THE
NEUROLOGICAL
ALLIANCE

Future-proofing neurology services

What emerging treatments mean for people, services, and policy in England

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Foreword

Cath Stanley, Chief Executive of the Huntington's Disease Association and Chair of the Neurological Alliance

As Chair of the Neurological Alliance and Chief Executive of the Huntington's Disease Association, I see every day both the profound impact of neurological conditions on people's lives and the extraordinary potential that advances in science and innovation now offer. We are entering a pivotal period for neurological conditions, in which new treatments, diagnostics and technologies are beginning to change what is possible for people who have historically had limited options.

But scientific progress alone is not enough. Without the right services, workforce, data and pathways in place, innovation risks widening inequalities rather than improving outcomes. This moment calls not just for optimism, but for deliberate action to ensure the health system is ready to deliver what science now makes possible, and address areas where research remains underfunded.

This report sets out why preparing the system for the future of neurological treatment is now an urgent priority, and calls on policymakers, system leaders and partners across health and care to act together, so that emerging advances translate into fair, timely and meaningful benefits for everyone affected by neurological conditions.

About the Neurological Alliance

The Neurological Alliance is England's leading coalition of organisations and professional bodies for the neurological community, over 100 organisations working together with people affected by neurological conditions to influence health and care policy in England so it reflects real-life experiences, ensuring that everyone affected by a neurological condition can access the support they need.

This report has been developed by the Neurological Alliance, which receives financial support from the Neurological Alliance's industry reference group. The members of the group are available here: https://www.neural.org.uk/membership/membership-subscriptions/

Editorial control rests with the Neurological Alliance alone.

Introduction

Neurological conditions affect at least one in six people in England and are a leading cause of disability, placing sustained demand on primary, community and specialist services across the NHS.[1] A neurological condition is any condition affecting the brain, spinal cord and/or nerves. Because these systems underpin movement, cognition, emotion and behaviour, neurological conditions can profoundly affect how people function, communicate and participate in everyday life, at any age.

Neurological conditions cost the UK economy an estimated £96 billion per year, £30 billion of which could be reduced through more efficient, optimised care.[2] Despite this scale, clinical neuroscience remains one of the least strategically supported parts of the NHS, and people affected by neurological conditions continue to experience some of the longest referral-to-treatment times in the health service, fragmented pathways and wide variation in access to diagnosis, specialist care and ongoing support.[3]

With neurology undergoing a period of acceleration in treatment development and having one of the largest pipelines for future medicines, there is reason for optimism. In some areas, advances in neuroscience are now starting to translate into late-stage and near-market therapies across a growing number of conditions, including those historically associated with limited or no disease-modifying options such as ataxias, Alzheimer's disease, motor neurone disease (MND), and Huntington's disease. Innovation in medical technologies and devices, including neurostimulation, implantable devices, imaging and digital diagnostics, are also reshaping both treatment and care delivery.

For people affected by neurological conditions, these developments offer the prospect of slowing disease progression and preserving function, meaning more time living independently, participating in work and family life and improving quality of life. However, with many neurological conditions progressive in nature and therapies most effective when given before the condition has progressed significantly, any delay in these advances reaching people can translate directly into lost opportunity for benefit.

Therefore, this progress also raises the stakes for the health system. Without investment in the system and structures that help deliver these treatments – for example, diagnostic pathways, access to consultant neurologists and specialist nurses, and networked models of care – these advances may fail to translate into practice and risk widening existing inequalities in outcomes.

This briefing, developed by the Neurological Alliance with the support of WA Communications, sets out what this next phase of neurological innovation means for England. It provides an overview of the late-stage treatment pipeline, identifies the emerging patterns shaping how new therapies are likely to be delivered, and examines the implications for key areas within the health system. **We argue the Department of Health and Social Care** must now:

1. **Commit to a Modern Service Framework** for neurological conditions, setting national expectations for pathways, outcomes and equity.
2. **Build on the NHS England national neuroscience transformation programme**, ensuring sustained leadership and consistent implementation as NHS structures evolve.
3. **Embed neurological workforce planning within future long term NHS workforce plans**.

