

# NHS Reset and Reform

A new direction for health and care in multiple sclerosis.

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## COVID-19

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The scale of the challenges facing multiple sclerosis (MS) service delivery after the third wave of COVID-19 is vast. The first pandemic precipitated rapid transformation in the way MS services were delivered through reduced face-to-face activity, outpatient appointments conducted via the telephone or video links, remote monitoring and medicines supply and changes to infusion and pharmacovigilance monitoring schedules. Neurologists and MS nurse specialists were redeployed to provide frontline NHS support, leaving a huge backlog of patients.

Aside from the impact of the pandemic, MS services have had insufficient funding and capacity for several years; many were only able to serve the needs of patients on disease modifying therapies (DMTs), making the need to change the service model apparent for some time. Staff wellbeing, expectation management and integrated planning are all going to be key to success for future services.

Providing an accurate picture of what the next 12 months will look like is not easy but it is important to begin having these conversations. The NHS is entering a new era through the introduction of integrated care systems (ICSs), place-based working and an emphasis on preventative healthcare. Although the NHS Long Term Plan sets out a clear ambition to shift to more collaborative working through ICSs, there remain several uncertainties about how these systems will operate for MS.



**‘Multiple Sclerosis Academy provides practical education in MS, producing specialist clinical leaders and transforming local healthcare. Part of innovative education provider Neurology Academy, and led by a practicing Faculty of experts, MS Academy supports clinicians, specialist nurses and professions allied to medicine to increase in knowledge, confidence and ability, improving services and support for people living with MS.**

[neurologyacademy.org](https://neurologyacademy.org)



# Acknowledgements

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## Foreword

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The impact of COVID-19 has been profound on people living with multiple sclerosis (MS) as well as placing a strain on MS services that were already challenged.

Across the NHS, the majority of specialist services, including those for MS, redeployed staff to support the wider health service. This meant that for prolonged periods over the last year, only minimum MS services have been provided.

COVID-19 resulted in delayed access to - or cancelled - outpatient appointments while face-to-face contact was replaced with remote consultations. MS waiting lists were already too long and they have grown significantly over the last 12 months. The outlook for the short and medium term is bleak unless fundamental changes are brought about.

The unprecedented challenge of dealing with COVID-19 for the NHS is likely to change the way health and care services for MS are planned, commissioned and delivered for the foreseeable future.


And yet, despite the challenges, there has been significant transformation across many MS services. The pandemic has provided a catalyst for change. I have heard time and again of services that were transformed in a matter of days enabling a leaner, more agile way of working. The speed of adoption of new ways of working has been mind blowing. At a time of crisis, health professionals across the MS sector have been the change-makers. The pandemic has stimulated greater innovation and service transformation, helping to consolidate ideas about how services must change and what now needs to happen.

MS services are at a crossroads. There is now an opportunity to reflect and learn about how each and every service has adapted and evolved over the last 12 months and to rethink how services could now be delivered differently.

Once the NHS gets a chance to reset as this most acute phase of COVID-19 eases there will be a huge opportunity for the MS health landscape to change permanently for the better. We could be on the verge of a new era for MS services. COVID-19 has provided an opportunity to 'reset and reform' through recognition of the innovative practices that have materialised during the pandemic.

This compelling report highlights six areas in particular that can help transform the MS sector. Nothing will change without addressing resource and capacity challenges through better utilisation of the MS workforce. There is a need for better leadership development for MS healthcare professionals, and the whole sector must work better together to ensure MS has a place in local priority-setting discussions to enable good service planning. Embracing these and the other recommendations in the report can only help to drive the successful implementation of the optimal pathway for MS which will finally emerge in 2021.

The MS sector has come so far in the last year. Many opportunities have emerged despite COVID-19. But they must now be seized proactively. Otherwise simply pressing Ctrl+Alt+Del and resetting MS services back to where they were in March 2020 would be letting down so many people living every day with MS.



**David Martin**  
CEO of the MS Trust • Chair of the Neurological Alliance

# Key points

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## 1. Leadership

Support leadership development and training opportunities for healthcare professionals (HCPs), commissioners and service managers working in MS. Identify clinical leaders who can actively provide a leadership role within MS networks and ICSs. Opportunities to develop patient leaders should also be a consideration. This would assist with improvement of MS services at a network level and also provide influence from a number of angles with ICSs.

## 2. Pathway mapping, implementation and innovation

Support implementation of the optimal pathway for MS and development of further symptom-related pathways. There is a need to understand how innovation can support pathway implementation and how the MS community can work with developers and artificial intelligence (AI) to develop management solutions.

## 3. Commissioning and service management

Ensure MS has a place in local priority-setting discussions to enable service planning. COVID-19 provides an opportunity for MS services to be 'reset' and to be 'reformed' through recognition of the innovative practice that has occurred in the pandemic. Use of data, backlog reporting, audits of services, self-management and monitoring, and incentives all play a part in future service reform.

## 4. Workforce capacity and funding

Address human resource and capacity challenges through better utilisation of the workforce. This could be through skill mix and wider engagement with HCPs to undertake new roles that are developing as a result of direct enhanced service (DES) in the community. There is currently insufficient capacity to manage the existing caseload of patients on DMTs, as well as the COVID-19 backlog alongside patients with the progressive forms of MS who are now eligible for new treatments.

## 5. Integration and system working

Ensure ICSs have a clear picture of the population that they are delivering services for, including the complex and differing needs of those with MS. Having a clear picture of the population can support systems to assess workforce capacity, inform strategic planning and outline the correct pathways for patients to follow.

## 6. People with MS: addressing health inequalities

Ensure patients are empowered to manage their own condition and respond to early warning signs of problems occurring. Implement digital technology, remote self-monitoring, patient-initiated follow-ups (PIFU), screening for and managing comorbidities and other social determinants of health. Ensure a focus on prevention, lifestyle interventions and wellness.

# Leadership

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## The issue:

Much of what has happened in the pandemic has been based on local teams coming together at pace to radically redesign MS services for their local communities. Services were transformed in a matter of days enabling a leaner, more agile way of working, with health care professionals (HCPs) feeling empowered to innovate and redesign services. During the crisis, HCPs didn't have to seek approval from the tiers of senior managers, which allowed many different solutions to emerge for the same problem. The environment the pandemic provided acted as a catalyst for change and demonstrated that - when decentralised - decision-making, innovation and service change can happen very quickly. However, there is a fundamental need to address the confidence and skills required to lead MS service change on a day-to-day basis without the 'catalyst' and relatively hands-off approach from senior management.

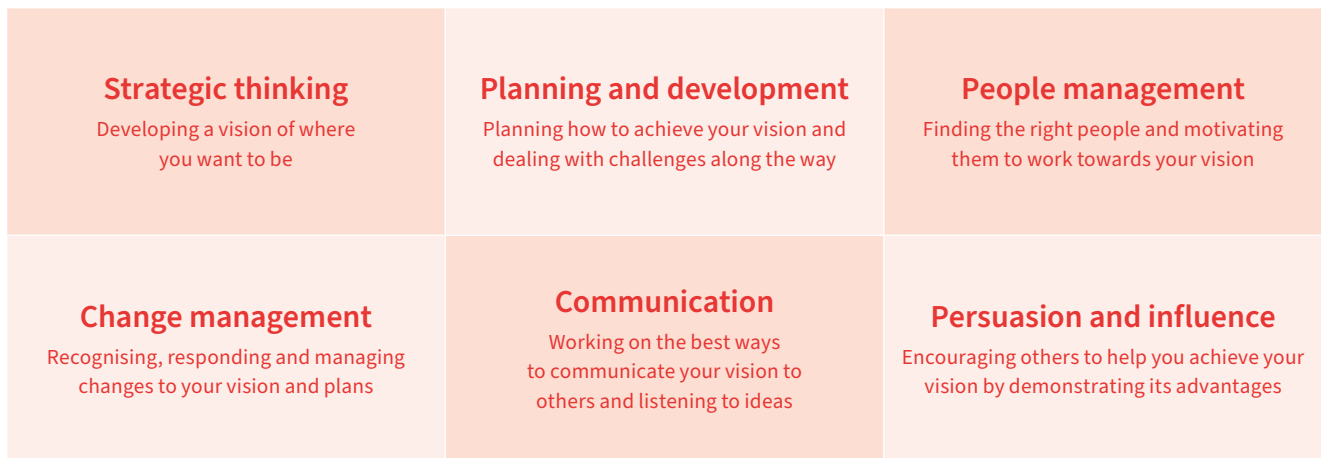
## Reset now presents an opportunity for MS services to change:

National and local leaders are absolutely necessary if MS services are to be prioritised in the future: this was the unanimous viewpoint of the expert stakeholder group. Current leaders like the Neurological Alliance and the MS charities are already lobbying nationally for service change, but to implement these proposed changes, leadership is something that needs to be done by HCPs at a local level, especially as the NHS moves to new service models with ICSs and integrated budgets. Capacity to influence will be limited if we are fragmented, so a joined-up approach is needed; coordination will be essential if the MS community are to effectively influence key decision-makers. This may need to involve working in partnership with a tiered approach:

- **MS specific:** highly specialised national approach with MS as the main driver;
- **Neurological:** less specialised where the approach may include other neurological conditions;
- **Long-term conditions:** where a wider reaching approach may be possible.

The skills that leaders need is not something that many MS HCPs feel they have. Leadership lies in the ability to get things done, allows communication of a clear vision with the team united around that vision. Leadership is a set of skills that can be mastered but it is not taught within the medical, nursing or other allied HCP syllabi. The pandemic focused on the need to bring about change but HCPs are now eager to develop leadership opportunities.





**Figure 1.**  
Skills good leaders need

Since neurology was de-prioritised in 2016 with the departure of the National Clinical Director and regional strategic clinical networks for neurology, the NHS has lost sight of the importance of neurological services and rarely includes neurology service improvement in their priorities. There is now a critical need for MS leaders to communicate opportunities that exist to improve services and address unmet need. Services for people with MS have, to date, remained virtually invisible under the nationally developed quality and accountability mechanisms. The overall vision for neurology has been limited to activity from the National Neurology Advisory Group (NNAG), patient charities and more recently for MS, the Raising the Bar for MS initiative by MS Academy.

