

# Raising the Bar for MS (RtB4MS) UK service and Disease Modifying Treatment (DMT) prescribing audit: ESTABLISHING THE BAR

## Part A: Summary Report, Recommendations, Next Steps

Spring 2021



A map showing the widespread engagement of the 70 UK MS services participating in the audit

## Contents

Authors' Comments .....	3
Contributors .....	5
Background.....	6
Objectives.....	6
Method .....	6
Results .....	7
Engagement:	7
Sample:	7
Caseload and Caseload Expansion:	7
Patient database:	7
Staffing:	7
Multi-disciplinary Team meetings:	8
Neuroradiology:	8
Clinical trials research:	8
Coping:	8
New referral waiting times:	8
DMT prescribing:	8
Qualitative Comments and Experiences:.....	9
Service development:	9
Caseload and workload:	9
Patient database:	9
Staffing	10
MDT meetings:	10
Neuroradiology:	10
Clinical trials research:	10
Coping:	10
New referral waiting times:	10
DMT prescribing:	11
Recommendations.....	12
1. Maximising influence for change	12
2. Maximising work efficiency and building MS team resilience	12
3. Maximising the insights gained from routinely collected data	13
Conclusions .....	14
Next steps.....	14
Abbreviations .....	15

## Authors' Comments

We feel privileged to publish this report, on behalf of the UK multiple sclerosis (MS) community, examining clinical services and disease modifying treatment (DMT) prescribing. We have synthesised data from 70 UK MS services, managing a combined caseload of 110,500 People Living with MS (PLwMS), spending over £275 million prescribing MS DMTs to 23,000 PLwMS in 2018-19. The report has two parts. Part A summarises the key audit findings and recommendations for future work so it can be read and digested in one short sitting. Part B provides granular detail.

This audit stemmed from an initiative, *Raising the Bar for MS (RtB4MS)*, established in 2018 by four MS specialist consultant neurologists<sup>1</sup> following discussions of MS DMT prescribing variance at the 2017 Association of British Neurologists (ABN) meeting. The initiative was born out of the broader recognition of looming significant challenges of increasing workloads and decreasing capacity, a need for MS teams to be facilitated to react and adapt, and the necessity for more effective partnership working across all stakeholders: healthcare professionals (of all disciplines), patient groups and charities, NHS commissioners and the pharmaceutical industry. The goal of RtB4MS is explicit from its name.

Our journey so far in undertaking the audit, reviewing previous work examining MS services, collecting and collating data and compiling this report, highlighted the considerable efforts MS teams have made over many years to try and improve local MS services. In the vast majority of cases these efforts have had limited success, in terms of developing sustainable or transferable services and where they have been successful there is no mechanism to share the secrets of success widely.

The audit was, and is, a diverse multi-disciplinary collaboration of contributors (listed below), representing MS services from across the UK. This unique inclusive approach has led to recommendations relevant to the wider multi-disciplinary team, including professions allied to nursing and medicine. This collaboration of the UK MS community demonstrates a significant appetite for understanding practice, sharing experiences and effecting change, for better patient outcomes and service sustainability. We think the ongoing collaboration is essential for success.

The aim of this report, and in particular its recommendations, is to facilitate sustained changes across the UK which will improve the services and outcomes for all PLwMS. This report is released as MS teams begin to emerge from the second wave of the COVID-19 pandemic, with sequelae for both PLwMS and health care professionals (HCPs). This heavy toll on MS teams highlights further the urgent need for a collaborative, coordinated and strategic approach among UK stakeholders<sup>2</sup>, to ensure MS services advance appropriately. Time matters, not only for PLwMS but also for MS teams; both require urgent improvements in MS services.