The neurological treatment pipeline: scale, pace and emerging patterns

The current Phase III and near-market pipeline demonstrates both the scale and pace of change in neurology. Far from a series of isolated breakthroughs, there is now a significant number of therapies moving towards adoption. As a result, decisions about commissioning, service design and delivery will need to be made in parallel with medicines approval processes across the NHS over the coming years in order for people to feel the benefit of innovation.

While individual therapies differ and some span more than one category, clear waves of innovation are emerging across the late-stage pipeline. These groupings are not rigid, but they provide a useful way of understanding the dominant treatment ambitions and system implications now emerging.

The three "waves" of innovation below categorises emerging therapies according to their system impact – that is, the type of commissioning model, infrastructure, workforce and pathway reform required to deliver them. Whereas, the accompanying infographic maps pipeline therapies by clinical subspecialty area – such as neuromuscular, movement disorders and neuroinflammatory services. While innovation emerges within subspecialities, the readiness challenges cut across them.

1. **Long-term disease-modifying therapies requiring sustained pathway capacity**. A growing number of therapies aim to slow the progression of chronic neurological diseases by altering disease trajectory over time. These treatments do not reverse disease, but aim to stabilise, delay deterioration or preserve function. Examples include prasinezumab for Parkinson's, tolebrutinib for multiple sclerosis (MS), omaveloxolone for Friedreich's ataxia (FA) and lecanemab and donanemab for Alzheimer's disease.[4,5,6,7] From a system perspective, these therapies depend on earlier and more accurate diagnosis, regular specialist monitoring and long-term follow up infrastructure.
2. **Advanced therapy medicinal products (ATMPs) dependent on highly specialised infrastructure and neuroscience capability**. This includes gene and cell-based approaches such as GNT0004 and deramiocel for Duchenne Muscular Dystrophy.[8,9] In some cases, these therapies offer the prospect of long-lasting benefit following a single or limited number of interventions. Their system impact is often concentrated and requires highly specialised infrastructure, multidisciplinary expertise and long-term oversight, shifting clinical expectations and service models.
3. **Scalable therapies designed for ongoing administration**. This includes oral medicines and self-administered injectables. Examples include govorestat for a subtype of Charcot-Marie-Tooth disease, and gefurulimab for generalised myasthenia gravis.[10,11] While these may act on underlying disease mechanism, their defining feature from a system perspective is that they are typically easier to deliver at an individual level. Instead, they will require workforce training and expansion across consultant, nursing, and allied health roles, as well as clear pathways between locally and specialised commissioned care.

