Neurological Conditions

The Case for a Modern Service Framework

May 2026

THE NEUROLOGICAL ALLIANCE

MS Society

Executive summary

Neurological conditions shape the lives of millions of people in the UK. One in six of us will be affected, and many more feel the impact as family, friends, or carers. They can affect anyone at any time, impacting every aspect of life. They cost billions of pounds to the health service and even more to the wider economy.

Yet neurological care remains fragmented, under-resourced and too often overlooked.

The consequences are stark. Long waits, inconsistent access to treatment and support, and severe unwarranted variation mean that where you live too often determines the care you receive. Services are reactive rather than preventative, with too many people reaching crisis point before getting help. The result is avoidable deterioration, poor experiences and rising emergency admissions that place further strain on the NHS.

This is not sustainable, and it is not inevitable.

The Government's 10-Year Health Plan provides a once-in-a-generation opportunity to transform neurological care. This report makes the case for a dedicated Modern Service Framework (MSF) for neurological conditions to drive that change. Without it, there is a real risk that people affected by neurological conditions are left behind.

We propose a clear, system-wide ambition:

Reduce avoidable emergency admissions for neurological conditions by 30% within 10 years.

This "moonshot" focuses on the point where system failure is most visible, when gaps in diagnosis, coordination and community support escalate into crisis. Delivering it would improve outcomes, reduce inequalities and release significant system capacity.

To achieve this, the report sets out five pillars for change:

1. **Right people:** a sustainable, multidisciplinary workforce, working at the top of their skills, with care coordination as a universal standard.
2. **Right care:** equitable, needs-based care that integrates physical, mental and social support, not limited by diagnosis or postcode.
3. **Right time:** earlier intervention, proactive monitoring and rapid access to specialist advice to prevent deterioration.
4. **Right place:** a shift from hospital-centred care to integrated, community and neighbourhood models, backed by specialist networks.
5. **Right systems:** robust data, digital infrastructure and accountability to drive improvement and reduce variation.

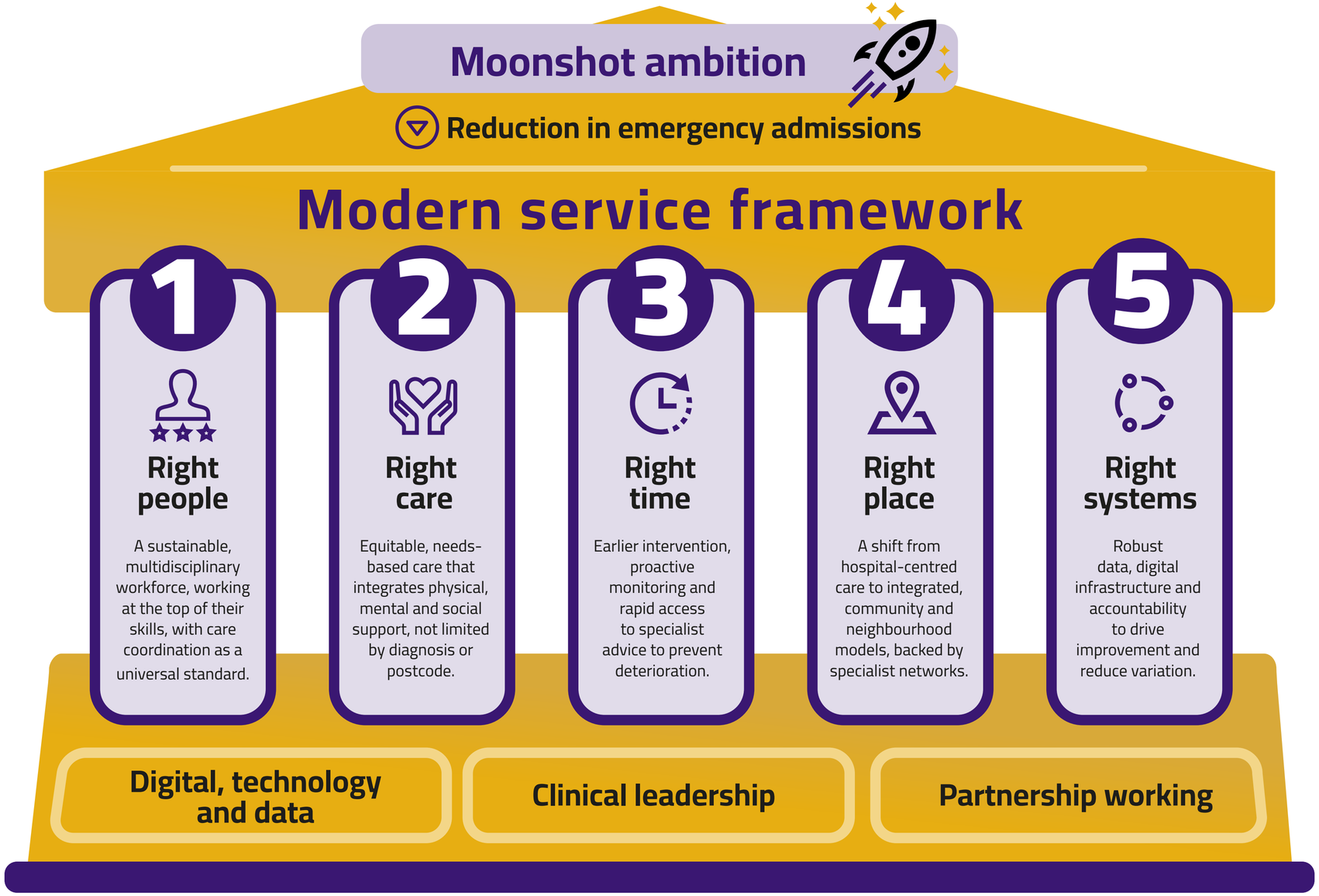
Together, these pillars provide a blueprint for delivering the three core shifts of the 10-Year Health Plan: from hospital to community, analogue to digital, and treatment to prevention.

These pillars are underpinned by key enabling factors for delivery: digital, tech and data; clinical leadership; and effective partnership working.

There is strong momentum to build on. Clinical leadership, national programmes, service specifications and a committed cross-sector coalition are already in place. What is missing is a unifying policy mechanism to bring these elements together, set clear expectations, and drive consistent implementation across the country.

A modern service framework for neurological conditions would provide that mechanism. It would anchor reform over the long term, ensure system readiness for emerging treatments and technologies, and place people affected by neurological conditions at the centre of care.

The case is clear. The neurological community is ready. We're calling on the government to join us and act for the one in six.