This audit was undertaken without external funding. This minimised bias. The trade-offs are that the work was done on top of our daily roles, has taken longer to produce and involved virtual meetings every weekend for the last six months. This statement is neither to seek pity nor respect, but to emphasize the importance and necessity of appropriate resourcing, in terms of time and personnel, for our recommendations to stand a chance of being successfully implemented and facilitated. The RtB4MS initiative requires the input, backing and alignment of clinical teams, managers, commissioners, patient groups and charities, professional bodies and

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<sup>1</sup> Gavin Giovannoni, Jeremy Hobart, David Rog, Gordon Mazibrada

<sup>2</sup> Stakeholders include MS clinicians, professional bodies, NHS bodies representing all four home nations (including NHS digital), local and national commissioners (including ICS), PLwMS, MS charities and an MS Pharmaceutical alliance

the pharmaceutical industry. Without strategy and alignment, MS services will continue to develop in a limited, siloed, uncoordinated and ultimately unsustainable manner.

We think it is worth noting the interaction of a few key results that are presented later in this report, and indicate that without change the MS community will quickly become overwhelmed and care standards will plummet further:

- No MS service we audited reported coping well with their *current* workload.
- The average MS service of 1600 patients “requires”, theoretically, a staffing level of 2.5 FTE MS consultants, 5 FTE MS nurses and 2 FTE coordinators along with the associated support from neuropharmacists and allied healthcare professionals (AHPs).
- MS teams expressed concerns that DMTs are now prescribable for all MS sub-types, with the resulting increase in workload.
- MS team caseloads are increasing by  $\approx 10\%$  per annum, equating across the UK to 7 (SEVEN) new (averagely-sized) MS services next year alone.

The cost, importance, increasing frequency and significant variance of DMT prescribing across UK MS services highlights the necessity for a nationally coordinated method of combining prescribing and patient outcomes. Many of these data elements already exist in isolation, but require strategic alignment and refinement to provide real world evidence suitable to underpin clinical decisions.

We recognise the limitations of this audit but hope it provides a platform and strategic framework for a wide alliance of multiple stakeholders to collaborate and support MS teams to realise the fantastic opportunities now available for PLwMS to alter the nature course of their disease<sup>3</sup>.

In isolation, none of our three recommendations: maximising influence, efficiency and data, are surprising. But their combined implementation will required strategic planning. Finally we have not undertaken this work as a task and finish exercise. The real work for improvement now begins for us all. We hope you will join us in this venture.

Jeremy Hobart, Joela Mathews, David Rog on behalf of the MS UK Audit Group

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<sup>3</sup> We recognise disease refers to pathophysiological abnormalities and illness due to the impacts on patients (Eisenberg 1977)

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## Background

Multiple Sclerosis (MS) is a chronic progressive incurable neurological disabling disease, estimated to cost the UK £1.4 billion per annum<sup>5</sup>. It is the largest cause of non-trauma disability in young adults.

The care of people living with MS (PLWMS) is a fast-developing field with high and escalating drug costs. Advances in our understanding of MS pathophysiology, and the availability of multiple treatments, highlight the significant opportunities for PLWMS and their care to be urgent, diligent and proactive as well as swiftly reactive and evidence based. If services can deliver care thus, the natural history of MS in the UK can be altered radically.

But there is a trade-off; the impact on MS teams and services. A consensus within the MS community, is that a perfect storm has formed. We are at a tipping point that something significant must be done to protect MS teams from collapsing. If this were to happen, it is hard to see how we would attract, recruit and retain staff, develop our field, let alone maintain current levels of care.

To understand the challenges and opportunities to effect change, more detailed information about MS services is required. A start point is an audit of MS teams and their disease-modifying therapy (DMTs) prescribing to establish the current state across the UK. Although there have been previous national MS audits these have been task and finish exercises concerned with adherence to guidance and lacked impact to effect change; the antithesis to our goal.

## Objectives

- 1) To understand better, via a comprehensive audit, the nature, similarities, differences and variation in UK MS services and their MS DMT prescribing.
- 2) To use the findings and insights to propose achievable recommendations for guiding service developments and models of delivery, effect meaningful change and improve sustainability of MS services for better patient outcomes.