Late-stage neurological treatment innovation across subspecialities

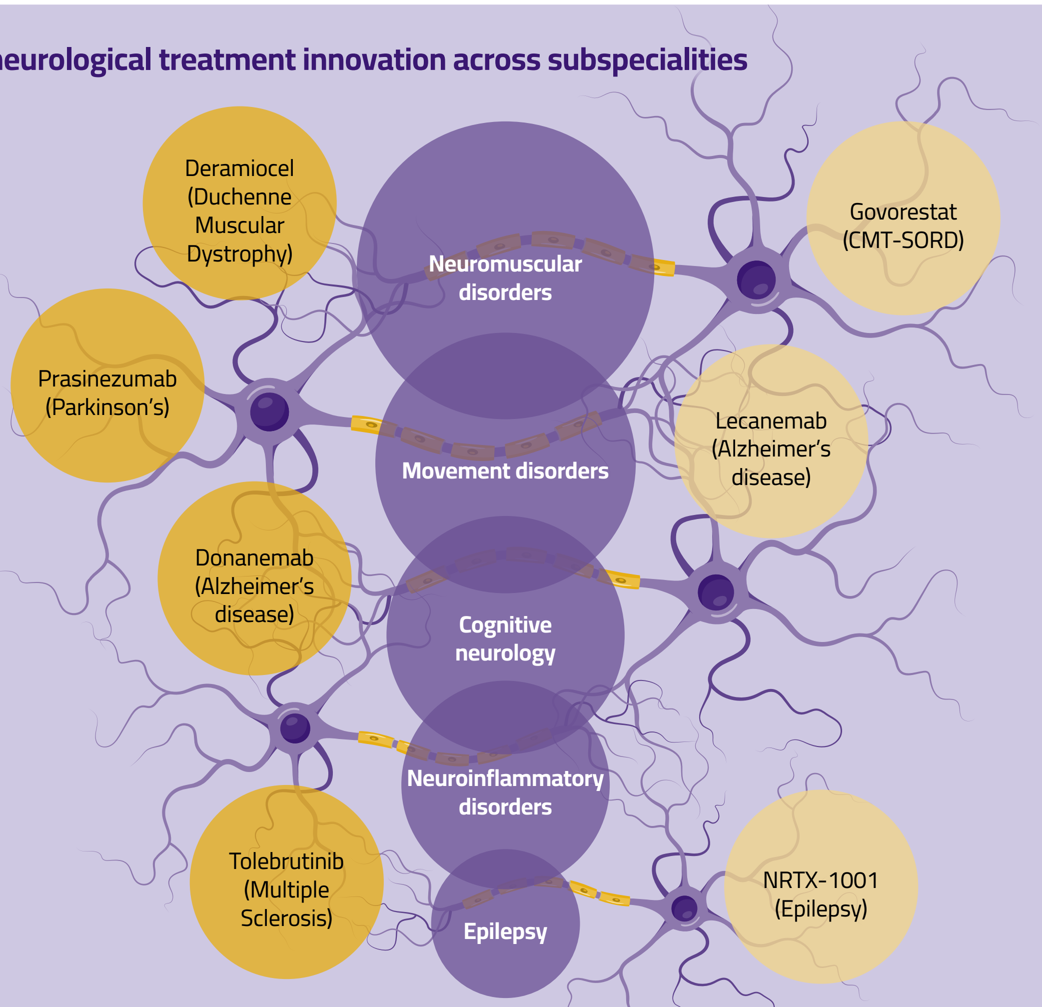

Figure 1: Distribution of late-stage neurological pipeline activity by subspecialty. This graph illustrates the distribution of therapies in late-stage clinical development and those that have entered regulatory or appraisal processes across major adult neurology specialties. Rather than forecasting approval timelines or access decisions, the graphic highlights the relative concentration of activity within each subspecialty pathway. Represents publicly reported therapies in Phase III for regulatory/appraisal stages at the end of analysis, gathered via desk-based research (December 2025).

The UK has the science and academic standing to be a global leader in showing how policy, research and health systems can work together to maximise the benefits of these waves of neurological innovation. But realising this potential will depend on preparing the system, to ensure that progress in treatment translates into fair and timely access for everyone affected by neurological conditions.

System readiness challenges

Momentum in the late-stage pipeline creates an opportunity to rethink how neurological innovation is valued, commissioned and delivered. For many therapies approaching decision points on NHS reimbursement, there is a central question as to whether the health system is equipped to deliver them. There are several common barriers which, if addressed, could unlock access to treatment options across a wide range of neurological conditions.

Explainer: How neurological treatments are commissioned and delivered by the NHS in England

The MHRA (Medicines and Healthcare products Regulatory Agency) is the UK regulator responsible for licensing medicines for use, based on standards of safety, quality, and efficacy. Once licensed, a medicine is then assessed by the National Institute for Health and Care Excellence (NICE) – the national assessment body responsible for determining whether medicines are clinically effective and cost-effective and therefore recommended for routine NHS use in England and Wales. NHS England and the relevant pharmaceutical company will be involved in price negotiation.

If a new medicine is recommended by NICE, it becomes eligible for mandatory funding through the NHS, which local systems must commit within a defined timeframe, but this does not guarantee immediate access for patients. In practice, delivery depends on commissioning arrangements, pathway design, and local service capacity.

In 2025, it was announced that NHS England would be abolished and its responsibilities transitioned into Government. This has resulted in a period of uncertainty for system managers, due to changes in role and decision-making processes across 2026/27.

Integrated Care Boards (ICBs) are responsible for planning and commissioning most NHS services for their local populations. They allocate budgets, commission local services, and are accountable for improving population health outcomes and reducing inequalities across their area. ICBs work with provider trusts, primary care and the voluntary sector to design and deliver pathways of care.

In recent years, ICBs have also taken on delegated responsibility for a growing number of specialised services, including many areas of adult neurology, neurophysiology and neurorehabilitation.[12] Most ICBs are expected to deliver specialised services through multi-ICB or regional arrangements because specialist neuroscience centres are unevenly distributed across England, so there has to be collaboration across boundaries to ensure access to specialist neurological care.