Disclosures

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Background

As part of the 10-Year Health Plan for England[1] the Government has committed to developing a series of Modern Service Frameworks (MSFs).

This approach is informed by National Service Frameworks[2] used from 1997 to 2010 to address inequalities and unwarranted variation in care and deliver improvements in outcomes for major conditions.

Neurological conditions were a key focus of the former National Service Framework for Long- term Conditions published in March 2005. Despite long waits, increasing variation in access to treatment and support and pressure across care pathways, neurological conditions were not included in the first wave of MSFs announced by the Government.

There is some overlap between neurological conditions and first-phase Modern Service Frameworks, including stroke within the cardiovascular disease pathway and the links between neurological conditions, frailty, dementia, end of life and palliative care. Focusing on these areas alone risks overlooking the majority of neurological conditions and the services required to support them. It also risks underestimating the capacity required within neurological services to deliver these frameworks effectively.

Without explicitly recognising and planning for this, neurological services could become overstretched, undermining the delivery of these frameworks and leading to inequitable care for people affected by neurological conditions.

This reinforces the case for neurological conditions to be addressed explicitly through a dedicated Modern Service Framework. There is strong groundwork to build on, including the Getting It Right First Time (GIRFT) neurology programme, updated adult neurology service specification and forthcoming specifications for paediatric neuroscience, complex rehabilitation and neurosurgery. There are also improvement tools developed by the NHS England national neuroscience transformation programme, updated National Institute for Health and Care Excellence (NICE) guidelines[3] and evidence that charities have gathered over recent years. With NHS structures still evolving, these positive steps may be lost unless they are anchored to a clear policy lever within the new NHS architecture.

Modern Service Frameworks represent a mission driven and outcome focused way of tackling unwarranted variation, improving outcomes and setting long term direction for major conditions. They are designed to endure over a decade in alignment with the NHS 10-Year Health Plan and to sit above short term spending rounds and political cycles, with a strong emphasis on value and reform rather than simply additional spending.

The National Quality Board will prioritise MSFs where there is a compelling case for change, an ambitious outcome goal that goes beyond current best practice, a strong partnership coalition, and credible plans for digital-first care pathways.

For neurological conditions, which have historically suffered from fragmented care, long waits and under investment, securing a dedicated MSF is both an opportunity and a necessity to prevent further widening of existing inequalities and to align neurological conditions with broader system priorities.

Securing a Modern Service Framework for neurological conditions is also critical to preparing the NHS for the next generation of treatments and technologies[4]. Neurological care is entering a period of rapid change, with a growing pipeline of disease-modifying therapies, advanced diagnostics (including genomics and biomarkers), and digital tools that enable earlier diagnosis, monitoring and intervention. Without system-level readiness, including workforce capacity, diagnostic infrastructure, data capability and coordinated pathways, these innovations risk increasing pressure on services and widening inequalities rather than improving outcomes. An MSF provides the policy mechanism to ensure that emerging treatments are implemented safely, equitably and at scale, with benefits realised across the system rather than concentrated in a small number of centres or populations.

Formulation of this report

This report is informed by insights from an expert roundtable held on 28 January 2026, convened by The Neurological Alliance and the MS Society. It brought together clinical leaders, policymakers, system partners, Voluntary, Community, Faith and Social Enterprise (VCFSE) organisations, health and care professionals and professional bodies, and people affected by neurological conditions.

It sets out a clear and timely case for change. Drawing on existing service improvement initiatives, it identifies a stretching yet credible ambition, alongside practical interventions capable of delivering meaningful improvements in care, support and outcomes. It also highlights how digital-first approaches are already improving access, coordination and patient experience.

Critically, the report reflects the strength of collaboration across the sector, a "coalition of the willing" spanning clinical, system and VCFSE leadership, united by a shared commitment to improve neurological care. This coalition is well placed to support the design and delivery of a modern service framework for neurological conditions.

About neurological conditions

Neurological conditions affect at least one in six people in England. They include any condition affecting the brain, spinal cord, intracranial vascular system or nerves, and can impact how a person thinks, feels and interacts with the world.

There are over 600 neurological conditions, including common conditions such as migraine, epilepsy and multiple sclerosis (MS); rarer conditions such as Motor Neurone Disease (MND) and Duchenne Muscular Dystrophy; and sudden-onset conditions like acquired brain injury (ABI). This also includes learning disabilities, neurodevelopmental conditions, and many other conditions that may be less visible in national policy but have a significant impact on quality of life.

Taken together, neurological conditions can affect anyone, at any age. They often span decades and have wide-ranging physical, cognitive, mental health and social impacts, shaping independence, relationships, education, employment and financial security.

Case for change

This case for change is organised around five themes that together describe a system under sustained strain but with opportunities to improve. These are not isolated problems. They are mutually reinforcing, creating a cycle in which long waits feed crises, workforce gaps amplify unwarranted variation, avoidable admissions drain resources, and fragmented care erodes lives.

We currently stand at a pivotal moment for treatment and support for people affected by neurological conditions. The combination of emerging treatments, improved diagnostics, and digital innovation creates the possibility of managing conditions earlier and more proactively. However, these advances also expose the limitations of existing service models. Without proactive reform, the NHS risks being clinically capable but operationally unprepared, unable to deliver new treatments at pace, ensure equitable access, or provide the long-term monitoring and support these innovations require.

Delivering a modern service framework for neurological conditions would be a catalyst for embedding the three shifts that underpin the 10-Year Health Plan for England in neurosciences. Below we set out the case for a MSF, and how this would drive the move from hospital to community, from analogue to digital and from treatment to prevention supported by innovative and scalable approaches to service design and delivery. The five themes are:

1 **Theme 1**
Scale and rising burden

2 **Theme 2**
Economic case for doing things differently

3 **Theme 3**
Persistent access failures and stark unwarranted variation

4 **Theme 4**
Ongoing workforce crisis

5 **Theme 5**
Unacceptable individual and carer experiences

1 Theme 1

Scale and rising burden

Globally the total number of people living with neurological conditions is expected to increase by 22% from 2021 to 2050[5] increasing pressure on already stretched services. Factors including an aging population and improvements in diagnostics and treatment will continue to increase the burden of these conditions to the health system and wider society. Neurology is also one of the largest drugs pipelines by specialty, second only to oncology, including potential treatments for conditions that are currently untreatable.

Globally, neurological conditions are the leading cause of disability and the second leading cause of death[6]. The global toll of neurological conditions now exceeds that of all other diseases, including cardiovascular[7].

