consideration should be given to an approach similar to cancer services where a service impact assessment is undertaken when horizon scanning moves to approving and commissioning new specialist medicines for neurology services to ensure appropriate pharmacy infrastructure is funded to support the clinical pharmacy input, supply and delivery of these medicines.

For conditions managed with biologics, there is the opportunity for biosimilar switches to be done when the originator comes off patent. This needs to be done in conjunction with Trust finance and planning teams to ensure switches are done at the earliest opportunity to maximise savings with an understanding of resources required to undertake the switches in lines with guidance.

At present, the drugs and staffing budgets associated with the supply of most red-listed medicines used to treat multiple sclerosis sit with the Belfast Trust. We note the work to devolve MS medication budgets across Trusts in NI and support this in order to fully fund and develop the initial limited investment in Neurology Pharmacy Teams. There is an established system of prescribing and supply across Trust Pharmacies, however the devolvement of budgets is essential to strengthen the patient centred model of care. Due to regional variation, this will be explored in the full pharmacy neurology workforce review later this year. There is ongoing regional sodium valproate safety work that has highlighted the gaps in need for provision of pharmacist and pharmacy team resources. The details will be added as this work will conclude whilst the wider pharmacy workforce review commences. Enhanced clinical pharmacist roles are limited across the region due to the demands of supply needs of organising prescriptions, dispensing and supply within specialist medicines service with any historical funding to pharmacy services. With pharmacy workforce planning for neurology services both roles can be scoped to ensure patient supplies are maintained and the clinical pharmacy role is realised and developed.

High level ask Year 1

1. **Belfast HSC Trust**

Belfast HSC Trust (BHSCT) has significant pharmacy workforce requirements due to the scale and complexity of housing the regional neuroscience centre and the linkages BHSCT Neurology Teams provide into other regional specialist services and specialities both intra- and inter- Trust.

BHSCT is the only Trust in NI with designated neurology inpatient beds - there are currently 18 neurology beds in RVH and 23 neuro-rehabilitation beds in Musgrave Park Hospital. These existing inpatient beds benefit from limited clinical pharmacist cover 5 days a week. Further pharmacy resource to include a clinical technician 5 day service to existing neurology beds is essential to fully support medicines management at ward level (similar to many other inpatient areas), realise the benefits of ward based dispensing for discharge and support patient flow.

It is also noted that there is proposal in the report to increase inpatient bed numbers in the centre from 18 to 36 over a 5 year period and additional corresponding inpatient clinical pharmacy resource will be required to support this and/or extension to a 7 day model of working.

With respect to paediatric neurology services, the report notes this area to fall under a separate Strategic document. RBHSC paediatric clinical pharmacy resource will need to be considered within the context of this document. As noted there may be needs for the transitioning service that can be scoped in a fuller pharmacy WFP year 2-5 planning.

Neurology MDT teams provide an in-reach service to many other BHSCT inpatient areas, the Emergency Departments and outpatient services, both within the Regional Neurosciences Centre and in other Trusts. As described by other Trusts there is no current pharmacy support commissioned for this. Commensurate with the size and scale of the medical and MDT Neurology Teams within the Neuroscience Centre and in line with the resource identified by other Trusts to establish a baseline, support teams and enable further scoping of the neurology pharmacy requirement for year 1 would be 5.0wte pharmacists. The vision for the development of this clinical neurology pharmacy team would be to have 3 wte x 8a clinical pharmacists and 2 wte x band 7 pharmacists to maximise appropriate use of skill-mix. A neurology consultant pharmacist post should also be established within the Regional Neurosciences Centre to lead the Neurology Pharmacy Teams across NI in providing highly specialist and complex patient care for these groups of patients and to provide strategic direction and lead on education and research for neurology pharmacy services across the region. This will be particularly important to align with the proposed growth in neurology services described within the report to meet population needs.

Further detail into year 1 and initial pharmacy workforce requirements across aseptic services, clinical pharmacy, interface specialist medicines, patient services including procurement will be provided once a pharmacy workforce review has been concluded.

	Initial Year 1
To support existing neurology inpatient beds across BHSCT sites	2 wte x band 5 clinical pharmacy technicians
To support BHSCT neurology team across other inpatient, Emergency Departments, outpatient areas	3 wte x band 8a pharmacists 2 wte x band 7 pharmacists
Consultant pharmacist post	To lead the pharmacy team within the neurosciences centre and provide strategic leadership and direction across the region

2. **Trusts outside of Regional Neurosciences Centre**

Noting the phased investment approach in the draft neurology workforce report, clinical pharmacy recommends starting in Year 1 with a minimum of 1.0 wte 8a neurology clinical pharmacist prescriber commissioned in each of these Trusts. Further detail into year 1 and initial pharmacy workforce requirements across aseptic services, clinical pharmacy, interface specialist medicines, patient services including procurement will be provided once a pharmacy workforce review has been concluded.

3. **All Trusts**

Each Trust pharmacy department will need to be included in respective Trust action plans referenced in the neurology report to ensure financial requirements include all pharmacy service needs are considered and met.

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