As a result, most services are working in a silo with little in the way of collaborative working across subspecialities and regions. For people who have MS there has been significant variation in the provision of services, particularly if they have not been receiving a disease-modifying therapy (DMT). The failure of the NHS Long Term Plan (2019)<sup>[1]</sup> to prioritise neurological conditions has led to concerns that MS services will continue to be marginalised at national and local levels and although cross cutting initiatives for long-term conditions may help to drive quality in MS services, this will not prevent the exacerbation of problems that exist for ensuring the best outcomes for people with MS.

Leadership needs go beyond the MS team; many neurology service managers and commissioners do not have a clinical background and may have a relatively low appreciation of the complexities and interconnectedness of elements of MS services and of ‘what works’. This impairs their ability to act as strong advocates for people living with MS. People with MS can also be strong advocates for services and the ability to have patient leaders within local services is extremely valuable.

The NHS Long Term Plan has set out an ambition for ICSs to cover the country by April 2021, bringing together local organisations to plan and deliver care at a population level. MS clinicians play an important role within local systems to drive change and investment. How can clinicians influence this process? Why should ICSs prioritise MS? Capacity to influence this is limited if we remain fragmented.





# Leadership: what's needed now?

- **A national 'beacon'** for raising the profile of MS, "Raising the Bar for MS"<sup>[2]</sup>.
- **Geographical identification** of the location of potential MS networks; shadow/virtual networks may develop initially to test proof of concept.
- **Locality 'MS Clinical Torchbearers'** so each network will have a designated MS clinical leader.
- **Leadership training** for MS HCPs, managers and commissioners to develop the skills to bring about service change and enhance commissioning.
- **Collaboration** with the National Neurological Advisory Group (NNAG) on wider neurological issues that can support improvements in MS services.
- **Use of the NHS RightCare progressive neurological conditions toolkit<sup>[3]</sup>** and the NNAG optimum clinical pathway for patients with MS<sup>[4]</sup> to support prioritisation of MS at ICS level.
- **Greater understanding** of how MS leaders can influence their local ICS.
- **Financial waste** – where can MS service improvements provide levers?
- **Audit of national standards** specific to MS services.

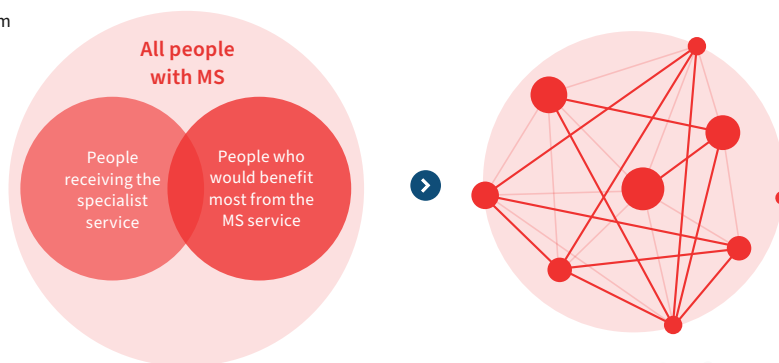
“For years neurology and MS has been a Cinderella service with minimal investment and no one at government level to really champion the cause. It's always lost out to other services that have higher profile, MS leaders need to challenge this nationally.

Part of the issue is that many services have had no identified leader for clinical and strategic direction and often have to navigate through experience as to what they think is right.”

**Karen Vernon** • Nurse Consultant in MS

## The new service paradigm = Shared care model

**Figure 2.**  
Future ways of working from hierarchy to network  
Source: Gray (2017)<sup>[5]</sup>



This requires clinicians, including specialists, to become population focused as well as delivering high quality care to referred patients which becomes part of a quality improvement programme. **We can achieve this through networks.**



“The COVID-19 pandemic taught us that flexibility, quick decision-making, and innovation are the three essential ingredients to business and healthcare survival.”

**Dr Agne Straukiene** • Consultant Neurologist

# Pathway mapping and innovation

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## The issue:

There is an inconsistent pathway approach to care across MS services currently and innovations that could improve patient outcomes are not sufficiently prioritised. Greater focus is needed to standardise and audit the care that patients get as well as increasing the range of innovations that could support improved care delivery and the wide adoption of these innovations.

A care pathway approach creates a consistent standard of documentation that also provides a basis for ongoing audit. Not only does an integrated care pathway (ICP) improve the quality and efficiency of patient care, it is an effective communication tool between HCPs to maintain standardised outcome-oriented care. The benefits of developing an ICP extend far beyond the production of a good pathway document. The discussions that take place during the development of the pathway also encourage closer team working. The wider health and care team need to be involved in pathway development as they may not previously have fully appreciated how their role fits into the patient pathway. These important discussions can help HCPs to understand and value their own contributions, and those of their colleagues, within the wider service.

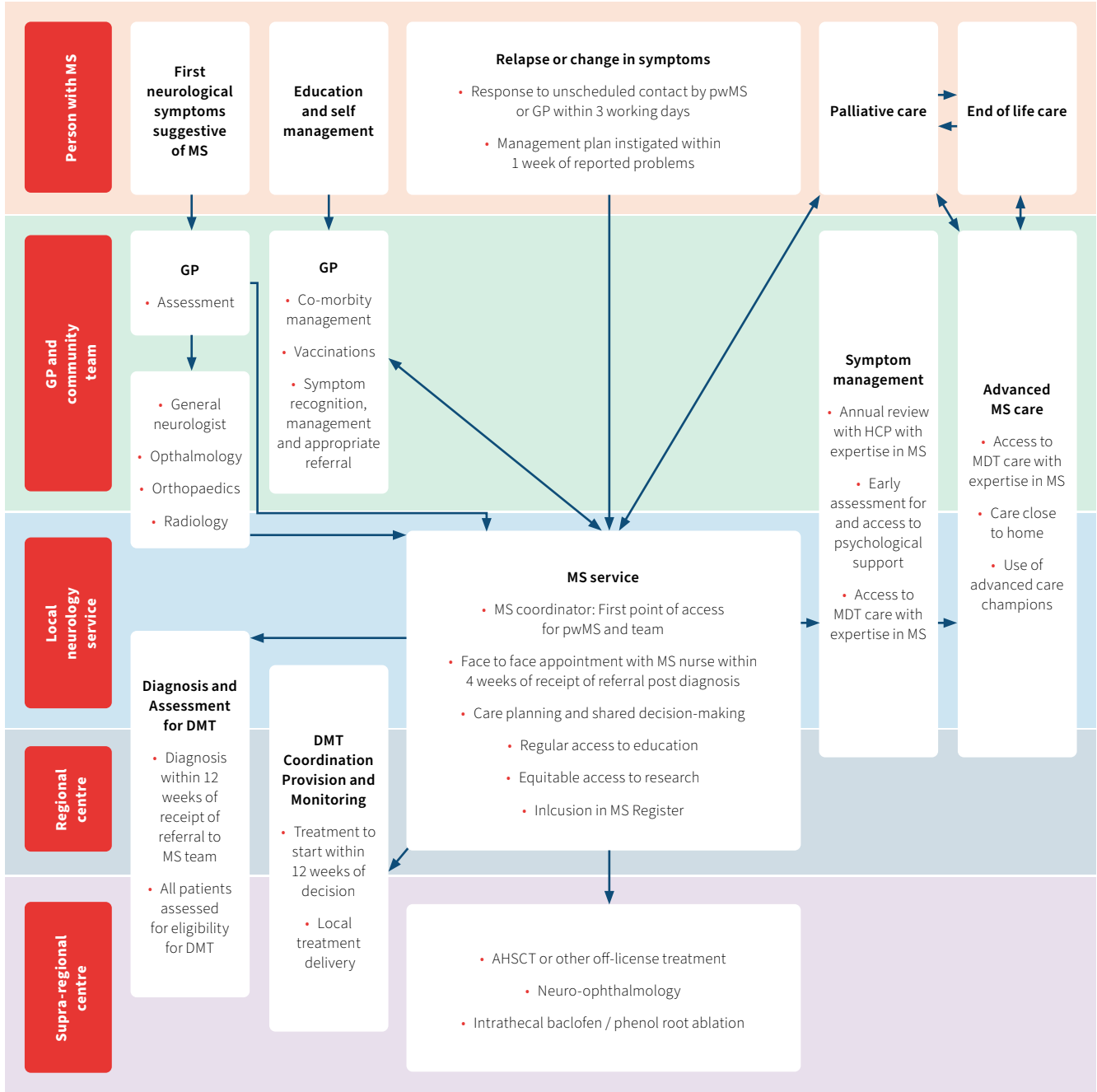
A key element of pathway development is the involvement of patients who can specify the care and services that are important to them.

The NNAG has developed an optimum MS pathway<sup>(4)</sup> with a group of specialist MS health and care professionals, MS patient groups and people with MS. It covers referral to diagnosis, diagnosis to specialist assessment, drug treatment, symptom management, advanced MS and specialised components of care (see Figure 3, on page 13). The pathway is currently in draft format but will be finalised during 2021.

Ensuring everyone is aware of this optimum pathway will be key for improving MS services, whilst how the pathway is translated, delivered and implemented across local integrated services will be a central issue.

Additionally, while the pathway provides an overview of key areas, if we are to provide holistic care for patients a number of other 'sub pathways' are needed. For example, more explicit pathways that deal with priority patient issues like fatigue, or those where proactive management could improve patient outcomes and reduce NHS costs such as bladder and bowel management, will need to reflect local service provision. Involvement of the wider HCP team will also be needed if pathways are to work.