2 Theme 2

Economic case for doing things differently

The economic burden of neurological conditions is vast, costing the UK an estimated £96 billion annually—around 4.3% of GDP. Over half of this (53%) is indirect, driven by lost productivity as people with neurological conditions and their informal carers are forced out of the workforce due to inadequate support[8].

This is a false economy of inaction. Implementing existing interventions, such as preventative care, proactive rehabilitation and improved care coordination, could reduce costs by more than £30 billion each year[9].

Fragmented pathways also drive significant avoidable costs. Parkinson's is seven times more prevalent among England's primary and secondary care service users by cost[10], with emergency admissions reaching £325 million[11] in 2024/25, a 24% increase since 2021/22.

A similar pattern is seen in epilepsy, which has the highest number of excess bed days and A and E attendances of any neurological condition, with around 18,000 excess bed days and 85,000 A and E attendances annually. Excess bed days have doubled since 2020.[12]

In multiple sclerosis (MS), more than one in seven people had an unplanned admission in 2023/24, with costs totalling £113.5 million. People with MS are 2.4 times more likely to be admitted unexpectedly than those without the condition, and have higher readmission rates (22.4%). Many of these admissions, often driven by preventable complications such as infections or bladder and bowel issues, could be avoided through earlier intervention and better community-based care.

3 Theme 3

Persistent access failures and stark unwarranted variation

Despite the scale of need, neurology and neurosurgery have some of the longest waiting times in the NHS and are among the worst-performing specialties against the 18-week standard[13].

In some areas, people wait up to a year for a first neurology appointment, with particular challenges for rare conditions and for pathways where timely genetic testing is needed to access emerging treatments. For people with MS, time to first neurology appointment rose 65% between 2019/20 and 2023/24[14].

During these delays, many receive little or no structured support, despite the anxiety of diagnostic uncertainty[15]. This leads to avoidable deterioration, preventable crises, and missed opportunities to access treatments within optimal windows.

Severe unwarranted variation is a defining issue. Timely diagnosis and access to treatments and support including disease modifying therapies (DMT), specialist nurses, allied health professionals, rehabilitation and psychological support varies dramatically by postcode, condition and local workforce.

MS prescribing data highlights this inequity[16]: in 2024/25, the proportion of people starting a high-efficacy DMT ranged from 27% to 89% across Integrated Care Boards (median 70%). Access to the most effective treatments is therefore shaped by geography rather than clinical need.

As a result, care is too often episodic and crisis-driven. With the right support, many people could remain stable, but when early signs are missed or services are unavailable, preventable complications escalate and emergency care becomes the default.

4 Theme 4

Ongoing workforce crisis

These access and outcome challenges are closely linked to a workforce crisis[17]. The UK lacks a single reliable dataset for the clinical neuroscience workforce, meaning service planning is too often based on incomplete information.

Available data indicates that more than a third of neurologists are concentrated in the South East of England. No region meets the recommended minimum baseline of 1.6 whole time equivalent consultant neurologists per 100,000 people[18]. In practice, limited neurology consultant capacity is often stretched across large geographical footprints, with community and other teams sharing resource. This impacts both equity of access and the consistency of care delivered.

Shortages extend across the multi-disciplinary team (MDT). Specialist nurse provision is far below recommended levels. For example, epilepsy services in England are described as having around 0.4 specialist nurses per 100,000 population compared with NICE guidance of 1.8[19].

There are also significant gaps in allied health professionals, neurosurgeons and specialist mental health services with specific neurological expertise including neuropsychologists and neuropsychiatrists. Highly skilled clinicians across disciplines report spending large amounts of time on administrative tasks that could be undertaken by trained support staff, reducing the time available for direct care. This includes Rehabilitation Medicine, where workforce capacity is particularly limited, with fewer than 0.27 specialists per 100,000 people in the UK compared with around 3 per 100,000 across Europe[20].

In primary care, many GPs report that neurological conditions can feel too complex, contributing to a tendency to refer or admit rather than manage common neurological issues with appropriate specialist support[21]. This is not a failure of primary care. It is a predictable response to limited access to advice, unclear pathways, and insufficient shared care infrastructure.

5 Theme 5

Unacceptable individual and carer experiences

Experiences shared by people affected by neurological conditions further illustrate why an MSF is needed. My Neuro Survey 2024/25[22] found that nearly half of adults with neurological conditions do not feel supported by the health system, and more than a quarter were unable to see a neurologist or specialist nurse in the previous year.

Access to neurorehabilitation is also a significant gap, with 64% of people reporting difficulties accessing these services, despite their central role in maintaining function, independence and quality of life[23].

Mental health support is particularly lacking. More than 60 percent of respondents who needed neuropsychology or neuropsychiatry could not access it, despite well documented higher rates of anxiety, depression, cognitive impairment and suicidality in many neurological conditions[24].

Nearly two thirds (65%) of carers who responded to the survey reported spent more hours caring than they would spend working a full-time job.

Just under a quarter of children and young people with a neurological condition (24%) reported they received no support outside of the home.

For many people, the system can feel geared towards acute crisis management rather than long-term maintenance of independence and quality of life, with financial strain, loss of employment and social isolation recurring themes.

Moonshot Ambition

A Modern Service Framework is anchored by a single stretching outcome that is meaningful to people, measurable for accountability, and ambitious enough to drive system-wide change.

Our proposed moonshot ambition

Achieve a 30% reduction in emergency admissions for neurological conditions within 10 years

This includes interim targets of:

A 10% reduction in emergency admissions for neurological conditions by 2029

A 20% reduction in emergency admissions for neurological conditions by 2032

For neurological conditions, emergency admissions are where system pressures are most visible—where long waits, fragmented pathways, limited community capacity and workforce gaps translate into crises that are distressing for individuals and costly for the system.

Focusing on avoidable or clinically divertible admissions creates a clear link between the case for change and delivery. It directs action towards preventing deterioration, intervening earlier, and supporting people to remain well at home, rather than defaulting to crisis care.

This is a stretching, system-wide ambition to address avoidable deterioration. The precise target should be refined through engagement with clinicians, people affected by neurological conditions and system leaders, alongside improved data and modelling.

For this report, avoidable emergency admissions are those that could have been prevented with timely, appropriate care. Too often, gaps in diagnosis, community support, rehabilitation and workforce capacity allow preventable complications to escalate until A and E becomes the default. This moonshot targets that shared system failure, rather than focusing on individual conditions.

Progress can be tracked through datasets such as the NHS England Emergency Care Data Set, Monthly Situation Reports (MSitAE) and Hospital Episode Statistics (HES), although current limitations in data quality and neurological coding remain a challenge.