## Method

All MS services represented at 2019's *Raising The Bar For MS* (RtB4MS) meeting, and others known to us via professional networks, were invited to participate by completing an MS service questionnaire and submitting their MS DMT prescribing data. We soon recognised that a service questionnaire was not able to capture the diversities, complexities and nuances of UK MS services, so we replaced this with semi-structured qualitative interviews of MS team members. Our MS service questions concerned: caseloads, databases, staffing (structure, roles, responsibilities), multidisciplinary team (MDT) meetings, neuroradiology support, research participation, new patient waiting times and ability to cope with workload. We also asked participants to estimate sustainable caseloads for MS neurologists and coordinators, standardised to full time equivalents<sup>6</sup> (FTE).

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<sup>5</sup> Kobelt G, Thompson A, Berg J et al. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler J* 2017; 23(8): 1123–1136.

<sup>6</sup> By FTE neurologist we mean an NHS neurologist with a standard job plan where all clinical activities are related to MS and related diseases (MSARD). We recognise FTE MS neurologists are very rare, and most MS neurologists have a part-time MSARD commitment. However, the concept enables comparisons to be standardised and aids service planning as 1FTE = 2x 0.5FTE = 5x 0.2 FTE etc.

DMT prescribing information for 12 months to 31<sup>st</sup> March 2019 was either downloaded from the Blueteq website or derived from local data sources by each service. Service-level data were anonymised for service and prescriber. This audit was undertaken to reflect clinical practice prior to the COVID-19 pandemic.

## Results

### Engagement:

Representatives from 71 UK MS services were approached, 70 participated. Fifty-six services have provided their MS DMT prescribing data to date.

### Sample:

These 70 MS services, shown on the front page, represent all four home nations and all nine UK regions. Together these services care for an estimated 110,000<sup>7</sup> PLwMS; ≈85% of the total UK MS population<sup>8</sup>. The 56 MS services<sup>9</sup> providing 2018–2019 MS DMT prescribing data spent £278 million across 23,000 UK PLwMS (≈25% of their combined total estimated sample).

### Caseload and Caseload Expansion:

The average MS team total caseload was estimated at 1600 people. The range was huge (100-5500). Caseload expansion is typically projected at 10% per annum<sup>10 11</sup>. Across the UK this level of expansion equates with 7 new average-sized MS services in the next 12 months; the average MS service's total caseload could be 2,575 in 5 years and 4,150 in 10 years, a 260% increase.

### Patient database:

Almost everyone (98%) had an "MS database". Most MS databases (≈70%) were Excel spreadsheets, many limited to lists of PLwMS on DMTs rather than total caseload. Very few MS services (<10%) used an MS database that was also a Clinical Decision Support System (CDSS) facilitating day-to-day care<sup>12</sup>.

### Staffing:

MS services' varied in their: caseload per team member; team discipline compositions and ratios; team member roles and responsibilities. All services audited had access to MS specialist consultant neurologists, albeit not always on site, and MS specialist nurses. Only 45% of MS services had MS coordinators and 40% neuropharmacy support.

The average number of PLwMS per neurologist and nurse, standardised to FTE job plans, was 1400 and 530 respectively. Few services (<10%) met the MS Trust recommendation of 315 PLwMS/FTE MS nurse.

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<sup>7</sup> All numerical results in the Part A Summary are rounded to the appropriate number, for ease of interpretation.

<sup>8</sup> UK total MS population estimated at 131,720 (MS Trust 2020)

<sup>9</sup> Services continue to provide prescribing data to the authorship team

<sup>10</sup> Independent analysis of two distinct services which collect accurate prospective caseload figures support this estimate

<sup>11</sup> The prevalence of MS in 2001 was 118/100,000 (Fox 2004) with a current prevalence estimate of 185/100,000 (Robertson, 2021 personal communication).

<sup>12</sup> CDSS is different to electronic patient records (EPR), as often in EPRs crucial longitudinal data items are not presented in an impactful visual form.