**Information, education, advice, supported self-management, shared decision-making and access to research opportunities at all levels**

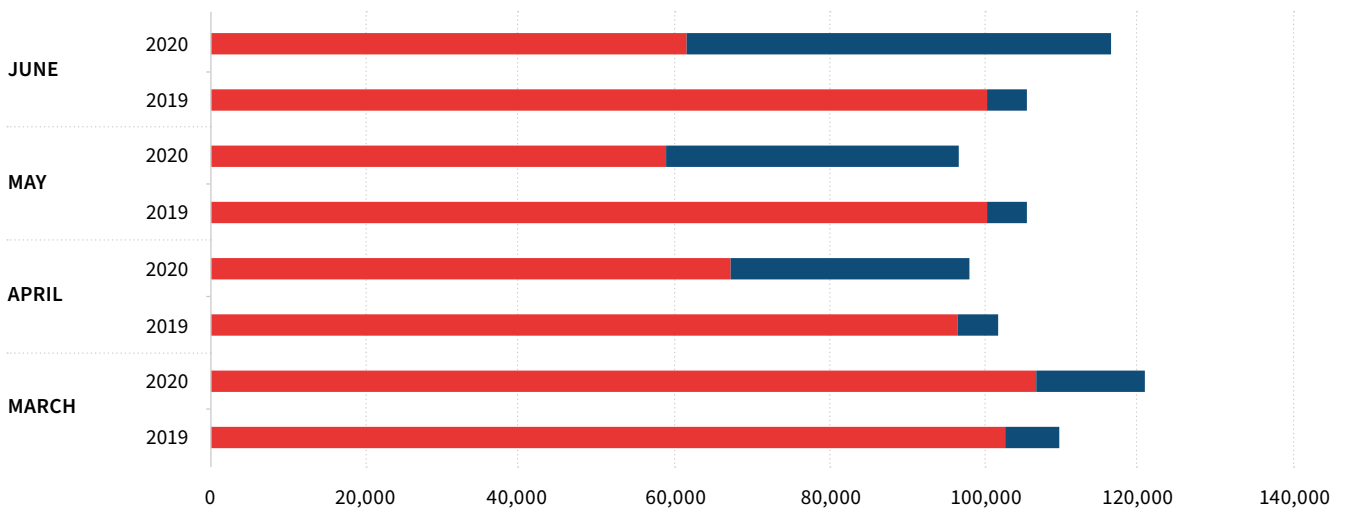


**Figure 3.**  
Draft optimum clinical pathway for MS<sup>[4]</sup>  
Source: NNAG 2019

## Innovation:

During the pandemic NHS services adopted remote consultations at an astonishing pace. In December 2019, NHS Digital reported that just 15% of 23 million primary care appointments during the month had taken place by phone or online<sup>[6]</sup>. By April 2020, 49% of appointments during the month were by phone or online, and in May GPs were reporting delivering 90% or more appointments remotely<sup>[6]</sup>. The Kings Fund states this has been equally dramatic in some hospital and community services<sup>[7]</sup>.

The Neurological Alliance analysed hospital episode statistics (HES) data in 2020 to examine changes to outpatient appointment delivery for MS during the COVID-19 pandemic period from March – June 2020 highlighting that over 60,000 appointments were conducted remotely for MS<sup>[8]</sup>. While remote consultations are acceptable to some patients, not all consultations can be conducted remotely and this can potentially increase health inequalities for those who do not have access to phone or internet.



**Figure 4.**  
Change between face to face and remote outpatients consultations for MS, March to June 2020  
Source: Neurological Alliance data on file

The expert group spoke of the benefits that digital technology has brought for MS both prior to and during the pandemic. Digital tools have enabled improved multidisciplinary working and data sharing across NHS bodies, for example, to support the vaccination programmes or to understand, monitor and respond to COVID-19 locally. What is now needed is the means to use the technology to support MS service improvement. There needs to be a much greater focus on innovation for the future but this needs to be done in conjunction with patients and IT developers.

By leveraging digitalisation, standardised data collection and potentially AI, barriers to integrated and personalised care could be overcome. Examples such as software-assisted MRI monitoring for more efficient reporting was mentioned alongside digital tools for monitoring, triage, prioritisation, patient activation and self management technology which require further development.

As such, there is a need to think innovatively about how to better utilise the existing workforce to address demand. To inform the process, we need to use data and the patient and clinical outcomes associated with the MS care we want to achieve. We will need to establish mechanisms to collect the data needed to assess if services are delivering these outcomes and the experience patients want. Utilisation of digital and data can make this happen; the burning question here is how can MS HCPs influence this process?

## Pathway mapping and innovation: what's needed now?

- Adoption of the NNAG's optimum clinical pathway for MS<sup>[4]</sup> at scale.
- Development of additional symptom pathways to support the spread of best practice.
- Discussion on how the MS community can work with developers and funders to provide digital technology and AI support.
- Opportunities to use digital innovations at scale.

# Commissioning and service management

## The issue:

We have far more expertise than ever in the proverbial ‘room’ to make positive commissioning decisions and integrate care across a whole system. Commissioners and service managers bring their knowledge of the overall system while HCPs offer their expert insight into the needs of people with MS and how these can be met, but unless everyone shares that knowledge, nothing will change. The expert group highlighted that currently there is little engagement between clinical teams, commissioners and service managers in relation to decisions about service development.

**“MS services across the UK have been chronically under-resourced for many years with neurology largely ‘invisible’ within national commissioning guidance and budget setting.”**

**David Martin • CEO, the MS Trust**

People with MS often have wide-ranging requirements spanning the whole system of care in the place that they live. The offer of ‘place based care’ will be met through providers of primary care, community health and mental health services, social care and support, community diagnostics and urgent and emergency care working together with meaningful delegated budgets to join up services<sup>[10]</sup>.

Lack of engagement between clinical teams and their commissioners and managers may lead to a lack of understanding about the benefits of some services and aspects of care.

## A local system approach for service transformation



**Figure 5.**  
Suggested system approach for service transformation

**“There is a real need for commissioners and service managers to upskill their understanding in neurology to support business case development. Using all available data and pathways advice from clinicians will support a local system approach for neuro service transformation.”**

**Prof Adrian Williams • Chair NNAG, Clinical Lead GIRFT**

The NHS Long Term Plan places a clear focus on a prevention agenda and an overarching set of priorities for the entire population. These are no less relevant to MS than any other healthcare population. Providing more place-based care and supporting people with MS regarding medication, therapies, mental health and their general wellness can boost out-of-hospital care. A large quantity of unnecessary emergency hospital admissions are also preventable through timely interventions and preventative care for issues like urinary tract and respiratory infections, falls and fractures, faecal impaction, pressure sores and issues with mental health that currently result in a high proportion of NHS costs (see Figure 6, below)<sup>[11]</sup>. Figure 7 (on page 18) highlights how costs of an MS hospital admission rise if the patient has a comorbidity like obesity or diabetes. This indicates that a wellness approach to lifestyle is important not only for the patients’ health outcomes but also NHS costs.

There is now a plethora of data available to inform service planning like Hospital Episode Statistics<sup>[10]</sup> but this is not as widely used as it could be. Additionally people with MS are central to service planning and should be consulted about what services are important to them as well as decisions about their care.

	% OF EMERGENCY ADMISSIONS	AVERAGE COST PER EMERGENCY ADMISSION SPELL	TOTAL
URINARY TRACT INFECTIONS	9.5%	£2,710	£7.9m
BLADDER & BOWEL ISSUES	11.3%	£2,567	£9m
RESPIRATORY ISSUES	13.4%	£4,185	£14.7m

**Figure 6.\***  
Primary reasons for emergency admission spells for people with MS in England (2019/20)<sup>[11]</sup>

“It’s about picking up what’s important to them [service managers] and bringing neurology in, so it has a foot in the door. Another innovation [in Cheshire and Merseyside] had been access to exercise which had been supported by Sport England and lottery funding. Even severely disabled patients had been able to take part in sport. There had been a strong message from patients that they wanted to live as normal a life as possible and not be over-medicalised.”

**Julie Riley** • Divisional Director of Operations Neurology,  
Walton Centre NHS Foundation Trust

**\*Disclaimer.**  
Secondary care data is taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital, the new trading name for the Health and Social Care Information Centre (HSCIC) Copyright © 2021, the Health and Social Care Information Centre. Re-used with the permission of the Health and Social Care Information Centre. All rights reserved.





## The issue (continued):

Costed models of care are important to show how capacity and service costs can be improved. Monitoring disease-modifying therapies (DMTs) is time-consuming. In an audit conducted by Dorsey Campbell<sup>[12]</sup> in 2019, initial data from four centres highlighted that 1,699 patients were treated, which meant carrying out 642 blood tests per month. Based on which HCP did the monitoring, the cost of delivering 200 blood tests per month ranged between £28,525 and £54,966. Costs include identifying patients requiring blood tests, arranging appointments, retrieving, recording, interpreting and acting on results. This significant level of variation warrants further exploration and shows how useful data can be.

DMT provision is an essential part of the care and management of people with MS and, because of the level of risk associated with these therapies, monitoring is an essential but resource and time-consuming part of patient care. Much of the monitoring is undertaken by MS nursing teams with monitoring prioritised by already under-resourced services to ensure patient safety. This has led to health inequalities for people with progressive MS who have been unable to access specialist MS care in some areas.

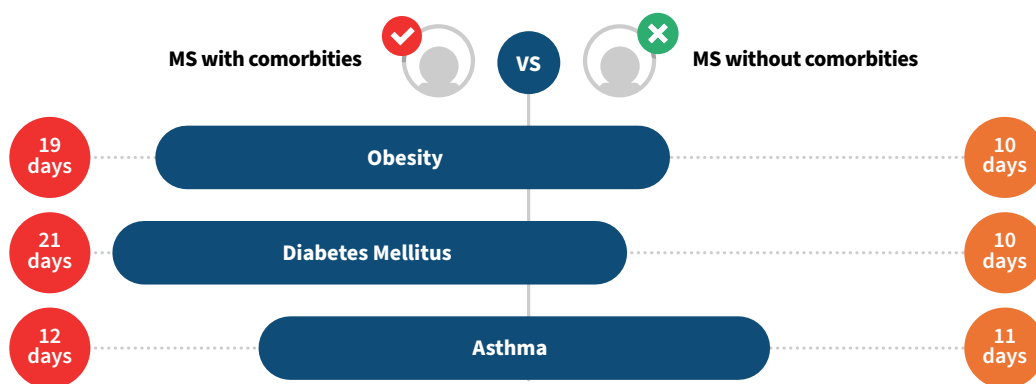
The Association of British Neurologists (ABN) recommends that treatment with a suitable DMT should be started as soon as possible after diagnosis<sup>[13]</sup> in all eligible patients in order to optimise long-term outcomes. During 2020 the licensing and approval of a DMT for primary and then secondary progressive MS<sup>[14]</sup> occurred which was eagerly welcomed but the impact of this on already overstretched teams is significant. Commissioners and managers need to consider the implications of this for future service planning to ensure equitable provision of services for those with progressive disease.