Roundtable participants stressed that this crisis-driven pattern repeats across neurological conditions: late presentation through avoidable complications rather than inevitable disease progression, high readmission rates, and heavy reliance on expensive acute care when earlier intervention could maintain independence and quality of life.

This is supported by wider evidence. For example, preventable admissions and readmissions for people with neuromuscular conditions were significantly reduced through improved monitoring and coordinated care, reinforcing the potential to shift from reactive to proactive models across neurology[25].

The 30% reduction target therefore addresses a cross-cutting manifestation of the problems detailed earlier. Long waits, workforce gaps, poor primary–secondary integration, weak care coordination, and inadequate community infrastructure.

The five pillars of the vision

Five pillars underpin the moonshot target, translating the case for change into a practical delivery framework. They set out how system-wide improvements can be organised and measured, addressing well-evidenced challenges including workforce gaps, fragmented pathways, crisis-driven care and poor data.

These pillars are:

1. **Pillar 1: Right people**
2. **Pillar 2: Right care**
3. **Pillar 3: Right time**
4. **Pillar 4: Right place**
5. **Pillar 5: Right systems**

Pillar 1: Right people

This pillar focuses on having the right people, in the right numbers, with the right skills, in the right places. It requires evidence-based workforce planning with clear baselines, ensuring sufficient neurologists, specialist nurses, allied health professionals (physiotherapists, occupational therapists, speech and language therapists), psychologists, psychiatrists, pharmacists, rehabilitation medicine specialists and care coordinators across the country.

Recommendations made in the recent Association of British Neurologists (ABN) workforce report[26] and Neurological Alliance workforce consensus document[27], should be taken forward at pace to support this.

> **[It's] not just about the amount of workforce, but using our workforce well and standardising how we do things without necessarily mandating a single model " - Roundtable Participant**

A key priority is enabling staff to work at the top of their competencies: specialist nurses managing stable patients, AHPs delivering defined interventions, pharmacists supporting medicines optimisation, and administrative staff reducing non-clinical burden. This allows neurologists to focus on complex diagnosis, treatment and supervision.

Workforce development is central, including upskilling in caseload management and decision-making for junior staff.

In our discussions, care coordination emerged as the single most important priority. Every person with a neurological condition should have a named care coordinator, embedded within multidisciplinary teams and linked to clear pathways. Evidence and lived experience show that effective coordination reduces avoidable admissions by identifying issues early and preventing people from falling between services.

> **We know certainly for MND that timely access to an MDT and care coordination is probably one of the best prognostic indicators in the absence of specific disease-modifying treatments. " - Roundtable Participant**

This is particularly important for people with rare neurological conditions, where care is often fragmented across multiple services. Genetic Alliance UK's work[28] on care coordination highlights the role of coordinated, person-centred support in improving outcomes and reducing the burden on individuals and families.

Care for children with severe and treatment-resistant epilepsy provides a practical example of how highly specialised co-ordinated multidisciplinary care can ensure improved seizure control, developmental outcomes and quality of life while reducing avoidable emergency admissions.

Delivering "Right People" through Complex Epilepsy Specialist Services (CESS)

In England, Complex Epilepsy Specialist Services (CESS) provide highly specialised care for children with severe and treatment-resistant epilepsy through a network of four centres. These services bring together paediatric neurologists, epilepsy specialist nurses, neurophysiologists, neuropsychologists, neurosurgeons and allied health professionals within a coordinated multidisciplinary model.

Demand for these services continues to grow, with referrals increasing by 44.5% between 2016 and 2023/24 (from 496 to 717), reflecting both rising need and improved recognition of complex epilepsy. Surgical evaluations and procedures have also increased, by 34% and 14.2% respectively over this period, demonstrating expanding access to specialist interventions.

Other examples of innovative approaches to care coordination for neurological conditions exist across the country, with the potential for shared learning and scaling to deliver equitable access. One such example from South West London and Surrey, is outlined below.

Delivering "Right People" through System-wide case management in South West London and Surrey Heartlands

As part of the SW London and Surrey Neurology Transformation Pilot, pilot funding was secured for three clinical roles - Functional Neurological Disorder (FND) Regional Care Advisor, Myasthenia Gravis Regional Clinical Nurse Specialist (CNS) and Regional Advanced Multiple Sclerosis (MS) Champion – working directly with the 7 acute trusts and 10 community teams across SW London and Surrey Heartlands.

Their functions include complex case management and care coordination, MDT facilitation, pathway linkage and providing a clinically facing contact point for patients and clinicians. There was a focus on supporting clinically vulnerable cohorts with high service utilisation across all roles.

Evaluation of the impact of these roles showed sustained reductions in emergency attendances, non-elective admissions and bed days as well as lower outpatient activity. Staff and services reported significant release of staff capacity and more sustainable workloads alongside marked improvements in coordinated multidisciplinary care. Those using the services noted improved confidence in decision making around their condition and quicker access to services and support[29].

Upskilling and supporting primary care are also essential. GPs and community teams need confidence to manage common neurological presentations. This should be supported by regular liaison with neurology teams, access to specialist advice (including virtual MDTs and advice and guidance routes) and clear shared care agreements. Community pharmacists can take an expanded role in medication management and adherence where appropriate, further relieving pressure on specialist services. These approaches are also key drivers of shifting care from hospitals to community and neighbourhood settings supported by digital-first approaches including virtual MDTs, remote monitoring of symptoms and appropriate remote advice and guidance.

An MSF would deliver "Right People" by:

- setting clear national expectations for workforce models across clinical neuroscience, including indicative staffing baselines, skill mix and team composition, to reduce unwarranted variation in access and outcomes.
- embedding care coordination as a core feature of services for people affected by neurological conditions, ensuring individuals have a named point of contact to support navigation, early intervention and timely escalation, helping to reduce avoidable emergency admissions.
- supporting multidisciplinary, "top-of-licence" working across neuroscience services, enabling specialist nurses, allied health professionals and pharmacists to lead defined elements of care, while medical specialists focus on complex diagnosis, treatment decisions and clinical leadership.
- strengthening capability beyond specialist services, including primary care, community teams and community pharmacy, through structured advice and guidance, virtual MDTs and shared-care arrangements.
- shifting care upstream and out of hospital, supporting earlier identification of deterioration, proactive management of long-term needs and better medicines optimisation in community and neighbourhood settings.
- providing a consistent national framework for workforce planning and accountability, helping to translate the ambitions of the 10-Year Health Plan into clear, practical models for neurological services and supporting systems to implement and scale effective approaches consistently.
- protecting training time and budgets across the workforce, supporting all staff to develop core research delivery competencies and embedding clinical research as part of routine NHS care provision

2 Pillar 2: Right care

This pillar focuses on the care people receive across the life course, including timely diagnosis and support throughout what can be a long and anxiety-provoking process. Support should be needs-based, not dependent on a confirmed diagnosis, so people are not left without help while "under investigation".