Some neurological treatments are delivered entirely within nationally commissioned highly specialised services, which are currently commissioned directly by NHS England. Others are initiated in specialist centres but rely on ICB-commissioned services for ongoing prescribing, monitoring and support. Funding for specialised services is not ringfenced, therefore ICBs have flexibility in how services are provided, creating scope for local variation.

Appraisal and evidence expectations can present challenges for neurological innovation

Historically, appraisal approaches have been designed around clearly defined populations and the ability to demonstrate impact quickly. However, many neurological therapies are slowly progressive, heterogeneous conditions, where outcomes are best measured through functional change over time.

In addition, emerging therapies increasingly target genetically defined or biologically distinct subpopulations. In some cases, treatment benefit may be limited to people with specific gene mutations or molecular characteristics. This can result in smaller eligible populations, greater uncertainty in clinical trial data, and challenges in generating conventional evidence at scale. This has created a structural mismatch between emerging neurological innovation and existing appraisal frameworks.

NICE has increasingly recognised the need for flexibility in appraisals, including greater acceptance of functional and patient-reported outcomes, managed access arrangements and structured approaches to handling uncertainty where evidence generation is challenging.[13] However, this has not been applied consistently or at scale yet, and many neurological therapies continue to face challenges when it comes to demonstrating cost-effectiveness, especially where benefits accrue gradually, rely on patient-reported measures, or involve unavoidable uncertainty at the point of appraisal.

If not addressed, this mismatch risks delaying access to new treatments in the UK, narrowing eligibility criteria, or undervaluing therapies relative to the outcomes that matter most to people affected by neurological conditions. For example, outcomes such as daily functioning, maintaining independence and quality of life are frequently prioritised by individuals, but can be challenging to evidence robustly within appraisal processes that rely primarily on demonstrating improvements in quality-adjusted life years (QALYs), often requiring the use of surrogate measures.

There is also a need to look at support for patient organisations who have not previously engaged with NICE's appraisal processes. The process is complex and routes to formal engagement can present challenges – risking the ability for the critical voice of the patient community to be heard. This is also important when considering reforms to NICE's processes, for example the incoming changes to NICE's cost-effectiveness thresholds. The patient community should be equipped to meaningfully engage in how these reforms are shaped and how they link to tangible benefits for patients, not just consulted once reforms are decided.

Earlier and more routine alignment between developers, NICE, local health systems, clinicians and people with lived experience could help ensure that evidence expectations reflect the realities of neurological conditions. Clearer routes to conditional adoption – including routine use of Managed Access Agreements – alongside structured evidence generation would allow therapies to reach people while continuing to build the long-term data needed to inform decision making.

Real world example: Using managed access to balance access and uncertainty

Nusinersen for spinal muscular atrophy (SMA) illustrates how managed access arrangements can support timely access to treatments while addressing uncertainty. When first assessed, Nusinersen demonstrated meaningful improvements in survival and motor function, but long-term outcomes remained uncertain due to small patient populations and the progressive nature of the condition. Rather than delaying access until further evidence was generated, a Managed Access Agreement was put in place that enabled eligible individuals to receive treatment while additional real-world data was collected.

This approach has since enabled progression to routine commissioning in some parts of the UK. In 2025, the Scottish Medicines Consortium (SMC) accepted Nusinersen for routine NHS use in Scotland for people with SMA types 2 and 3, following full review of the evidence generated during the managed access period. The decision explicitly reflected growing clinical evidence and the contribution of people living with SMA, families and clinicians to the appraisal process.[14]

In England, NICE is still reviewing the evidence with a recommendation expected in 2026.

Commissioning and pathway complexity risks creating gaps between approval and delivery

Neurological care spans specialised services, local neurology, primary care, community services, and voluntary sector support. Many emerging therapies will require joined up pathways that support people from diagnosis through to initiation, monitoring, and longer-term management. However, current commissioning arrangements often divide responsibility across organisational and funding boundaries, creating uncertainty about who is accountable at each stage of the pathway.