NICE has published clinical guidelines intended to underpin the provision and commissioning of care for people with MS across England and Wales<sup>[15]</sup> alongside additional Quality Standards for MS<sup>[16]</sup> to support effective population management, but there is little evidence to date that these standards are being implemented or audited.

COMORBIDITY	WITH	WITHOUT
Obesity	£6,878	£4,254
Asthma	£6,196	£4,258
Diabetes Mellitus	£8,456	£4,183

**Figure 7a.**  
Cost of admissions to hospital for people with MS and a comorbidity  
Source: Dr Agne Straukiene NHS  
Digital HES data 2018/19 data on file

## Length of stay (with day cases) when primary diagnosis MS +/- comorbidities



**Figure 7b.**  
Length of stay in MS +/- comorbidity  
Source: Dr Agne Straukiene NHS Digital  
HES data 2018/19 data on file

## MS quality standards:

- Specialist support at diagnosis
- Timely follow-up after diagnosis
- Coordination of care
- Facilitating appropriate physical activity
- Timely management of relapse
- Undertaking comprehensive, annual reviews

The Getting It Right First Time (GIRFT) neurology report will outline recommendations for improving neurology services including MS. The GIRFT methodology report subdivided neurological diagnoses according to the perceived likelihood of a better outcome from direct neurological care. The categories were ‘definitely’ (such as epilepsy, MS or Guillain-Barre), ‘probably’ (meningitis and Parkinson’s) and ‘possibly’ (tumour or hydrocephalus). This means that in the expert opinion of the GIRFT team, people with MS will definitely have better outcomes if they are seen by a neurologist – particularly one who specialises in MS. This fact is important for managers to note when planning workforce capacity.

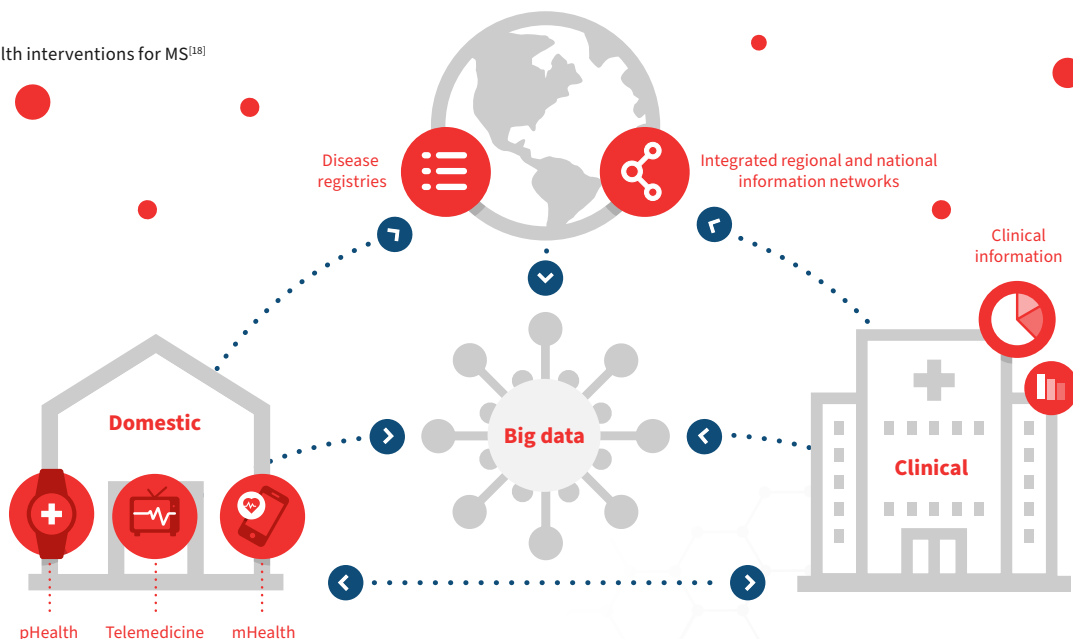
The importance of early referral, diagnosis and treatment in MS is also critical for GPs, commissioners and service managers to understand if people with MS are to receive the support and care they need. Service planning needs to provide sufficient capacity to ensure all people with MS receive care.

Optimising brain health and the holistic management of MS is an important message to impart, but timely access to the MS specialist team will be dependent on services and workforce availability. Examples of service models that are transferable could support many areas to understand how they can achieve transformational change (see Figure 8).

**“There is an emerging field in medical informatics, public health, using information and communication technologies. Such technologies are shown in the graph (Figure 8). This may involve personalised health (pHealth), public health, telemedicine, mobile health (mHealth), clinical information systems (e.g., electronic health record), disease registries and other non-clinical systems, integrated regional and national and international information networks and ‘Big data’ based on AI datasets.”**

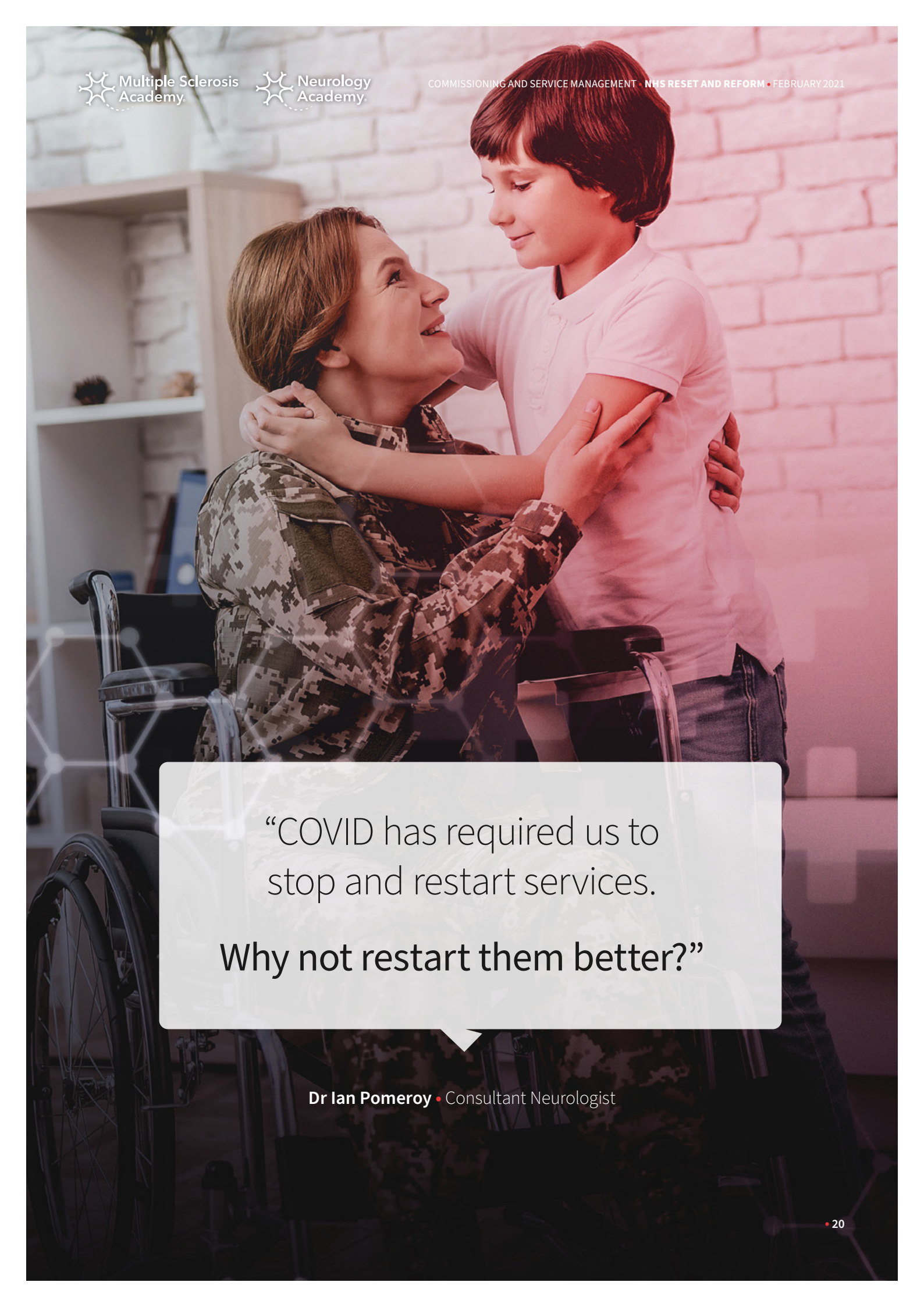
**Dr Agne Straukiene • Consultant Neurologist**

**Figure 8.**  
Electronic health interventions for MS<sup>[8]</sup>



## Commissioning & service management: what's needed now?

- **Backlog reporting** of COVID-19 induced workforce redeployment is needed to better understand its exacerbation of issues already prevalent due to chronic under-resourcing across the UK.
- **DMT management** has been prioritised by under-resourced services to ensure patient safety leading to inequalities in care for those with progressive MS. The size of the problem should be quantified.
- **Opportunities for engagement** between commissioners, service managers and MS HCPs like the Neurology Manager Network can support service understanding and transformation.
- **Awareness of tools** like the NNAG optimum clinical pathway for MS<sup>[4]</sup> and NHS RightCare progressive neurological conditions toolkit<sup>[3]</sup> could provide management with stimulus to address service change.
- **Audit of improvement standards** such as NICE Quality Standards<sup>[1,5]</sup>, the GIRFT neurology report and Raising the Bar for MS<sup>[2]</sup> serve as a stimulus for change for commissioners and service providers.
- **Use of data** to highlight how understanding service problems can aid in making improvements.
- **Incentives** like the Commissioning for Quality and Innovation (CQUIN) scheme could help implement Quality Standards.
- **Wider partnership engagement** of voluntary sector partners and people with MS to support care provision.

A photograph of a woman with short brown hair, wearing a camouflage-patterned shirt, sitting in a black wheelchair. She is smiling and looking up at a young boy with short brown hair, wearing a light pink polo shirt. The boy is standing and embracing her from behind, with his arms around her shoulders. The background is a white brick wall. The entire image has a soft, warm, reddish-pink tint. A white speech bubble with a downward-pointing arrow is overlaid on the bottom half of the image, containing text.

“COVID has required us to  
stop and restart services.  
Why not restart them better?”