MS Specialists' subjective opinion was that the average sustainable number of PLwMS per FTE MS neurologist was  $\approx$ 650, with the caveat of appropriate support. For coordinators, the subjective opinion was  $\approx$ 800 PLwMS. Therefore, theoretically, for the professions considered, the average MS service caring for 1600 PLwMS "ought" to have: 2.5 FTE MS consultants, 5 FTE MS nurses, 2 FTE coordinators.

Comparing observed and expected staffing levels implied theoretic current UK shortfalls of 125 MS neurologists, 210 MS nurses and 130 MS coordinators (all FTEs). And, considering caseload expansion estimates, 18 new MS neurologists, 35 new MS nurse and 14 new MS coordinators, all FTE, in the next 12 months. Whilst we recognise these estimates are imperfect, they would have to be wildly inaccurate to imply no notable shortfall.

### **Multi-disciplinary Team meetings:**

Two thirds of services reported holding regular MS MDTs, of which two thirds were weekly. One third of all MS services had an MDT with a neuro-radiologist present. Specialist training registrars (SpRs) and research registrars attended approximately two thirds of meetings, utilising the educational and training benefit of MDTs.

### **Neuroradiology:**

Most MS services (85%) felt that their MRI scans were not reported in a timely manner, and nearly half (45%) felt restricted access to MRI scans and/or reporting impacted on patient care quality. Many NHS trusts audited (64%) outsourced MS scan reporting, with 70% of respondents expressing concerns about the variable quality of MRI scan reporting, both internally and outsourced. Many neurologists self-reported their MRI scans to counteract the delays and quality control concerns.

### **Clinical trials research:**

The majority (66%) of MS services were research active. However, most of these reported that limited capacity restricted their levels of research participation. Most (79%) of research inactive MS services expressed a desire to be research active if they had capacity. A number of people recognise this is a missed opportunity for service development and in attracting staff.

### **Coping:**

No adult MS service reported coping well with their workload. The vast majority (85%) described their MS service as very challenged or struggling to cope, with 10% of services explicitly stating that they had to compromise on patient care quality.

### **New referral waiting times:**

Half of MS services reported waiting times for new non-urgent MS referrals of 8-16 weeks, 20% exceeded 16 weeks wait.

### **DMT prescribing:**

Interviewees' estimates suggested the average proportion of total MS service caseloads on DMT was 40% (range 7%-80%). Prescribing data suggested an average of 25%<sup>13</sup> (range 2%-83%). Within-service ratios of higher-to-lower efficacy MS DMTs varied  $>6$ -fold (9%-56%). Per-patient DMT costs varied 3.5-fold (£7k-£25k; mean £13k), extrapolating to a spend variance of £11.2 million-£40 million/1,600 PLwMS (average sized service)

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<sup>13</sup> The total estimated caseload for the 56 services was 97,617 – of these 22,997 were on MS DMTs. We say "suggested" rather than demonstrated because, total caseload values were estimates.



across the UK. NHSEI<sup>14</sup> (note this is only for English services not all home nations), reported their annual increase in MS DMT spend for 2019/2020 was 7% (> £285 million). For an average centre of 1600 patients with the mean percentage<sup>15</sup> of patients on each DMT, the safety monitoring burden requires there will be 108 blood tests monthly to review due to DMT safety monitoring.

## **Qualitative Comments and Experiences:**

Semi-structured qualitative interviews enable people to highlight issues and recount personal experiences. These are some of the more common comments:

### **Service development:**

- Everyone interviewed had tried to improve their MS service over a number of years. In part due to limited success, some had stopped trying to service develop due to a feeling of futility. Most felt unsupported by their trusts, in terms of taking appropriate actions, in this context. Developments were piecemeal. None reported having dedicated time for service development;
- Most were unaware of successful service development examples, where and how these had been achieved. There was a lack of knowledge about how others manage workloads, dealing with the same routine challenges, and of access to potentially relevant documents produced by others;
- Everyone interviewed agreed that a national-level cohesive approach to service development would be welcomed and considered appropriate given the difficulties and complexities of influencing service development locally.

