The Future of MS Care:
a consensus statement

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Foreword

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The care we provide for people living with multiple sclerosis (MS) is at a critical juncture. As the NHS navigates profound changes driven by increasing demand, workforce pressures, and a shift towards integrated, community-led care, it is more important than ever that we re-examine how we deliver MS services and ensure they are equipped for the future.

In recent years, we have seen advances in our understanding of MS and the treatments available, particularly for relapsing forms of the condition. Yet too many people still experience delays in diagnosis, fragmented care, and a lack of personalised support - especially those living with progressive MS. These gaps have been made more visible by growing pressures across the NHS.

This consensus process is rooted in the belief that change must be collaborative, informed by lived experience, and focused on the full spectrum of MS. Through a series of roundtables bringing together clinicians and patient advocacy organisations, we have sought to build a shared understanding of the challenges in MS care today, and the changes it will take to improve it for the future.

These discussions are taking place at a time of major transition for the NHS following the abolition of NHS England. Integrated care boards (ICBs) are merging and reshaping how services are commissioned and delivered at a neighbourhood level, with an increasing focus on prevention and population health management. This presents a real opportunity to embed more responsive, joined-up MS services within local systems if we act decisively now.

At the same time, the publication of the Government's 10 Year Health Plan has set out a bold vision to meet the country's growing and evolving care needs. Taken together with the Neurology Transformation Programme, which is reshaping how neurological services are organised and delivered, these represent critical opportunities to improve MS care for both patients and providers. Aligning improvements in MS care with these programmes will be essential to support delivery against national ambitions for the future of healthcare in the UK.

The recommendations set out in this consensus statement are not just the reflections of a small group - they are a call to action from across the MS community. If we are to meet the needs of people living with MS in a NHS under strain, we must work together to rethink what good care looks like, and how we make it a reality.

Introduction: developing MS recommendations based in expert insights

To better understand the challenges within the MS care pathway and identify opportunities for meaningful improvement, a group of leading voices from across the MS clinical and patient community have come together with the support of Sanofi.

Their shared goal is to develop a robust, evidence-informed consensus statement that reflects the realities of current MS care and lays the groundwork for impactful change. From the outset, the group has placed strong emphasis on addressing the full spectrum of the disease, not just relapsing MS, but also progressive forms, which are often underserved and under-recognised in existing care models and treatment pathways.

This work also comes at a pivotal time for the commissioning and delivery of MS services, with the publication of the new Neurology Specialised Services Strategic Specification and its forthcoming Appendix A, which will set out in detail what MS services are expected to provide going forward.[1] Importantly, this is the first time NHS England has set out minimum service requirements not only for specialised neurology, but also for core neurology services commissioned by ICBs. This represents a critical opportunity to ensure that MS services are delivered consistently across the country, with clear expectations on workforce, pathways, and equitable access.

Through the first two roundtables, the group identified key areas where change is urgently needed across the MS care pathway. This includes gaps in early diagnosis, inconsistencies in community-based care, challenges in managing progressive MS, and the increasing strain on healthcare workforce capacity. The group has also explored the practical barriers that hinder progress, such as fragmented services, inequitable access to resources, a lack of clarity around professional roles and responsibilities within multidisciplinary care, and a lack of prioritisation by ICBs.

The ambition now is to build on this foundation. Future roundtables will aim to dig deeper into these barriers; while redefining where simple, achievable changes could have a significant impact for the lives of people living with MS. As part of this process, the conversation will widen to include new perspectives, bringing in GPs, physiotherapists, psychologists, menopause specialists, and other professionals whose roles are essential to delivering holistic, person-centred care.

The focus will be on translating the group's consensus into practical, system-level actions, ensuring that the insights gathered so far lead to meaningful improvements across policy, commissioning, and day-to-day care delivery.

This consensus document captures the group's shared insights and recommendations. It sets out a clear and collaborative agenda for delivering a more responsive, joined-up, and future-proofed approach to MS care in the UK.

The Future of MS Care Group

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Why is change needed in MS care and treatment?

More than 150,000 people in the UK live with MS, and more than 7,100 people are diagnosed with MS each year in the UK. MS, which causes a wide range of symptoms,[2,3] does not impact any two people the same way and as a progressive condition services must be flexible, personalised, and built around what patients truly need at each stage of their journey. There is also a need to provide patients with the right care, at the right time, in the right place. More than 1 in 7 people with MS in England had an unplanned admission in 2023/24, which is 2.3 times more likely than people without MS.[4]

As the number of people living with MS continues to rise,[1] we must tackle persistent inequalities in care and ensure services reflect the diverse and evolving needs of the MS community.