**Dr Ian Pomeroy** • Consultant Neurologist

# Workforce, capacity and funding

## The issue:

Workforce capacity and funding for MS is a significant problem and has been an issue both pre and post-COVID-19. The expert group highlighted that during the first wave of the pandemic, the majority of specialist services, including MS services, were asked to redeploy staff across a variety of alternative areas and to provide only the minimum services required for people with MS.

A survey to understand the impact of the first wave revealed that 24% of MS specialist HCPs reported over half of their MS team were redeployed. 70% of the respondents felt their services could not meet the needs of people to the extent that they had, pre-COVID-19<sup>[19]</sup>. 73% of HCPs felt neurorehabilitation had been the hardest hit. The mental impact of COVID-19 on the workforce has been immense as HCPs in all parts of the system were mobilised to help. There is now concern about resilience and retention of staff in what were already overstretched services, and worry that some may leave their profession.

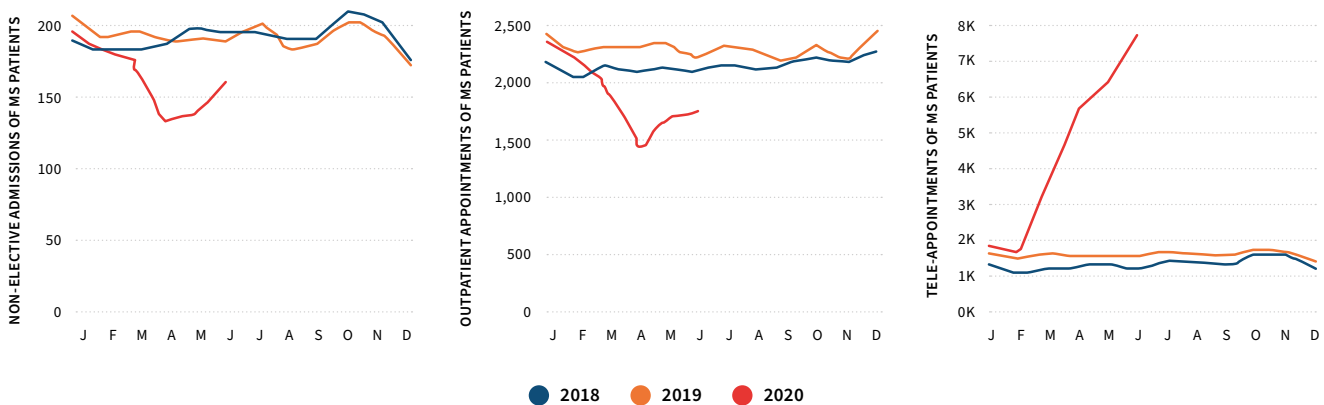


Figure 9.\*  
Changes to ways of working in England during COVID-19 March to August 2020

## Reset now presents an opportunity for MS services to change:

There are several key challenges that need to be managed if we are to return to pre-COVID-19 capacity. These challenges include the backlog of patients needing care (75%), lack of physical space in clinics and wards (66%), a reluctance of people with MS to attend hospital for appointments (60%) and an overall lack of staff (37%)<sup>[19]</sup>.

There are a number of issues that need to be tackled to address the shortage of HCPs required to appropriately meet the needs of people with MS. Management of MS requires a multidisciplinary, multi-agency approach across health and social care and the pandemic has brought challenges to what were already under-resourced services. There is a shortage of trained MS neurologists, MS specialist nurses and HCPs alongside an ageing workforce. Coupled with the demands placed on staff in the pandemic across all settings and disciplines, this has additionally led to significant levels of workforce stress and anxiety.

\*Disclaimer.  
Secondary care data taken from the English Hospital Episode Statistics (HES) database produced by NHS Digital, the new trading name for the Health and Social Care Information Centre (HSCIC)

The Royal College of Physicians and Higher Specialty Trainees Census<sup>[21]</sup> of the medical workforce as a whole further reveals that 2020 has been dominated by the profound effects of the pandemic. Although this latest census covers the pre-COVID-19 period, as the NHS moves from crisis management to recovery, longer-term issues such as the fact that the number of consultant posts continues to significantly outnumber supply need to be addressed. The latest census outlines the continuing pressures on the medical workforce and systems.

The need for MS specialists far outstretches capacity. The most recent mapping of MS nurse services<sup>[20]</sup> by the MS Trust showed that 69% of people with MS live in areas across the UK where MS nurses have a caseload higher than the recommended number. They estimated that approximately 105 additional MS nurses are required across the UK to ensure everyone living with MS has access to the specialist, proactive care that the sustainable caseload figure represents.

Hobart et al<sup>[22]</sup> (2020) identified the observed staffing counts and average caseloads in MS teams in a pilot audit for the Raising the Bar for MS<sup>[2]</sup> programme in 2020 which highlighted significant variance. The audit provided suggested caseload sizes, but it will take considerable investment and new ways of working to achieve these.

TEAM MEMBER	MEAN (SD)	MEDIAN	RANGE
Neurologist	615 (243)	550	250–1260
MS nurse	315*	N/A	N/A
MS coordinator	862 (605)	600	250–2500

\*MS Trust recommended sustainable caseload for a whole time equivalent (WTE) MS nurse specialist with a mixed caseload in an urban/rural geography is 315.

**Figure 10.**  
Hobart et al<sup>[23]</sup> suggested caseloads for team members

Figure 11 further illustrates the number of whole time equivalent (WTE) consultants working in neurology which reinforces the regional variation in consultant support for neurology patients.

NATION	NHS REGION	SUB-REGION	FEMALE	MALE	TOTAL HEADCOUNT	TOTAL FTEs	POPULATION	POPULATION PER FTE
England	London	London - Central and NE	498	793	1,291	1,170	3,506,448	2,998
		London - NW	216	346	562	502	2,095,479	4,173
		London - South	606	723	1,329	1,214	3,306,154	2,724
	Midlands and East	East Midlands	310	594	904	833	4,805,149	5,770
		East of England	443	807	1,250	1,159	6,201,214	5,353
		West Midlands	424	938	1,362	1,262	5,900,757	4,677
	North	North West	567	1,195	1,762	1,656	6,793,205	4,103
		Northern	245	500	745	679	2,879,534	4,239
		Yorkshire and the Humber	499	847	1,346	1,248	5,756,878	4,612
	South	Kent, Surrey and Sussex	399	630	1,029	948	4,740,249	5,001
		South West	429	667	1,096	992	4,879,675	4,921
		Thames Valley	221	327	548	502	2,407,593	4,797
Wessex		259	384	643	593	2,705,843	4,562	
N. Ireland	Northern Ireland	Northern Ireland	171	275	446	415	1,881,641	4,533
Scotland	Scotland	Scotland - East	49	86	135	130	511,600	3,931
		Scotland - North	67	127	194	180	786,580	4,416
		Scotland - South	180	218	398	367	1,384,950	3,778
		Scotland - West	264	373	637	595	2,744,970	4,611
Wales	Wales	Wales - North	40	86	126	121	698,369	5,758
		Wales - South	190	413	603	567	2,440,262	4,301

**Figure 11.**  
Royal College of Physicians 2018-19 consultant census data<sup>[21]</sup>

## Reset and reform:

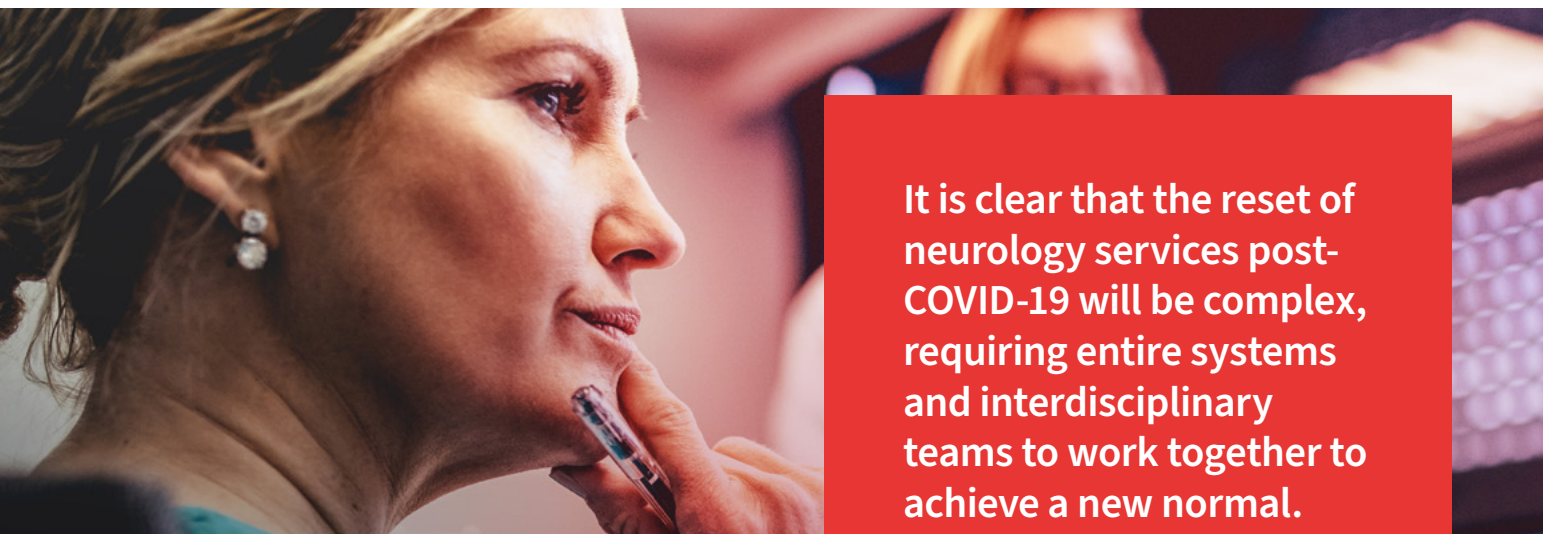
**At the immediate time, patient safety is a primary concern and there is a delicate balance to be managed between minimising immediate risks to patient safety in the pandemic, and mitigating against the long-term risks associated with delays in patient consultations.**

Early diagnosis and the provision of disease-modifying therapies (DMTs), when appropriate, needs to take priority to improve long-term outcomes. Monitoring patients receiving DMTs in accordance with the individual drug guidelines will need to take priority to mitigate patient risk but this should not be at the expense of patients with more progressive disease; ways need to be identified to meet these patients' needs too. The MS Trust has illustrated how beneficial their Advanced Champions programme<sup>[23]</sup> is, but this is currently limited to just six areas; further expansion is required to increase the benefits this service brings.