This complexity means that therapies recommended at a national level can face delays in implementation or variable uptake locally. While specialised neurology centres often have the infrastructure and expertise to deliver complex therapies, the capacity and confidence at a local level often lags behind, contributing to regional variation in access following reimbursement.

There is also a need for clearer guidance and direction for emerging treatments that will not sit within delegated commissioning and what multi-ICB commissioning should look like to support effective service delivery across different areas. This is particularly important for rare neurological conditions, where there will likely be one specialist centre within a broader multi-ICB area.

NHS England's Specialised Neurology Services Specification update acknowledges some of these challenges and sets out a clearer framework for integrated, networked models of care. By connecting specialist expertise with local delivery, these models offer a practical route to reducing variation and supporting timely access to new therapies.[15] The specification should be implemented from April 2026.

However, the successful transition to and implementation of the Specification is also tied to the availability of funding and workforce. Without these in place, it is likely that resistance will emerge at a regional level. Such concerns are likely to be compounded by uncertainty that is being felt across the wider health system, as a result of the DHSC / NHS England merger.

Real world example: Overcoming variation in access following NICE approval

Despite NICE approval of CGRP antibody treatments in 2020, access has remained highly variable. By 2023, only 52% of eligible individuals had been offered treatment and CGRP therapies were available in just 29% of responding NHS Trusts in England, largely due to workforce and pathway constraints.[16] NHS England estimates 16,500 emergency admissions for headache and migraine could be avoided with the right care pathways, demonstrating how delays in planned, coordinated care can increase pressure on urgent and emergency services.[17]

On the ground, however, teams are looking into how workforce restrictions can be bypassed to address access barriers. For example, the Bradford Community Neurology Service has worked to diagnose and manage people affected by complex migraine in a primary care neurology service, using the clinical expertise of GPs with an extended reach (GPwERs) in headache. All eligible individuals are then able to receive injectable CGRP mAb treatments (as per NICE guidelines) alongside ongoing monitoring in a primary care service – delivering access to innovative treatment options and reducing unnecessary referrals to secondary care.

Diagnostic capacity increasingly acts as a bottleneck to therapy access

There are efforts across the system to treat neurological conditions earlier to prevent or delay progression and allow for more proactive care. With many of the emerging neurological treatments either being indicated earlier in the progression of the condition, or dependent on genetic, biomarker or imaging confirmation to determine eligibility, effective diagnostic pathways will increasingly determine whether people can access a particular treatment.

Diagnostic capacity for neurological conditions is already under strain, with substantial variation in access to MRI, neurophysiology and lumbar puncture, alongside long waits for first neurology appointments. In some conditions, delays to diagnosis extend over months or years, increasing the risk that people miss the window in which some of these therapies are most beneficial.

Efforts must be directed to reduce time to confirmed diagnosis for all neurology conditions, regardless of the treatment pipeline. This includes through better use of triaging, supporting advice and guidance mechanisms, improving referral criteria and expanding commissioned diagnostic capacity.

> **“Waiting times are stressful. (I) discussed DMT’s [Disease Modifying Therapies] with a neurologist when diagnosed 15 months ago. Still waiting to start treatment. There has had to be a lot of chasing on my end for appointments etc. Don't feel there has been much support. I feel like I have to get on with it myself."**
>
> Response to My Neuro Survey,
> Adult living with a neurological condition

Real world example: Diagnostic delays as a barrier to timely treatment

When people present with symptoms of MS, there is an urgent need for a neurological assessment and access to diagnostic investigations. Yet delays between symptom onset, referral to neurology and confirmed diagnosis remain common. The MS diagnostic pathway requires clinical evaluation, MRI imaging and often lumbar puncture, and delays can occur at each stage due to workforce shortages, imaging capacity constraints and variation in referral pathways.[18] Early initiation of treatment is associated with improved long-term outcomes, meaning delays can directly reduce the window of opportunity for effective intervention.

As the therapeutic landscape for MS continues to expand, ensuring rapid access to specialist assessment and diagnostics will be critical to translating innovation into patient benefit.