Care must integrate physical health, mental health and social care, recognising the high levels of anxiety, depression, cognitive change, financial stress and social isolation. Care coordination should be a universal entitlement, ensuring people are not expected to navigate complex systems alone.

> **Local authorities often do fund things that we don't utilise as well as we should, and patients either stumble upon them or they need to be integrated into pathways " - Roundtable participant**

Right care means redesigning neurological services so that specialist expertise reaches people based on need. Current pathways are fragmented and inequitable, with access to diagnosis, treatment and specialist input varying widely. A Modern Service Framework should simplify pathways, enable appropriately skilled clinicians to deliver care closer to home, and ensure consistent access to effective treatments through networked models of care.

Addressing health inequalities is central to this. Outcomes are strongly shaped by factors such as deprivation, ethnicity, geography and access to services. People in more deprived areas often face longer waits, fewer resources and higher unmet need. For example in epilepsy, deaths are around three times higher in the most deprived areas. A Modern Service Framework should use population data and local intelligence to identify and reduce these disparities, ensuring equitable access to diagnosis, specialist care and ongoing support.

The recently revised NHS England adult neurology service specification[30] provides a core foundation for this, setting out minimum service requirements and actions to address inequalities.

Delivering "Right Care" through the NHS England Specialised Neurology Service Specification (Adults)

Addressing Health Inequalities

Services should be organised on a population health basis across an Integrated Neurology System. Services must ensure that patients:

- have equitable access to general and specialised neurology outpatient and inpatient services for the purposes of diagnosis and management.
- have equitable access to all commissioned specialised treatments for neurological conditions.
- have care provided as close to home as possible - with appropriate governance and oversight where necessary from multi-disciplinary teams linked to a Specialised Neurology Centre.

Services should:

- ensure that patients are central to decisions about their care, with consideration of individual access needs and reasonable adjustments.
- take appropriate steps to actively include people from seldom-heard and marginalised groups.
- support access to clinical trials and research in an equitable manner through engagement with Clinical Research Networks

To support inclusion of seldom-heard groups, services should work to:

- identify which populations currently experience inequitable access with particular reference to patients with protected characteristics (including learning difficulties and disability) deprivation, ethnicity, pregnancy and maternity and patients within the Justice system.
- identify barriers to access at service level for these populations.
- have appropriate adaptations.
- implement inclusion measures to improve equity.

Access to multidisciplinary teams, bringing together neurology, nursing, AHPs, psychology, psychiatry, social care and the voluntary sector are a core component of right care. Ideally these are delivered through one stop community clinics that minimise the burden of multiple appointments. This pillar also underlines that support must be based on need rather than diagnosis alone. People may require rehabilitation, psychological support and social care while investigations are ongoing, and the MSF should make clear that "no diagnosis" is not a reason for "no support".

An MSF would deliver "Right Care" by:

- promoting integrated, multidisciplinary models bringing together clinical neuroscience, mental health, rehabilitation, care of the elderly, social care and the voluntary sector.
- setting clear expectations for holistic, needs-based support across the pathway, including during the diagnostic process and not dependent on confirmed diagnosis.
- supporting equitable access to clinical research opportunities, including clinical trials, to drive innovation in condition management, monitoring and treatment.

Pillar 3: Right time

The right time pillar responds directly to the current pattern of episodic, reactive care in which people are "fine until they aren't" and then present in crisis. It calls for early intervention to prevent deterioration, along with proactive monitoring and anticipatory care planning. It also emphasises ongoing, episodic rehabilitation across the course of a condition rather than just after acute events or at the end of life. Structured follow-up and surveillance for progressive conditions should anticipate deterioration and trigger early intervention, instead of waiting for crises that often lead to emergency admissions.

Getting the timing right also requires planned, supported transition between paediatric and adult services. Poorly managed transition is a well-recognised point of risk for people with neurological conditions, often leading to loss of continuity, gaps in monitoring, disengagement from services and avoidable deterioration. The Modern Service Framework should therefore set clear expectations for early, coordinated transition planning, with joint paediatric–adult working, clear ownership, and continuity of care during this period.

The NHS England Getting it Right First Time neurology programme[31] has published guidance for services to address increasing demand for neurology outpatient services, a section of which is set out above. The guidance speaks to actions that are referenced elsewhere in this report, including the role of the wider multidisciplinary team, alongside recommendations relevant to the Right Time pillar such as active triage and the use of remote consultations and PIFU where appropriate. Embedding best practice equitably in outpatients is critical to delivering on the proposed moonshot ambition.

Delivering "Right Time" through Clinically-led Specialty Outpatient Guidance (GIRFT/ NHS England) (Neurology)

Top tips for Neurology services:

- Provide advice and guidance for GPs to allow immediate delivery of treatments and avoid outpatient referrals.
- Active triage of referrals aiming to provide advice where possible or pre-order investigations where indicated
- Protect time in senior clinical decision-maker job plans or diaries for Specialist Advice and triage of referrals
- Agree local protocols for optimal follow up for patients with chronic neurological disorders including use of PIFU (patient-initiated follow-up)
- Maximise use of PIFU pathways and close these within indicated timeframes
- Utilise allied-health professional multi-disciplinary workforce including specialist nurses, other advanced practitioners and pharmacists
- Analyse and understand root causes of DNAs (did not attends), cancellations and under-utilised clinic slots
- Analyse DNA patterns in services, and trial programmes such as stand-by reserve patients where it is least likely to cause over-capacity
- Implement or maintain remote consultation provision to ensure a range of appointment modalities are available to suit patient needs
- Providers should ensure all outpatient referrals or patients waiting for their first appointment are validated clerically and then clinically

Active triage and streaming of referrals, supported by digital tools, is a key element of getting the timing right. This includes use of AI and decision support tools to aid diagnosis, risk stratification and treatment optimisation.

Urgent cases should be identified and prioritised rapidly, while routine follow-ups are directed to the most appropriate member of the team, including nurse-led clinics patient-initiated follow up models where safe.

> **[We too often] wait until people come, and then people feel like they are a burden [when they do use services], and so they don't come and ask for help "**
> **- Roundtable participant**

Rapid access to specialist advice when conditions change through telephone or virtual advice lines for primary care and community teams can prevent unnecessary admissions and give professionals the confidence to manage more issues closer to home. For conditions such as MS, this means identifying and treating the common triggers of avoidable admissions, urinary tract infections, catheter problems, constipation, lower respiratory tract infections before they escalate.