The significant time taken for monitoring DMTs has been highlighted<sup>[12]</sup> and the expert group agreed solutions are required for managing monitoring with more administrative help, MS coordinators and automated systems for management. There has been a reluctance by some HCPs to give up elements of their role, but teams need to reorganise and make better use of skill mix and resources to build capacity.

There are co-dependencies that exist within MS services, and the expert group stated that consideration will need to be given to these for services to return to normal. These include access to shared resources such as MRI scanning for diagnosis and monitoring; common diagnostic tests including lumbar punctures and blood monitoring. Additionally, the shared demand for and limited availability of supporting services, such as rehabilitation and community support, means that neurology services across the board could quickly run into difficulty. The relationships between speciality provision and supporting services will have a direct knock-on effect for patients whose care will be impacted.

Failure to attend outpatient appointments without any advance intimation, commonly known as “did not attend” (DNA) in the UK, is a common problem encountered globally. The cost of missed outpatient clinic appointments in NHS England in 2017/2018 was projected to be £1 billion but people are now frightened to visit hospital for fear of infection. Pre-appointment contact with patients and short message service alerts in reducing DNA rates may be a useful way forward. Careful selection of patients and planning in advance by employing medtech for tracking, reporting, alerting, monitoring and booking is essential.



**It is clear that the reset of neurology services post-COVID-19 will be complex, requiring entire systems and interdisciplinary teams to work together to achieve a new normal.**



## Virtual consultations:

The rapid revolution in the way care has been delivered in the pandemic through virtual consultations has been unprecedented and it is likely that virtual appointments will continue for the longer term. MS specialist nurses have always provided a significant amount of their consultations via telephone<sup>[24]</sup> but telephone calls cannot and should not entirely replace face-to-face consultations. And while they do create extra capacity, they are not acceptable or suitable for all patients, for example to carry out accurate assessments for those with cognitive issues.

Regarding remote monitoring, aside from reduced risk of interacting with COVID in hospital settings, this also offers patients convenience and savings, eliminating the time and expense related with travel to a hospital appointment. However, patients obviously need to attend for appointments where scans or infusions are required. Those who deploy virtual consultations should be able to assess the patient experience – ultimately it comes down to what works best for the patient.

In a survey conducted by the Royal College of Physicians with its membership, 51% of respondents reported that they were unable to access a computer with a webcam for video appointments<sup>[25]</sup>; it is therefore difficult to see how some of the aspirations for virtual consultations can be met.

IT providers who build the tools that allow GPs and other healthcare providers to communicate more efficiently with their patients, and with each other, in order to deliver care are essential going forward. However, to date there has been seemingly limited engagement with NHSX (developed to drive digital transformation) and IT providers such as AccuRX.

“It all boils down to manpower. We need more people to do the job; currently one person is doing the job of two to three people. Group consultations could be developed across MS networks so that resources are maximised - both virtual and face to face - and we need networks for MS where staff can work across networks.

**Evaluation of virtual consultations must be part of the learning process.”**



# Workforce capacity and funding: what's needed now?

- **Investment and support for staff wellbeing,** physically, mentally and emotionally, must be prioritised if we are to retain staff.
- **Workforce challenges need to be identified:**
  - Number of people currently estimated to be living with MS in a locality,
  - Average clinical capacity required to achieve best-practice care and quality of life,
  - Current locality MS service capacity,
  - Red Amber Green (RAG) rating of local MS workforce so that capacity is explicit.
- **Greater use of skill mix within teams – administrative staff and coordinators have a key role.**
- **Expansion of the neuro-pharmacist role in DMT provision.** This needs to be both at a local and regional level to coordinate DMT prescribing and monitoring and to reduce regional variation.
- **Service development time identified within job plans.** Without the necessary bandwidth there is no capacity for innovation, service development and adoption of new service models developed elsewhere.
- **Utilisation of the new roles within primary care networks (PCNs)** through directed enhanced services (DES); independent prescribers, specialist pharmacists, dieticians and physiotherapists as well as social prescribing link workers. These new roles have the potential to support the MS team and patients providing they have sufficient training in MS.
- **Increasing GP awareness of their role in MS.** Patient management could enable improved triage to secondary care.
- **Education** is a key element of developing new expertise; accessible training for a range of professionals should be made available.
- **Increased digital connectivity will enhance MDT secondary and primary care communication** through virtual team meetings, electronic communication and prescribing.
- **Digital technology** to support patients overall and better manage their interactions with the MS specialist teams.
- **Evaluation of patient perceptions of remote management.**

“New developments require more time and have not been matched by resources.”

**Dr Ian Pomeroy** • Consultant Neurologist

“We need the right person to do the job – nurses doing nursing aspects, coordinators doing administrative aspects.”

**Karen Vernon** • Nurse Consultant in MS

“No one has a job plan including a service development time slot. We don't plan for the future.”

**Joela Mathews** • Lead Neuroscience Pharmacist

# Integration and system working

## The issue:

The health and care system which includes hospital, community and local authority services has been working towards a more integrated model of service delivery through the introduction of ICSs. The NHS's Integrating Care document<sup>[26]</sup> brings into one place the service's plans for reform in 2021 and beyond. It sets out how ICSs will be the basic unit of the local NHS, how devolved finance will work for population-based healthcare, what will be expected of all the partners within systems – at all levels – and who will be responsible for what. ICSs will also have the specialised commissioning budget devolved to them over time meaning that most - if not all - MS care, including DMTs, is likely to be commissioned at ICS or sustainability and transformation partnership (STP) level.

## Reset now presents an opportunity for MS services to change:

More than ever before it is important that MS services liaise with their local ICS, identify service leaders, understand the organisation's strategic priorities and ensure they use these for engagement. How MS services embed into these systems is key.

ICSs have to:

- Assess population health needs, planning and modelling demographic, service use and workforce changes over time,
- Plan and prioritise how to address need,
- Improve the health of all people in their area and tackle inequalities,
- Ensure that priority areas are funded to provide good value and health outcomes.


### **This needs to include neurology and MS so that ICSs are aware of patient and service need.**

The expert stakeholders drew attention to the fact that during the pandemic, coordination of services around place level was a critical success factor, so it is vital that neurology and MS are visible within 'place'. At the moment, MS is not specifically referenced in ICS strategic plans. In January 2021 there were 29 ICSs in operation covering 60% of the population, while the rest of the population is covered by STPs. Of the 29 ICSs, only nine have published their official response to the NHS Long Term Plan and only one ICS (South East London) has included a reference to neurology. From draft plans, a further seven ICSs have included a reference to neurology, but none of these make any mention of MS.

The expert stakeholder group agreed that decisions about MS services and treatment must be led by secondary and tertiary care clinical specialist teams supported by a network clinical lead – a 'torchbearer'. The torchbearer would be supported by the wider MS teams in that network area: neurologists from local hospitals, MS nurse specialists, neuropharmacists and therapists. Service reset should also be informed by service users outlining what services they feel are required. Experts felt the best approach for MS management in local systems will be to use a preventative philosophy for healthcare: early diagnosis is a key driver to improve health, placing a premium on personalised integrated care. This can be enabled by developing joint pathways with primary and community care, developing new models of care such as digital technology solutions for healthcare, one-stop shops and community clinics and a focus on the lifestyle and behavioural changes that form part of the optimal treatment for MS.



The expert stakeholder group agreed that decisions about MS services and treatment must be led by secondary and tertiary care clinical specialist teams supported by a network clinical lead – a ‘torchbearer’.



“In a cash strapped NHS it’s important to consider funding issues and where these can be improved, for example emergency use of the NHS for complications.”

## A ‘fit for purpose’ financial framework:

System working models need to be strengthened by the right financial framework and for MS it is essential that evaluation is based on outcomes rather than activity. The rationale for this is that system budgets should be spent to best reflect the needs of patient cohorts. A ‘Time is Brain’ holistic management approach will be helpful to promote, as disease activity can be undetected in the early phases of MS. However, ensuring timely access to treatment can potentially prevent impairment and disability, whilst proactive assessment and monitoring can prevent costly problems from arising like complications and emergency hospital admission.

Ensuring there is sufficient investment in services will need a partnership approach and engagement on how system budgets should be spent to best reflect the needs of the local health economy. It is essential to bear in mind these might be affected by issues of prevalence, ethnicity, deprivation, facilities and workforce that may not be visible at system or place level.

In terms of costs, MS is one of the costliest neurological conditions due to its early onset, long duration and significant effects on work and daily activities. The annual mean cost of MS per patient in Europe in 2015 was estimated as €22,800 for mild disease, €37,100 for moderate disease and €57,500 for severe disease which does not include welfare benefits<sup>[27]</sup>. Mean annual costs in the UK were £11,400 for mild disease, £22,700 for moderate disease and £36,500 for severe disease<sup>[29]</sup>.

The costs and use of services for MS are highly correlated with disease severity<sup>[29]</sup> (see Figure 12), but resource consumption is also heavily influenced by healthcare systems’ organisation and availability of services. For example, there are co-dependencies for running MS services and these should be noted as services cannot run efficiently unless they are in place. These include MRI, blood monitoring, home delivery of DMTs, continence services, community rehabilitation, podiatry and speech therapy assessments.