> **"We see our neurologist once a year, and the same with the Parkinson's nurses. It is not enough, but until there is an improvement in treatment of the disease, such as new drugs, I can understand their helplessness in the situation."**
>
> Response to My Neuro Survey,
> Adult living with a neurological condition

Workforce capacity and skill-mix are the binding constraints on delivery

There is significant strain on the neurological workforce, with wide variation in access to specialist nurses and neurologists limiting access to care. Despite improvements in the number of neurologists over the past two decades, the UK varies significantly in number of neurologists per 100,000 population. The national average is 1.6 WTE neurology consultants per 100,000 population, and is recognised as inadequate.[19] This is compared with around four per 100,000 in countries such as France and Germany.

These pressures extend beyond consultant neurologists. In England, there is a 40% vacancy rate among consultant stroke physicians, while Royal College of Psychiatry census data shows there are just 19 full-time and 30 part-time permanent neuropsychiatry consultants nationally.[20,21] Specialist nursing capacity is similarly stretched. 80% of people with MS live in areas with unsustainable caseloads, and workforce modelling indicates that current capacity would need to increase by around half to deliver safe and sustainable care.[22] And for epilepsy, there is one epilepsy specialist nurse for every 1,397 people, across a population of approximately 626,000 people with epilepsy in the UK.[23]

These workforce gaps are particularly concerning at a moment of rapid therapeutic change. New treatments will likely increase the need for timely diagnosis, specialist interpretation, patient education, monitoring and long term follow up. New therapies are extending life expectancy and improving outcomes, but also fundamentally changing the nature, intensity and duration of care. This includes introducing novel modes of administration, such as infusion-based therapies or device-supported delivery mechanisms.

These new therapies will require both additional staff, and upskilling of the existing workforce, from neurologists to specialist nurses, allied health professionals, pharmacists, neuropsychologists and rehabilitation services. Yet while medicines may be approved and funded, the workforce expansion and service infrastructure needed to deliver them safely at scale are rarely funded in parallel.

Workforce capacity issues also present wider challenges from a delivery perspective, with the upcoming implementation of the Specialised Neurology Services Specification update (April 2026) likely to be negatively impacted.

There is a clear opportunity to look at neurological innovation as a potential case study for effective multidisciplinary working, and delivery of care closer to home through stronger integration between specialist neurology services, follow-up clinics and community-based therapy and rehabilitation and investing in roles that act as capacity multipliers (e.g. care co-ordinators) and reduce avoidable follow up. Standardised monitoring protocols, clearer role delineation and expanded use of specialist nurses and pharmacists could enable safe delivery at scale while improving patient experience and continuity of care. As NHS workforce planning looks towards the next decade, neurology provides a clear test and potential blueprint for whether future workforce strategies are sufficiently aligned to emerging models of care.

Data and learning infrastructure are not yet fit to support long term learning and adoption of innovation

Many neurological therapies require evidence to be built over time to understand their impact on function, independence and quality of life. However, currently, neurology outpatient activity is not routinely coded by diagnosis, meaning the system often cannot identify who has which condition, where they are in the pathway, or how services differ between areas.[24] Further to this, access to routine prescribing data is limited, meaning decisions about capacity and uptake are often based on estimates rather than accurate patient numbers, particularly for rare neurological conditions.

This absence of data means commissioners and providers can struggle to identify where access is delayed, which populations are missing out, and how new treatments are affecting service demand over time. This makes it harder to demonstrate value, refine pathways or build confidence in adoption – particularly for therapies where benefits accrue gradually. RightCare identifies better use of data and technology as a shared system priority across progressive neurological conditions, recognising that fragmented information contributes to delayed diagnosis, uncoordinated care and avoidable variation.[25] Without strengthening this data, we risk repeating the same debates for each new therapy, slowing adoption and undermining confidence in the system to deliver innovation.

Building neurological care that can adapt to ongoing innovation

As neurological innovation accelerates, its impact will increasingly depend on system readiness. The following spotlights explore two areas of neurology where emerging science will continue to reshape expectations of care and the health care system over the next decade.

Genetic and inherited neurological conditions – From diagnostic odyssey to treatment-enabling diagnosis

Inherited neurological conditions have been characterised by long diagnostic journeys, limited treatment options, and a focus on supportive care. Advances in genetic science and a growing pipeline of targeted therapies mean this model is likely to change substantially. Over the next decade, genetic neurology is likely to become one of the areas where innovation most visibly changes what diagnosis means for impacted individuals and families.