While there has been progress in faster disease modifying therapy (DMT) access and some service models, these improvements are inconsistently demonstrated and not yet widespread. In some areas, a lack of specialist nurses and neurology specialists, and delays in access to treatment mean some patients wait months, even years, for the right support. Research suggests that up to 80% of MS patients live in areas where MS nurses are handling unsustainable caseloads,[5] leaving many without the regular care they need. People with MS are also currently waiting longer for their first neurology appointment than in previous years.[4] In 2023/24, people with MS waited 22 weeks on average for a first neurology appointment compared with an average of 13 weeks in 2019/20. Despite recent updates to the McDonald criteria,[4] a set of guidelines that neurologists use to diagnose MS, there are still challenges present in the diagnosis of MS.[4]

Retention and sustainability of the MS workforce represent a growing challenge. MS nurses are central to continuity of care, yet retention is undermined by heavy caseloads, limited opportunities for career progression, and insufficient protected time for training and development. Strengthening retention and succession planning strategies, alongside formal recognition of advanced nursing and allied health professional (AHP) roles, is essential to ensure long-term workforce resilience. Role clarity across the MDT, particularly as new professions become more closely involved in MS care, will also be vital.

Patient groups working in the MS space highlight inequalities in care for people with progressive MS compared to relapsing MS. For example, those with progressive forms of MS are often less likely to be under the care of a neurologist when they need to be.[6]

Our understanding of MS as a condition is also changing. The way in which symptoms and disease progression are measured is not always aligned with the experiences of people living with MS who describe challenges in sharing ‘hidden symptoms’ due to limitations in terminology and clinical practice.

As treatments have improved, so have people’s needs; the goal is no longer just about managing relapses, care needs to also focus on preventing disability, protecting independence and helping people live full, meaningful lives. This also supports the Government’s commitment to breaking down barriers that prevent people with disabilities from fully participating in society, including efforts to help more people stay in and thrive at work.

To meet the rising and evolving needs of people with MS, care must keep pace with science and digital innovation - prioritising earlier identification, smarter monitoring, and more integrated, community-based support to benefit people living with MS, their carers and families, and the NHS.

Our MS Care Consensus Statement

MS care in the UK is not keeping pace with what we now know about the condition. Too many people still face delays in diagnosis, fragmented care, and limited access to the right support at the right time, particularly those living with progressive MS. We believe there is a clear and urgent need to redesign services around what matters most to people with MS: early intervention, compassionate communication, personalised care, and support that is accessible and responsive throughout the course of the condition. We have identified three immediate priorities for change:

1. Increase accountability and empowerment of MS multidisciplinary teams (MDTs) to manage patient need:

- Redefine the roles, responsibilities and purpose of MS MDTs to improve system readiness and reduce unnecessary delays. This includes empowering a broader range of health and social care professionals, such as pharmacists, physiotherapists, nurses, and neuro navigators with clear responsibilities so patients are seen by the most appropriate clinician at the right time. By streamlining processes and enabling confident delegation, MS MDTs can work more effectively across the patient journey ensuring that each professional contributes their expertise at the right stage of care. This approach frees up time for consultant neurologists to focus on managing newly diagnosed patients and more complex cases.

2. Transform MS services to increase effective use of clinicians' time across the MS clinical network:

- Improve the speed of diagnosis and the quality of early conversations with newly diagnosed patients.
- Ensure patients are seen by the right clinician, at the right time, in the right place.
- Provide more effective engagement with a range of clinicians, to enable more face-to-face time between the MS clinical network and individuals, and maximise the existing workforce.

3. Strengthen access to and availability of community-based services, which appropriately respond to patient need:

- Empower patients with access to the right digital tools, adapted patient-initiated follow-up (PIFU) and local support services by introducing a simplified self-management toolkit, provided at the point of diagnosis and routinely reviewed at every clinical appointment as part of a structured self-management checklist. The toolkit should help set clear expectations from the start, clarifying who patients will hear from, at what point, and what to expect, while digital tools such as PROMS and triage features can support early identification of deterioration and embed proactive care into routine workflows.

As this work continues, our focus will be on translating insight into action. Future discussions will seek to identify practical, high-impact changes that can be implemented quickly within existing system structures. Central to this will be defining what a 'gold standard' patient journey looks like – from diagnosis through to ongoing support – and ensuring that funding models are aligned to deliver this consistently across all regions, reducing variation and setting clear expectations for the system.

Our collective ambition is to help build a more responsive and equitable MS care pathway, one that empowers people to manage their condition confidently and protects what matters most: independence, wellbeing, and quality of life.

Immediate priorities in more detail

The below sets out the three priority areas of focus in more detail. Further insights and best practice approaches to enact change will be provided in our Future of MS Care report, which is in development, and will set a clear agenda for meaningful, system-wide improvement.