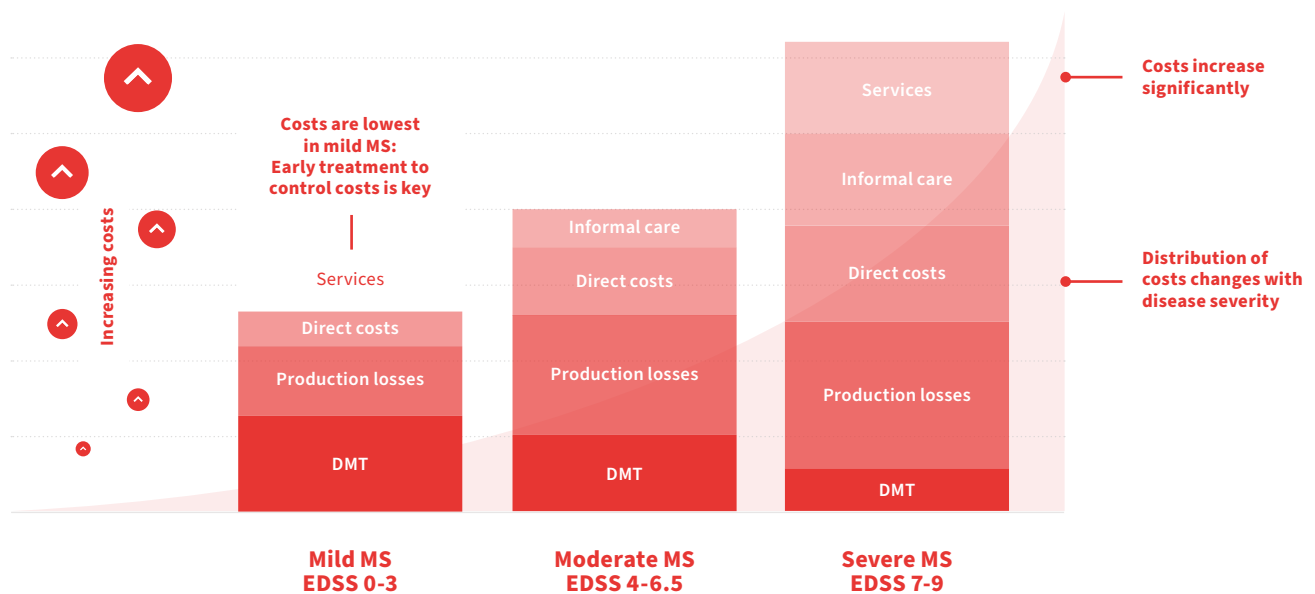


Figure 12. Relationship between MS disability and costs  
Source: Adapted from Kobelt G et al 2017



## Specialised commissioning, DMTs and integration:

NHS England and NHS Improvement have outlined intentions to establish ICSs as key bodies for financial accountability with a single pot of money for every ICS. This will bring together current budgets for: CCG commissioning, primary care, the majority of specialised commissioning, other directly-commissioned services, central support or sustainability funding and nationally-held transformation funding that is allocated to systems.

**“For specialised commissioning reform, numerous opportunities for MS (and neurology more broadly) need to influence this – be it through the legislative proposals to underpin reform in 2021, through the Neurology Clinical Reference Group or Neuroscience services.**

**A focus on MS could help ICSs realise wider improvement goals, e.g. on mental health, but we don’t consistently make these arguments.”**

**Phillip Anderson • MS Society**

Specialised services will continue to adhere to national service specifications but the strategic commissioning and accountability will be at a population level. While the detail is unclear, currently ICSs will definitely have a role in the planning and prioritisation of specialised services through the new NHS England-led Specialised Services Planning Board.

The intention is that these planning boards will bring local systems (ICSs/STPs) together with national commissioners (NHS England) to:

- Ensure that specialised services and plans are based on the specific requirements of the local population,
- Give local systems more say in how specialised budgets are spent in their area and make greater use of their insight into local patient needs.

**“Someone needs to take control and responsibility for these vital services rather than them be forgotten or an afterthought. ICSs need guidance on why MS should be a priority.”**

**Joela Mathews • Lead Neuroscience Pharmacist**

## Disease modifying therapies:

### There is currently significant variation in the availability of DMTs in the UK and the prescribing decisions that underpin them.

A study undertaken by Cameron<sup>[28]</sup> concluded that 56% of people who could benefit from DMTs were doing so, but that access to the treatments varied from region to region within the UK. Prescribing practices were found to be influenced by a number of different factors, including familiarity and previous experience with DMTs, as well as peer networks. Neurologists were found to be more comfortable prescribing a drug they had prescribed previously, rather than prescribing a newer drug. Prescribers were also likely to be influenced by what colleagues were doing locally and nationally, as well as if there were positive or negative experiences from people taking one of the drugs previously. Treatments are now also available for progressive forms of MS but prescribing for this new cohort of patients is currently in early stages.

The MS Trust study identified some of the major factors that are likely to contribute to variation in prescribing DMTs, highlighting the need to acknowledge the influence of professional attitudes. Strengthening peer networks was suggested as a key way of being able to improve confidence in prescribing the full range of DMTs.

**“NNAG could be a helpful source of national leadership for neurology and support for ICS’s.”**

**Georgina Carr • Neurological Alliance**

The expert group was concerned about the impact of reforms to the specialised commissioning budget where the budget will be devolved over time. This has potentially huge implications for DMTs.

## Integration and system working: what’s needed now?

- **Clarity on the structure and leaders within ICSs**
- **Strengthened partnership working with ICSs**, and their local populations of primary care networks, GPs etc
- **Clarity on the levers** that will support the integration of MS into local ICS plans
- **Identification of key issues** that need to be prioritised for efficiencies within the ICS
- **Workforce planning across ICSs and MS networks** with strategic coordination of care, e.g. a mobile staff passport to support cross-organisational working
- **Proactive not reactive** MS services are essential, with forward planning the key to making a difference.



# People with MS: addressing health inequalities

## The issue:

The impact of COVID-19 has had an unequal and profound impact on people across the UK, particularly on people with neurological disabilities and those from black, Asian, minority ethnic (BAME) groups. It has shone a light on the differences in health outcomes, on disparities in access, quality and experience of care and on the range of social and economic factors that impact a persons' health.

Fair Society Healthy Lives, the Marmot Reviews<sup>[29,30]</sup> set out an analysis of the causes of health inequalities in England and what needed to be done to address these, highlighting the importance of identifying and acting on social determinants of health. The second review published in early 2020 stated that: *“life expectancy in England has stalled, years in ill health have increased and inequalities in health have widened. Among women, particularly, life expectancy declined in the more deprived areas of the country. Some areas, especially in the North, have been ignored, left behind, as health has improved elsewhere”*.

It is time for a reset in public policy to improve the population's health and tackle deeply entrenched inequalities. This includes responding to the direct impact of Covid-19 and redoubling efforts to reduce health inequalities more broadly, including addressing socio-economic drivers of health such as housing, education, employment and access to affordable healthy food. Addressing these issues will be a test of how serious the government is around its 'levelling up' agenda.

Sustained and coherent action is needed on the prevention and management of inequalities in health at all levels, including through local place-based partnerships spanning the NHS, local government, voluntary sector organisations and communities themselves.

In the pandemic, specialist MS teams have had to support frontline colleagues and alongside increased measures around infection prevention and social distancing this has reduced service capacity. COVID-19 has resulted in delayed access to - or cancelled - outpatient appointments, replacing face-to-face contact with virtual consultations as well as causing challenges around reduced service capacity. The physical and mental health of patients has been impacted; many patients were too confused or frightened to see their care providers, worried about catching COVID-19, and lacked trust in information that was being given.

Mental wellbeing has further been jeopardised through isolation with vulnerable groups, already facing inequities in care, at higher risk. People from poorer socio-economic backgrounds have been hardest hit in terms of their increased likelihood to develop more severe forms of the disease and financial hardship because of the impact of furlough or job loss. Implementation of patient initiated follow up (PIFU) means patients will need to be aware of problems that may be arising so that they can seek help promptly.



## Social determinants of health:

Prior to COVID-19 the MS Society reported from the My MS, My Needs<sup>[30]</sup> survey of 2019 that 15% of the 8,000 people who responded said that they were struggling on their household income. Of those, 58% felt their health had deteriorated, one third had either had to reduce their working hours or stop work entirely and 12% had needed hospital treatment. 65% felt lonely or isolated and this was linked to a range of physical and mental conditions including hypertension, cardiovascular problems, mental health problems and cognitive decline.

Those struggling on their current income were less likely to have access to the services and support they needed and those with an annual income of less than £25,000 (below the UK median average) were less likely to have seen a neurologist, be on treatment or get the physiotherapy they needed like those in higher income brackets. Lifestyles present a serious threat to population health, particularly for more disadvantaged groups.

	OBESITY	INACTIVITY	SMOKING	ALCOHOL MISUSE
Percentage of adult population affected	26%	61-71%	21%	6-9%
Impact on health and wellbeing	Increased risk of chronic disease. Reduces life expectancy by up to 10 years	Causes 10% burden of many chronic diseases and 17% of all causes of mortality	Increased risk of chronic disease. Reduces life expectancy average by 10 years	Increased risk of 60 medical conditions and significant social impact
Estimated cost to the English economy per year	£15.8 billion	£8.3 billion	£5.2 billion	£20 billion
Estimated cost to the NHS per year	£4.2 billion	£1-1.8 billion	£2.7 billion	£2.7 billion

**Figure 13.**  
Impact of unhealthy behaviours on the NHS and wider economy<sup>[31]</sup>  
Source: Department of Health (2009)



## Encouraging people with MS to adopt the 40-30-30 rule:

The 40-30-30 rule is the argument that when you prepare for anything in life, only 40% of the preparation is physical – the rest is mental. 30% of preparation is technical skill and experience, and the other 30% is the willingness to take risks.

The 40-30-30 rule can provide a beneficial framework for success for people with MS, which HCPs could encourage in patients as part of a toolkit to adopt a healthier lifestyle.

- **Make a change for the better**, whatever that change might be. The first 40% of the journey is the act of trying to do something different.
- **Keep at it** (the next 30%) is simply encouragement to not let a new initiative slide, because the more you work at it, the easier it becomes – Couch to 5K is a good example.
- **Take risks** (the final 30%) simply means to not do things the same way every single time. When you've managed your 5K, it's easy to become wedded to the same routine. Never stop looking at what you do next and trying out alternate paths. Not only does this improve your fitness but it helps to challenge you more.
- So how can we get people with MS to apply the 40-30-30 rule in their life? The first step is to **figure out the area of their life they want to improve**.
- Once they have figured out what they want to do, suggest they **research it**. Figure out what they will need to do accomplish that goal.
- After that, they can **start practicing and building skills**. The best way to do that is to start doing the thing they want to master every day. A target of thirty days is useful to commit to and there are online supports for this for example the Couch to 5K app or SitFit mytherapy NHS app.