For example, spinal muscular atrophy (SMA) has recently seen the approval of disease-modifying therapies including nusinersen and risdiplam for ongoing treatment, and the gene therapy onasemnogene abeparvovec. These therapies have the potential to fundamentally alter the prognosis of many affected children and adults. Crucially, outcomes are strongly linked to early diagnosis and treatment initiation, shifting the emphasis towards rapid genetic confirmation and, increasingly, newborn screening.

Across other inherited conditions such as muscular dystrophies, inherited ataxias, and neuropathies, there has also been a growing emphasis on identifying people living with these conditions earlier, sometimes before major functional loss, to allow intervention at a point where outcomes can still be altered. This places new demands on services. Genetic testing becomes a critical gatekeeper to treatment eligibility, increasing demand on specialist neuromuscular and neurogenetic services.

Alongside this, there will be a growing need for coordinated counselling, multidisciplinary assessment, and structured follow-up over a longer period of time.

With early investment in genetic testing pathways, specialist capacity, and national data infrastructure, these developments could significantly shorten diagnostic delays and support more consistent outcomes across England. Inherited neurology therefore offers a clear test case for whether the system can move from reactive to anticipatory care.

> **“For too long, neurological conditions like inherited ataxia have meant years of uncertainty and limited treatment options. But advances in genetic science are transforming what it means to receive a diagnosis. With the right investment in testing, specialist services and coordinated care, we have a real opportunity to move to earlier, more proactive care that can truly change outcomes for individuals and families.”**
>
> Sue Millman, Chief Executive of Ataxia UK

Progressive neurological and neuromuscular conditions – From late-stage symptom control to lifelong condition management

For much of the NHS's history, care for progressive neurological conditions such as Parkinson's, Alzheimer's disease and MND has focused on managing symptoms once disability is established. Diagnosis often marks the start of a gradual functional decline, with limited options to alter disease trajectory and services responding reactively as needs escalate.

Advances in scientific understanding of disease mechanisms and the emergence of therapies designed to slow progression are beginning to change expectations of what neurodegenerative care could look like. Earlier diagnosis and more proactive management are increasingly seen as central to improving outcomes, both for individuals and the sustainability of the health system. For example, emerging Alzheimer's disease therapies require intensive ongoing monitoring, repeated imaging and access to specialist neurological expertise. These are demands that current service models are not yet set up to deliver at scale.

Similarly, in muscle-wasting conditions, emerging therapies aim to preserve muscle function and delay loss of mobility, placing new emphasis on the importance of early diagnosis and timely intervention.

Progressive neurological and neuromuscular conditions are therefore increasingly being reframed as long-term conditions requiring sustained monitoring over many years. This brings new opportunities to monitor changes in function and cognition over time, support self-management, and provide timely specialist input before acute or crisis care is needed.

Early detection and diagnostic services, particularly imaging and biomarker testing, will become critical gateways to care. Specialist nurses and multidisciplinary teams will play a central role in coordinating long-term management, providing education, and supporting continuity of care. Data systems will also be essential to track progression and outcomes over time to inform both clinical decisions and commissioning.

With the right preparation, this shift offers a significant opportunity to reduce avoidable admissions, preserve independence for longer, and improve quality of life for people living with progressive neurological and neuromuscular conditions.

> **"We are entering a new era in Parkinson's and other neurodegenerative conditions, where earlier diagnosis and management could have a tangible impact. Emerging treatments bring real hope, but the system is not yet set up to deliver these at scale. With the right preparation, including in areas like imaging, specialist expertise and sustained follow-up, we can ensure people impacted by Parkinson's have access to treatment and care that supports them to live well for longer."**
>
> Caroline Rassell, Chief Executive of Parkinson's UK

> **“Science holds huge potential for muscle wasting conditions. Slowing disease progression or reducing the impact of a condition can transform daily life for those who need it most. We are at a critical point when it comes to designing pathways that support long-term management of muscle wasting conditions. Only by looking at what needs to change now, can we ensure that the system is set up to deliver the future of treatments in this space.”**
>
> Andy Fletcher, Chief Executive of Muscular Dystrophy UK

Recommendations to future-proof access to innovation in neurology

This is a highly promising period for the neurological space, as years of sustained investment in research and innovation are beginning to deliver real-world impact. Realising the full benefit of this progress is not just about individual therapies, but critically, whether the health system is equipped to deliver them consistently, safely, and at scale.