Increased accountability and empowerment of MDTs to manage patient needs

A well-functioning MDT is critical to MS care because of the complexity, long-term and individualised care required.[7] However, the current implementation and accessibility of MDTs vary widely across the country.[8]

We are clear that MDTs play a critical role in MS care, particularly in making complex decisions such as initiating DMTs, managing fluctuating symptoms, and coordinating social and psychological support. These decisions are split between MS MDTs, and MS DMT MDTs. Both have different purposes but are as vital as each other. They have access to a broad set of expertise, from neurologists, MS nurses and pharmacists, to physiotherapists, occupational therapists, and psychologists, and are crucial in providing care.

However, there are several barriers to effective MDTs, such as workforce capacity, geographical variation resulting in unequal access and in some settings, overly complicated processes that undermine consistency and access. In some areas, routine assessments still default to consultant neurologists, even where other clinicians would provide appropriate care. There are also areas where community MS and neurological services are not available. Alongside clinical roles, community-based support – including health coaches, social prescribing link workers, and peer group support – can play a valuable part in helping patients manage their condition while also easing pressure on specialist teams.

To improve the efficiency of multidisciplinary care and deliver more responsive, sustainable follow-up, we recommend:

1. Expanding the use of virtual MDTs to improve access, particularly in remote or under-resourced areas, and reduce the logistical burden of in-person meetings
2. Clarifying professional roles within MDTs to ensure that patients are seen by the most appropriate clinician based on clinical need, rather than default pathways or availability
3. Implementing tailored follow-up schedules informed by disease stability, treatment status, and individual patient preferences, and embedding MS-specific follow-up within broader neurology clinics where appropriate

This would allow specialist teams to focus time and resources on those with the greatest need, while ensuring all patients continue to feel supported and connected to their care team. Setting clear expectations at diagnosis around the team-based model, and who patients are likely to see and why, can also reduce pressure on all members of the MS MDT and improve patient experience. By clearly defining professional roles and optimising MDT use, MS services can deliver more efficient, patient-centred care, even in the face of growing workforce and system pressures.

Transform MS services to increase effective use of clinicians' time across the MS clinical network

As a variable and progressive neurological condition, delays in diagnosis not only risk irreversible disease progression, but also contributes significantly to patient anxiety and poor long-term engagement with services.[9] We agree that addressing both the speed and quality of diagnosis is a top priority in improving the MS care pathway.

We believe delays in diagnosis are a source of avoidable distress, inefficiency, and inequity, and result in unnecessary loss of function for people living with MS. While the clinical need for prompt diagnosis has long been recognised, given the evidence that early treatment can delay disability progression and improve quality of life, systemic barriers continue to hinder progress.[10] These include:

- Long waiting times for specialist neurology appointments
- Inconsistent referral pathways from primary care
- Limited local access to diagnostic tools, particularly MRI scanning

We are aware of reported delays to diagnoses as a result of ICB-level cost-saving measures to restrict MRI access, resulting in regional variation in access and further compounding inequalities.[11]

Beyond speed, we have raised concerns about the quality of the diagnostic experience. Members of our group have examples of individuals receiving an initial diagnosis of MS via a letter, without adequate clinical explanation or immediate access to support that a newly diagnosed patient requires. We know such experiences are unacceptable, distressing and harmful, with lasting implications for how patients relate to healthcare providers.

Diagnosis represents a pivotal moment in a person's MS journey, one that must be handled with clarity, compassion, and appropriate support to set the foundation for lifelong engagement with care. Poor communication and a lack of psychological or informational support at this stage can:

- Erode trust in the healthcare system
- Limit future engagement with services
- Negatively affect treatment adherence and wellbeing
- Cause unnecessary harm to patients

Improving diagnostic communication is essential, not just from a compassionate care perspective, but as a foundation for effective, long-term disease management. Early engagement with a range of clinicians, neurologists, MS nurses, pharmacists, neuro navigators, and others, can ensure patients feel supported and know what to expect.

We believe there are several key reforms needed to improve both the speed and quality of MS diagnosis, including:

1. GP access to MRI scanning to expedite diagnosis. While this could reduce delays, participants raised concerns about the risk of overuse, false positives, and additional pressure on already overstretched neurology teams.
    - We suggest this could be supported by consultant neurologist developed guidelines on MRI use, and criteria from local MS specialist centres to ensure appropriate referrals.
2. Development of "red flag" systems or clinical prompts to support GPs in identifying potential MS symptoms earlier and making more targeted referrals. This is something that has already been established in some areas, including Southampton.
3. Introduction of minimum standards for diagnostic delivery, including in-person communication of diagnosis and immediate signposting to the MS clinical network for support.