### The 40/30/30 rule:

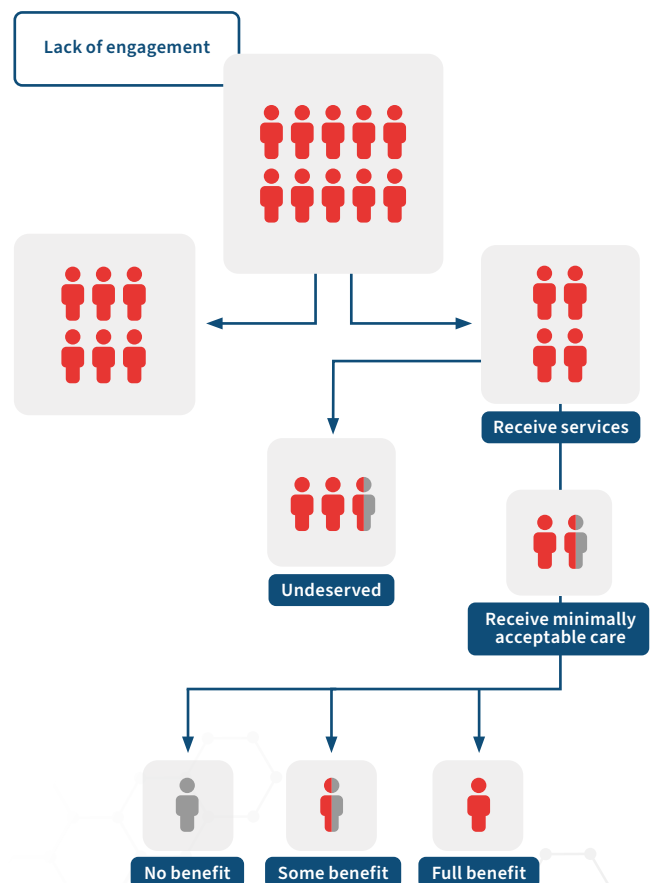
There are 130,000 people with MS in the UK

- 40% will adapt to their condition and adopt a healthy lifestyle
- 30% will need encouragement to do this
- 30% will experience health inequality and must not be excluded

“Leave no person with MS behind.”

Professor Gavin Giovannoni

Figure 14. 40-30-30 rule.



## Reset now presents an opportunity for MS services to change:

The expert group stated they had experienced considerable challenges in the pandemic and understandably people with MS had not always been able to receive the care they need. This had provided an opportunity to stop routine work for the first time and rethink how services could be delivered differently. The speed of adoption of new ways of working has been ‘mind blowing’, they said.

Where appropriate, the expert group felt HCPs should be encouraging people with MS and their families to understand the importance of self-managing symptoms and to do this in conjunction with charities and other partners working at both locality level and using web-based and other platforms. Additionally, there was discussion about the importance of people with MS (and other neurological conditions) being supported to campaign for improvements to their local neurology service, engage with their ICS (alongside neuro clinical leaders), and the importance of the role of the Voluntary Community and Social Enterprise (VSCE) in supporting that to happen.

One of the positive aspects of COVID-19 has been much better access to patient healthcare notes during the pandemic. Access to the primary care record has allowed visibility of patients’ primary care health utilisation, access to blood records, medications and comorbidities, which has saved significant time. It was felt that increasing digital connectivity through virtual meetings, electronic communication between primary and secondary care for DMT monitoring, shared access to patient records and electronic prescribing would reform current outdated ways of working. Where previously there had been reticence to adopt these models, the pandemic has demonstrated it can be done.

Conversely, there have been numerous surveys of the impact of COVID-19 and the views of service users from the MS Trust, MS Society, Shift.ms and the Neurological Alliance, which provide greater understanding of the impact of the pandemic and what we can do to better support patients in the ‘new normal’ world of uncertainty. While the scale of digital innovation has transformed care delivery, there are concerns that digital platforms may create and exacerbate health inequalities across different demographics. There is concern that some patients may be left behind in the digital shift including those who do not have internet access, low income families and those who do not speak English as their first language.

“What gets measured gets managed — even when it’s pointless to measure and manage it, and even if it harms the purpose of the organisation to do so.”

Peter Drucker

### Why have we failed to bend the curve?

- 1 **Imprecise Dx** • Lack of biological validity
- 2 **Lack of engagement** • 60% not receiving care
- 3 **Quality** • Fragmented, episodic, delayed
- 4 **Lack of measurement** • We don't manage what we don't measure

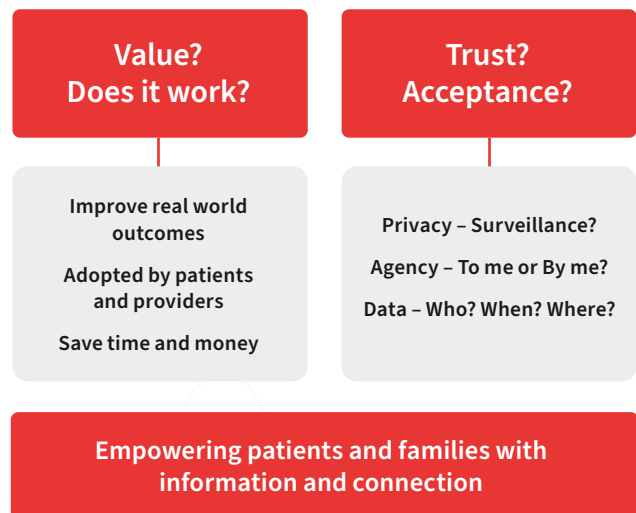



Figure 15. Why have we failed to bend the curve?



“Invest time and education in developing a rapport with MSers from diagnosis for 6–12 months, this will allow patients to build confidence in self-management.”

**Mavis Ayer** • Senior MS Nurse Prescriber

## How can we help patients?

The expert group felt the following were priority areas to better support patients:

- **Improving communications** and ensuring communication is in accessible formats
- **Consistent messaging** across all professionals is essential
- **Dispel fears**
- **Avoid technological discrimination** and ensure those without the internet can get quality information and support offline
- **Encourage access to the voluntary sector** to help improve people's understanding and to make informed decisions
- **Patient partnerships are key**
- **Screen for social determinants of health** in routine MS assessments. Identify risk factors opportunistically, and liaise with other HCPs including GPs and community teams

We can additionally help patients to adopt healthier lifestyles and there is increasing evidence that MS HCPs need to look at the wider picture of a person's health, wellness and lifestyle including nutrition, movement, sleep and stress.

“Developing local, regional and national directories of services can really help with our understanding of what services are available.”

Dr Ian Pomeroy • Consultant Neurologist

“The ultimate goal should be for healthy lifestyle practices and self-management to be built into the core care pathway for MS, from diagnosis onwards. The challenge of how we can share this information well and encourage people with MS to take control of their lifestyles is becoming an essential aspect of treatment, not solely self-management.”

Dr Agne Straukiene  
Consultant Neurologist

## People with MS: addressing health inequalities: what's needed now?

- **Redoubling our efforts as an MS community** to improve our understanding of health inequalities in MS, and to undertake targeted activities to reduce health inequalities, including those possible brought about through greater adoption of digital care
- **Tackling health inequalities** needs to be core business for MS services
- **Culturally appropriate services** need to prioritise those groups most likely to be affected
- **The wider social determinants of health should be addressed**
- **Target care attached to tariff**
- **Improve communication and ensure consistent information**
- **Make mental health information more visible**
- **Expand the base of communicators with volunteers**
- **Remote care, remote monitoring and rapid adoption of technology** should be adopted where feasible
- **Support patients and families** to take an active part in campaigning in their ICS to improve services.

“Consider the use of non-clinical staff to act as a conduit to care – sorting prescription queries, triaging calls and filtering appropriately.

Group consultation has allowed us to reconfigure the DMT clinics to improve this so that patients can see both the consultant and nurse in one appointment rather than two different ones.”

**Karen Vernon** • Nurse Consultant in MS

“Given the harsh light that COVID-19 continues to shine on health inequalities and the propensity of digital models of care to possibly ‘leave some people behind,’ a successful recovery from COVID-19 would surely put a commitment and action to tackle inequality at its heart.”

**Georgina Carr** • CEO Neurological Alliance

“IT solutions allow greater participation in care, e.g. patient portals, information sources as well as communication on hot topics such as COVID-19, vaccines and safety scares.”

**Dr Ian Pomeroy** • Consultant Neurologist



## Next steps

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COVID-19 has, and continues to be, an unprecedented challenge for the NHS and is likely to change the way health and care services for MS are planned, commissioned and delivered for the foreseeable future. As we move forward in 2021, we are in the midst of the third wave of the pandemic and while MS teams are doing their best to maintain services, they still have to manage the COVID-19 threat and keep themselves and their patients safe.

The pandemic has stimulated greater innovation and service transformation, consolidating ideas about how services must change and what now needs to happen.

Each of the separate key points identified from the research has generated recommendations for action and moving forwards, and these need to be translated into action. Partnerships to do this will be key.

## Methodology

The findings of this report are based on three strands of information:

- Expert opinion gathered from virtual workshops held in November and December 2020. A mind mapping approach for development of the key issues facing MS service reset and reform was conducted using online mind map software, Ayoa. This enabled participants to provide simultaneous input of qualitative data to the online mind map. The multidisciplinary clinical stakeholders, managers and commissioner stakeholders were steered through the process to obtain their experience and views and following the workshops were allowed access to the mind map to further input their thoughts. Four individual workshops were held which built up the qualitative data.
- One-to-one interviews were conducted with neurology commissioners using a semi-structured questionnaire to obtain their views on commissioning.
- Desk-based research of ICS and STP strategic plans was also undertaken utilising search terms of NEUROLOGY, MULTIPLE SCLEROSIS and SPECIALISED COMMISSIONING.

Following the information gathering exercise, NVivo qualitative data analysis computer software was used to organise, analyse and find insights in the data. Thematic analysis has identified the key emerging themes from the expert group, interviews and desk research.

## Glossary of abbreviations

**ABN** • Association of British Neurologists

**AI** • Artificial intelligence

**CQUIN** • Commissioning for Quality and Innovation

**DES** • Direct enhanced service

**DMT** • Disease-modifying therapy

**GIRFT** • Getting it Right First Time

**HCP** • Healthcare professional

**HSCT** • Haematopoietic stem cell transplantation

**ICP** • Integrated care pathway

**ICS** • Integrated care system

**MS** • Multiple sclerosis

**NNAG** • National Neurology Advisory Group

**PCN** • Primary care network

**PIFU** • Patient initiated follow up

**STP** • Sustainability and transformation partnership

**WTE** • Whole time equivalent



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