This approach should extend to end of life care, with earlier identification of deterioration and coordinated planning across neurology, rehabilitation and palliative care, so people are supported to remain well and maintain quality of life for as long as possible.

An MSF would deliver "Right Time" by:

- ensuring every person with a neurological condition has a personalised care plan, co-designed with them and their carer where appropriate, and regularly reviewed to support coordinated, holistic care.
- requiring structured follow-up and monitoring for neurological conditions to detect deterioration early, alongside patient-initiated follow-up models where appropriate.
- supporting anticipatory care and rehabilitation throughout the condition pathway.
- defining national triggers and pathways for early escalation and intervention to standardise response times and outcomes.
- setting clear national expectations for planned, supported transition from paediatric to adult services, recognising transition as a period that requires early preparation, joint working and continuity of care to prevent disengagement with services.

Pillar 4: Right place

Right place is about where care happens. At present, too much care is hospital centred, with people travelling long distances for relatively routine appointments, while community provision is patchy and fragmented. This pillar envisages integrated community neurology teams operating at neighbourhood or place level, providing multidisciplinary support closer to where people live. Networked models of care, in which specialist centres provide expertise, complex diagnostics and treatments while supporting local teams to deliver routine and supportive care, were strongly endorsed as a way to reduce unwarranted variation and bring care closer to home without losing access to specialist input.

Neighbourhood health teams with neurological expertise, one-stop multidisciplinary clinics, and home-based care (where appropriate) all contribute to the "left shift" –moving care out of hospitals and into community and neighbourhood settings. Accessible local services are essential to overcome barriers such as travel, transport, and rurality, which currently prevent people from receiving timely care.

Delivering "Right Place" through the provision of specialist migraine treatments within a primary care setting in Bradford (NICE)

In Bradford, people affected by complex migraine, beyond what can be managed by their own GP practice, are diagnosed and managed in a primary care neurology service by GPs with an extended role (GPwERs) in headache reducing unnecessary referrals into secondary care.

When new specialist migraine treatments were approved by NICE, the service wanted to use clinical expertise within the community neurology service to prescribe these medications as per NICE guidelines without the need to refer eligible patients into secondary care. This was to avoid strain on an already overstretched secondary care service, utilise local expertise in headache care, and to avoid unnecessary wait times for patients already managed in a specialist service.

With support from the integrated care board to overcome barriers, all patients in the primary care service who meet eligibility criteria for specialist migraine treatment can now receive them without the need for secondary care appointments.

Digitally enabled opportunities include virtual MDTs to connect specialists with local professionals, reducing the need for patients to travel while maintaining high quality decision-making. Integrated community neurology services with proactive monitoring, strong links to social care, primary care and the VCSE sector were seen as critical to preventing crises and supporting independence.

A practical and scalable example of digitally enabled care is set out below utilising digital remote monitoring tools alongside multidisciplinary reviews within a community neurology service and primary care networks to provide at home support. The case study[32] highlights the outcomes of this model, including reduced symptom fluctuations and fewer emergency admissions related to medication errors and falls.

Delivering "Right Place" through Digital Transformation in Parkinson's Care at King's College Hospital (Kings College London)

King's College Hospital has introduced digital remote monitoring tools — a Personal Kinetigraph (PKG) watch that provides a continuous, objective assessment of movement disorder symptoms - coupled with virtual multidisciplinary reviews to support people with Parkinson's in their own homes. This digital initiative worked across a community neurology service and associated primary care networks in collaboration with a regional NHS Trust.

People with Parkinson's used a mobile app or wearable device to record daily symptoms—such as tremor, mobility, and medication adherence—which clinicians monitored via secure dashboards. This early flagging mechanism allowed specialist teams to make timely adjustments to medication or physiotherapy plans without the need for an outpatient visit. The fundamental goals were to enhance self-management, integrate care across neurology and community teams, and ultimately reduce avoidable hospital admissions by up to 20%.

Outcomes included improved medication adherence, reduced symptom fluctuations, and fewer emergency admissions related to medication errors or falls. Health professionals benefitted from greater collaboration between hospital and community teams, more efficient use of specialist time, and upskilling of clinicians in digital health tools. The Parkinson's service saw reduced outpatient follow-ups by up to 20%, freeing capacity for complex cases.

An MSF would deliver "Right Place" by:

- supporting research capacity to grow across services.
- setting clear expectations that specialist neurological expertise should be accessible at neighbourhood or place level, supported by networked delivery rather than concentrated solely in hospital settings.
- formalising networked (hub-and-spoke) models so specialist centres provide outreach, virtual MDT support and clinical leadership to local services.
- expanding one-stop community clinics, home-based assessments and digital options where clinically appropriate.
- aligning commissioning and funding to enable care "left-shift" from hospital to neighbourhood settings.
- reducing travel and access barriers, ensuring equitable care for rural and underserved populations.

Pillar 5: Right systems

The final pillar recognises that none of the above is sustainable without the right infrastructure, particularly data, digital tools and governance. It calls for comprehensive population health data across all settings, so that systems know how many people with which conditions live where, which services they use, and with what outcomes and costs. Standardised outcome measures, including patient reported outcome measures (PROMs) and experience measures (PREMs), with carer reported versions where cognitive or communication impairments are present, are essential for capturing what matters to people.

To ensure the framework drives change, these metrics must be tied to explicit accountability mechanisms. Options include neurology-specific incentive schemes or targets, clear reporting lines into the National Quality Board and Department of Health and Social Care. Explicit responsibilities for integrated care boards should be monitored through national neurology dashboards and local health inequalities dashboards. This should include transparent public reporting of performance and outcomes, with regular updates to enable scrutiny and drive improvement.

ICBs and NHS England regions should have statutory responsibility to ensure that services for people affected by neurological conditions meet national service specifications, with escalation where outcomes lag. Sustained "invest to save" funding for workforce, care coordination, data and digital, and VCSE partnerships will be critical. This should be combined with clear choices about how resources are used, including reducing duplicative assessments and unnecessary outpatient follow-ups, and reinvesting those resources into proactive community support.

An MSF would deliver "Right Systems" by:

- establishing comprehensive, linked data across primary, community, hospital and social care to understand population need and outcomes.
- embedding explicit accountability for ICBs and NHS regions, including escalation routes when outcomes lag.
- aligning incentives and funding to support workforce, care coordination, digital capability and VCSE partnerships.
- providing national prioritisation and accountability to support the implementation of the revised adult neurology service specification and forthcoming specifications in complex rehabilitation, paediatric neuroscience and neurosurgery.