By ensuring patients are seen at the right time by the right clinician in the right place, and better engaging the full MS network, we can create more responsive, efficient services and protect time for meaningful early conversations. This approach will also help maximise the existing workforce, reduce pressure on consultants, and improve long-term engagement with care.

Strengthen access to and availability of community-based services, which appropriately respond to patient need

We recognise the urgent need to move away from hospital-centric models of care and towards more accessible, community-based services, aligned with national priorities and supported by greater opportunities for self-management and digital innovation. This shift must be underpinned by better system coordination, earlier intervention and more effective use of the whole MS clinical network, which includes local, regional, and national services.

The ambition to deliver care closer to home is well-established in NHS policy, yet in practice, it often lacks the infrastructure, visibility and coordination to deliver tangible improvements in support for people with disabilities. We acknowledge that both patients and clinicians often lack awareness of what community services are available, how to access them, and where responsibilities sit across the system, contributing to gaps, inefficiencies, and missed opportunities for care. This disjointedness contributes to duplication, gaps in care, and avoidable reliance on secondary care teams. We have concerns that "care closer to home" risks becoming an empty policy slogan unless it is supported by genuine investment in community infrastructure, workforce capability, and shared decision making between providers. There needs to be clear regional mapping of existing MS, neurology and neurorehabilitation services to identify existing gaps and avoid duplication of services.

We believe there is a pressing need to establish clear care footprints within each ICB, defining what services are available, how specialist care is connected, and who holds responsibility for delivery. Just as roles within MDTs must be clearly defined, specialist centres, district general hospital and community teams must be properly supported and upskilled to deliver more MS care locally and regionally, underpinned by structured collaboration across all services.

This shift is particularly urgent for people with progressive MS, who often experience a lack of structured service response. We acknowledge that progressive MS is too often treated as a 'dead-end' in service design, with limited pathways, fewer interventions, and insufficient focus on proactive care. Without regular check-ins or proactive support, symptoms can deteriorate unnoticed and are seen as inevitable. Additionally, patients may underreport changes or avoid raising concerns due to a perception that little can be done. A lack of consistent recording of Expanded Disability Status Scale (EDSS) scores in primary and secondary care patient notes exacerbates the problem. These issues underline the need for clearly defined roles, personalised care plans, and better integration between specialist and community services.

We appreciate that patient-initiated follow-up (PIFU) models could also support this ambition, when thoughtfully adapted to reflect the complexity of MS. While a generic PIFU approach may not be appropriate, tailored models offer promise. Embedding adapted PIFU pathways into care planning can empower patients, improve service responsiveness, and reduce the strain on specialist teams, provided they are supported by appropriate digital infrastructure and clinical judgement.

Digital tools can also play a significant role in bridging this gap, empowering patients to self-monitor symptoms, providing clinicians with early-warning data, and helping to triage clinical contact based on real-time need. We identified strong potential in PROMS and triage tools, particularly when embedded into clinical workflows, such as clinician nurse assessments, to identify deterioration early and prioritise contact based on need. In addition, setting clear expectations at diagnosis about who patients will hear from and when can improve long-term engagement and reduce avoidable demand.

To support effective self-management and care closer to home, we recommend:

1. Establishing clear local service maps and proactive care models for progressive MS within each ICB to define available support and referral pathways
2. Upskilling and resourcing community teams to manage stable patients and escalate appropriately
3. Embedding proactive care models for progressive MS, including regular contact, defined roles, and early intervention pathways
4. Expanding access to digital self-monitoring tools and pre-clinic triage questionnaires to prioritise care based on need. Implement a National Standard to record patient-facing and clear EDSS scores in patient notes and as part of updates to the NHS App, to ensure visibility across the system and support long-term planning
5. Develop and fund digital PROMS and establish a reactive service model that enables clinical teams to respond promptly to emerging needs flagged through digital monitoring tools

In summary, the time for change is now

Our understanding of MS has changed, but the healthcare system has not fully kept up. We now know progression can start early, without visible signs, and that delays in care can have life-altering consequences.[12] It's time to build a service model that reflects modern science, protects independence, and meets the real needs of people living with MS today.

During a period of ongoing health system reform at a national and local level, and with the Government having set out its ambitions for the next 10 years of care delivery under the NHS, now is the time to look at the changes needed in MS and how they can be integrated into planned reform.

Long-term system change requires collaboration across sectors, bringing together industry, healthcare, and patient voices, to create a future where MS care is as innovative and dynamic as the people it serves. This must be met by Government action to champion policies and services which reflect the latest scientific understanding.

We remain committed, alongside Sanofi, to working towards a future of MS care which is proactive, personalised, and preventative. Together, we will continue to call for action on the areas outlined in the statement to deliver a care pathway that helps people living with MS retain their independence in the ways that matter to them, for as long as possible.

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