These recommendations focus on the shared system enablers that would strengthen neurological care across conditions – supporting early diagnosis, coordinated pathways, and a sustainable workforce. Irrespective of decisions on individual treatments, these recommendations provide a practical framework for ensuring neurological care keeps pace with scientific progress over the coming decade, to the benefit of individuals and the wider health system.

Faster, fairer routes from evidence to access to neurological treatments

1. **The Department for Health and Social Care (DHSC) should commit to delivering a Modern Service Framework for neurological conditions within this parliamentary term.** This should build on existing best practice, and be co-developed with clinicians, people with lived experience, commissioners and system leaders. This should set national expectations for pathway standards, service configuration, outcomes, and equity, providing neurology the same prioritisation that other major disease areas receive, and creating the framework for consistent implementation across England.
2. **DHSC should build on the NHS England neurosciences transformation programme to ensure continuity and national oversight.** As NHS structures evolve, this programme should provide funded clinical leadership, dedicated programme management and networked delivery infrastructure, supporting ICBs and offices for pan-ICB commissioning (OPICs) to implement standardised pathways and reduce variation across England.

3. **NICE should review and modernise its appraisal framework to ensure it is fit for emerging neurological treatments.** This should include:
    a. Proportionate application of evidence expectations, routine use of managed access approaches where uncertainty is inherent, and methodological flexibility for slowly progressing, heterogeneous conditions with small populations.
    b. Appraisal methods should better capture long-term disease modification, patient-reported outcomes, and wider societal and social care impacts.
    c. Development of a proportionate evaluation route for rare neurological conditions that fall between existing Technology Appraisal and Highly Specialised Technologies frameworks, to ensure these conditions are not structurally disadvantaged.
4. **Medicines and Healthcare products Regulatory Agency (MHRA), NICE, NHS England, and partners in the life sciences sector should formalise earlier joint alignment for neurology products most likely to face appraisal and adoption barriers. Earlier agreement on endpoints, subgroups, data collection plans and delivery assumptions** could reduce the risk of delays between regulatory approval, health technology assessment and real-world adoption.
5. **DHSC and NHS England should embed neurological workforce planning within the 10 Year NHS Workforce Plan and future updates.** This should prepare and be based on explicit modelling of how emerging neurological therapies will affect demand for diagnosis, specialist review, monitoring, and long-term follow-up. This must prioritise growth and retention of the wider neuroscience workforce - including specialist nurses, allied health professionals, and neurorehabilitation roles - alongside consultant neurologists.[26]
6. **DHSC and ICBs should establish clear frameworks for supported implementation of complex neurological innovations, including structured collaboration with industry.** This is particularly relevant for therapies that require additional workforce capacity, new delivery mechanisms, or specialist training.
7. **DHSC should appropriately resource the UK Neuro Forum**, supporting system preparedness across the country by providing a shared space for national and regional leaders, clinicians, people with lived experience and partners to align on priorities, workforce implications and delivery readiness for emerging innovation.

Joined-up commissioning and pathway accountability

8. **Regions should operationalise Integrated Neurology Systems as the default delivery model for neurology care.** Building on the adult specialised neurology service specification, this should require networked pathways that connect specialist centres, local neurology, community services, and the Voluntary, Community, and Social Enterprise sector (VCSE) support, with clear expectations on coordination, escalation, and equitable access.
9. **ICBs should designate a single accountable professional lead for end-to-end neurology pathways across specialised and locally commissioned services.** The role should have clear authority to coordinate across organisational boundaries, resolve gaps between specialised and community provision, and ensure pathways are implemented consistently across the ICS footprint.

Embed the neurological patient voice as a core driver of access and value

10. **DHSC, NICE and NHS England should strengthen and standardise patient involvement across regulatory, appraisal, and service design processes in neurology.** This must include consistent, early engagement of patient organisations and people with lived experience in appraisal scoping, service redesign, and pathway development, rather than reliance on late-stage consultation.

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For further discussion on the findings and recommendations in this briefing, please contact the **Neurological Alliance** at info@neural.org.uk

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