Cross Cutting Themes

Digital by default

Digital transformation offers significant opportunities and is a core element for Modern Service Frameworks. By modernising pathways and harnessing technology, services can become more proactive, data-driven and person-centred. Digital tools can enhance access, reduce variation and support clinicians to deliver specialist input more efficiently, helping to deliver the five pillars and ensure that people receive the right care at the right time.

Key opportunities include:

- Remote monitoring via wearable devices and homebased technologies to track symptoms, relapses and treatment side effects (including the "right place" pillar case study example).
- Virtual MDTs that allow specialists to advise local teams, supporting hub and spoke models and reducing the need for patients to travel.
- Integrated digital care records and data infrastructure that enable information sharing across primary, secondary, community and social care.
- Targeted care using digital data and predictive tools to identify who is most likely to need support, when they are likely to need it, and how care can be tailored in a way that is more individualised and responsive to changing needs.

These tools can improve access, support proactive care, and free up specialist time to focus on people with the most complex needs. Realising these benefits will also depend on improving digital capability and confidence across the clinical workforce, which remains a significant gap.

This approach aligns with the 10-Year Health Plan's commitment to move from "analogue to digital" and with the MSF programme's principle of being "digital by design." Embedding digital innovation at every

stage, from diagnosis to long-term management, ensures that neurological services are accessible, coordinated and responsive. By building digital capability into service design rather than adding it as an afterthought, the MSF can help reduce variation, enhance data- driven decision making and empower both clinicians and people living with neurological conditions.

Risks and digital inclusion

However, participants also highlighted serious concerns about digital exclusion. Cognitive impairment, fatigue, communication difficulties, visual and motor problems and financial barriers can all limit people's ability to use digital tools. Some people value in-person contact highly and may feel further isolated if digital channels are overemphasised.

> **People living with these conditions need our support. They need to be able to talk to a person. We could make them feel further alone."**
> **Roundtable participant**

Digital tools must therefore be designed for accessibility from the outset, with simple interfaces, assistive features and clear support. Digital must be an option, not a requirement, and no one should lose access to high quality care because they cannot or do not wish to engage digitally.

A blended digital model

The emerging consensus is for a blended model in which digital solutions augment, rather than replace, human care. Digital tools should be used to help those who can safely and confidently self-manage to do more for themselves, thereby releasing professional time for those with greater needs. PIFU and remote monitoring should be offered based on clear criteria and robust risk stratification, with safeguards and wraparound support which ensures patients are aware of what these are and who they apply to their care. Particularly given the cognitive and physical impairments common in neurological conditions.

Fully digital pathways should be described where they make sense. For example, digital triage, remote MDT review and homebased monitoring for some stable patients but always alongside explicit, accessible alternatives. In this way, digital transformation becomes a means of improving access, responsiveness and value, not a driver of new inequalities.

Partnership working

Partnership working is fundamental to a credible MSF for neurological conditions because outcomes depend on more than specialist neurology services. They depend on how primary care, community services, mental health, rehabilitation, social care and the voluntary sector work together, and on whether national expectations translate into consistent delivery locally.

Working in partnership also provides the route to sustained change over a decade. Neurology needs a coalition that can align national ambition with clinical leadership, system delivery, and lived experience, with a shared approach to implementation and accountability.

National leadership and governance

The complexity of neurological conditions mean that partnership working is fundamental to any MSF. At national level, leadership and governance must be clear. The National Clinical Director (NCD) for Neurology should act as a visible champion for the MSF. They should be supported by a Task and Finish Group bringing together clinicians, commissioners, data experts, digital leaders, people with lived experience and the voluntary sector to coproduce the framework. This group should report to the National Quality Board with regular updates and transparent performance reporting, and there should be parliamentary accountability through reporting and scrutiny.

Maintaining and strengthening national clinical leadership and governance as a central part of an MSF for neurological conditions is vital given ongoing changes within existing structures. The national neuroscience transformation programme is set to conclude in 2025/2026 alongside ongoing uncertainty around the future of the NCD role and Clinical Reference Groups as part of wider system reform.

Alongside this, leadership across the wider multidisciplinary workforce should be recognised and embedded. As outlined above, neurological care depends on AHPs, psychological services, nursing and community teams, and an MSF should ensure these roles are represented in decision making and supported to lead service improvement.

Cancer was repeatedly cited as a model: national cancer policy is built around a unified narrative and coalition that focuses on "cancer" as a whole, rather than on individual disease types, while managing specific priorities underneath. Developing an MSF offers an opportunity to articulate a single, compelling "mission" that spans conditions while still recognising condition specific needs beneath.

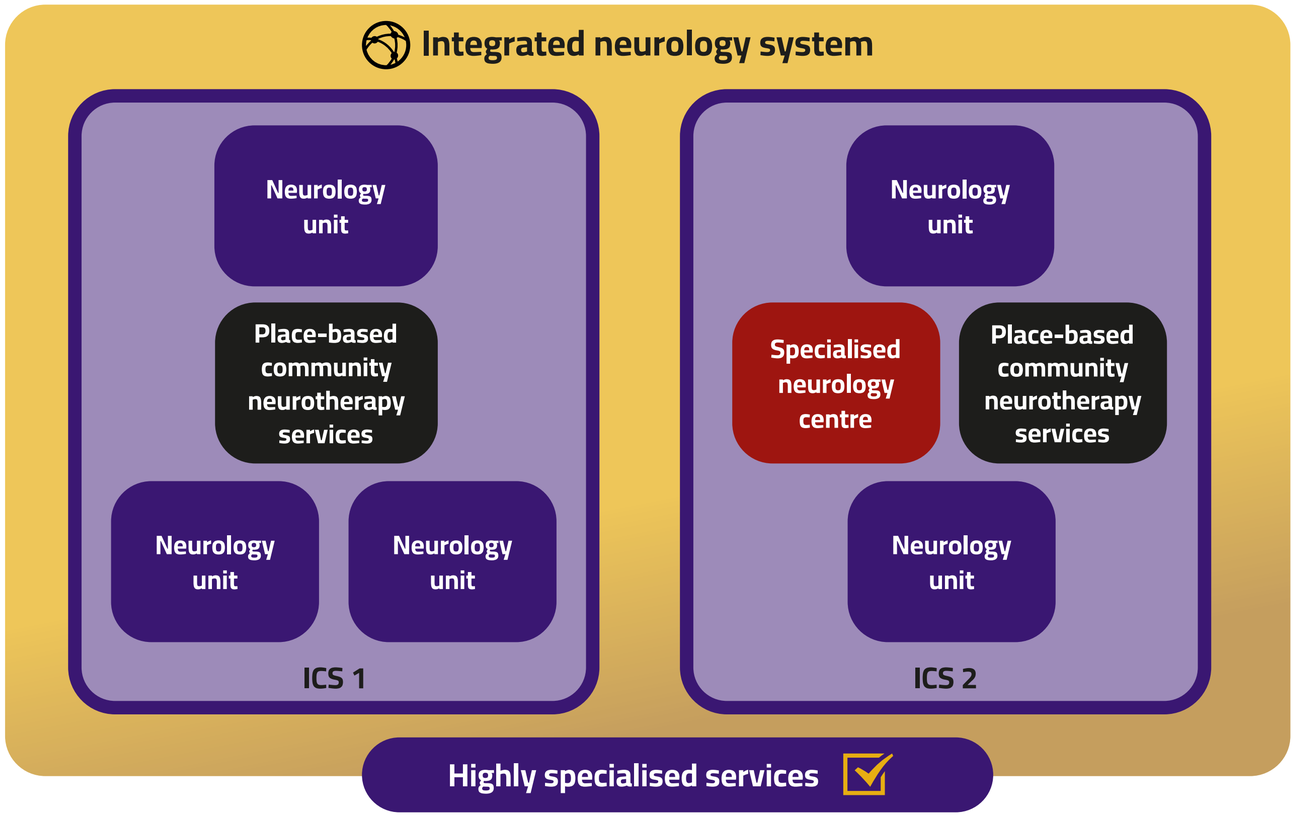
Regional networks and system level leadership

Regionally and locally, there is a "missing middle" where national ambition and local frontline innovation can fail to connect. Integrated neurology systems[33] should fill that gap, providing a practical structure for networked delivery and governance across a footprint, led by specialised neurology centres and linked directly to ICB priorities and accountability. This model is central to the recently revised adult neurology service specification and is outlined in the diagram taken from the specification over the page.

The below is an example of an Integrated Neurology System encompassing a Specialised Neurology Centre and local neurology units working together to provide comprehensive care to a defined geographical population. Specialised neurology clinical leadership is provided through the Specialised Neurology Centre[34].

Organisation of neurology services

The precise delivery infrastructure will vary according to local service structure and geography. However, services must be organised according to the principles below.



Neuroscience Networks and neurorehabilitation networks can be the backbone of this approach. This is only true where they are genuinely multidisciplinary. They must have clear mandates, proper resourcing, and explicit links into ICB decision-making. This enables them to set and spread pathways, support workforce models and reduce unwarranted variation consistently, rather than relying on goodwill. These networks should bring together acute, community and primary care providers, alongside wider system partners, to avoid reinforcing existing imbalances in pathway design

ICBs play a crucial role in translating national frameworks into local delivery. The MSF should expect each ICB to designate neurological conditions leads and embed neurology within provider collaboratives that bring together acute, community and primary care providers. Greater Manchester was highlighted as an exemplar, having adapted stroke network models to deliver community neurological rehabilitation. Their approach has been driven by a network of providers and partners, including but not led solely by the neuroscience centre, demonstrating the value of a more inclusive and system-wide model of leadership [35].

Cross-government working

Many of the determinants of outcomes for people with neurological conditions sit outside the NHS, so delivery cannot succeed through health policy alone. Cross-government working should therefore be explicit, aligned to the Government's mission-led approach, which focuses on core priorities including an NHS fit for the future, economic growth, safer communities and opportunity, and designed around shared outcomes rather than parallel initiatives.

Critical cross-government partnerships include:

- The Department for Work and Pensions, to address unnecessary benefit reassessments and conditionality for people with neurological conditions and improve access to vocational rehabilitation and employment support.
- The Department for Education, to support children and young people with neurological conditions in education settings.
- The Ministry of Justice, to provide more support for the approximately half of prisoners who have brain injuries or other neurological impairments, requiring tailored rehabilitation and support[36].
- Local government, to improve connections and improvement across social care, housing and accessible transport, all of which are central to independence and quality of life.

Without clear, intentional links people will continue to fall through the cracks. That leads to preventable harm and a "revolving door" between the health and social care, welfare and justice systems leading to avoidable expenditure while outcomes and lived experience get worse.

Role of VCSE and lived experience

The voluntary, community and social enterprise (VCSE) sector is a core part of the partnership coalition and should be treated as delivery infrastructure, not an optional add on. Charities have repeatedly stepped into gaps by providing education, counselling, peer support and support self-management, and by generating evidence on workforce, access and outcomes when official data have been limited.

The MSF should formalise these relationships by integrating trusted VCSE expertise into clinical pathways and commissioning charities to deliver high quality, low-cost interventions such as vocational rehabilitation and self-management programmes.

People with neurological conditions and carers should be involved throughout MSF development, implementation and evaluation as co-designers and co-governors, shaping priorities, pathways, measures and accountability arrangements and participating in governance at national, regional and local levels.

> **"How can we [The VCSE sector] play a greater role in being part of that neighbourhood care package as well? Because we stand ready to do that"**
> **- Roundtable Participant**

Conclusion

There is a strong consensus that neurological conditions need a dedicated Modern Service Framework that reflects their scale, complexity, and impact. The case for change is overwhelming: one in six people are affected, care is often fragmented and crisis-driven, waiting times are long, variation is widespread, workforce shortages persist, and the economic burden is estimated at £96 billion[37]. The moonshot ambition and delivery pillars proposed in this report are grounded in a wider goal of enabling people with neurological conditions to achieve the best possible quality of life, only achievable through system-wide transformation.

The MSF should be explicitly data-driven and built on a population health management approach. It must be supported by strong national clinical leadership, clear outcomes and performance measures, evidence-based workforce planning, robust data infrastructure, and coordinated leadership at regional and local levels. Cross-government working and sustainable, value-focused funding are also essential. Meaningful partnership with the voluntary sector and people with lived experience should sit at its core, recognising their central role in designing, delivering, and monitoring services.

There is already a strong foundation for change, including the Neuroscience Transformation Programme, GIRFT neurology programme, updated service specifications, National Neurology Data Dashboard, ABN Workforce Report, and extensive evidence from charities.

The next step is explicit prioritisation of neurological conditions through a Modern Service Framework. Stakeholders across clinical practice, professional bodies, charities, commissioners, and people with lived experience are united in calling for action and stand ready to coproduce a framework that will transform care for millions of people in England.

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