### **Caseload and workload:**

- Most people only had a rough idea of their total caseload. Numbers on DMTs were better known but not easily available or routinely fed-back to MS teams. There were concerns about the accuracy of lists particularly for their updating and especially for people switching DMTs;
- There was widespread comment that MS care involved substantial non-patient facing clinical work. This “behind the scenes work” (eg case reviews, preparation for MDT, MRI ordering and reviewing of routine MRIs, safety monitoring), was typically unrecognised by trusts and some neurology colleagues even though it can be classed as direct clinical care (DCC). It was not uncommonly a source of tension;
- Many recognised their care of people with progressive disease was limited, often poor, due to the focus on people with Relapsing MS (RMS).

### **Patient database:**

- All interviewees recognised the value of good quality data and MS databases;
- Most acknowledged that their own data had limited value, due to its quality or accessibility, in being able to facilitate day-to-day care or to invoke change. This was due in part due to poor clinical data collection mechanisms, both per patient and for total service caseloads, and limited resourcing from local trusts;
- Many had tried and failed to introduce MS databases. Some on multiple occasions;
- Most iMed users did not appear to maximise its use to assist day-to-day clinical care.

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<sup>14</sup> Note that the total spend in our audit includes spend from all the home nation NHSs, explaining the differences in totals. We did not seek the annual increase in spend for the home nations outside England.

<sup>15</sup> The average percentage of patients on DMTs from our audit is 23.48%

**Staffing:**

- Everyone interviewed recognised the value of coordinators and neuro-pharmacy support. Many people had tried to get local funding for these, but with limited success;
- MS nurses, coordinators and pharmacists had variable roles within different services. Most services reported MS team members “acting-down”: performing tasks that could be done by less skilled team members or non-MS team members;
- MS teams were stretched, morale was low, recruitment was difficult;
- The impending retirement of many experienced senior MS professionals will further compound the staffing issues locally, due to difficulty in recruitment of appropriate individuals at all levels.

**MDT meetings:**

- MDT meetings were infrequently formally job-planned;
- All recognised the value of having neuro-radiologists in MDTs; many had found this hard to achieve for a variety of reasons.

**Neuroradiology:**

- A number of services had been unable to engage neuro-radiologists in participating in MS MDTs;
- Many commented that MRI scan reports were often incomplete in terms of answering the clinical questions posed;
- Many externally (and internally) reported scans require re-reporting by a “trusted” neuro-radiologist;
- External reporting neuroradiologists were unknown to local clinicians so report quality was difficult to judge.

**Clinical trials research:**

- The value of participating in research was recognised – for patients and revenue for service development;
- There were frustrations about trust R&D support for research, and concerns about the sub-optimal use of finances and mechanisms to reinvest back into the MS service.

**Coping:**

- MS clinicians of all professions expressed real concerns about care quality, patient safety, staff mental health (associated with burnout) and service sustainability;
- Recent changes in DMT eligibility – especially the approval of drugs for Secondary Progressive MS (SPMS) - were welcomed as a great advance and opportunity for PLwMS. However, the impact of these advances on MS teams and their workload concerned many.

**New referral waiting times:**

- There were no major concerns about the time to see urgent referrals, although it was recognised these people were often added to already full clinics;
- There were considerable concerns about the time taken to see GP referrals.

**DMT prescribing:**

- The licensing of DMTs for people with SPMS was a concern in terms of MS service capacity, and the increasing associated workload;
- There were concerns about the provision and reliability of safety monitoring mechanisms, which creates risks for PLwMS.

## Recommendations

In order to improve services for PLwMS, we think 3 priority areas have emerged directly from the audit findings and our broader round-table discussions with significant stakeholders<sup>16</sup>. Each area, whilst interconnected, represents a programme of work that can improve the current trajectory. We have listed these below and proposed priority actions for each area, and the anticipated benefits to MS care.

### 1. Maximising influence for change

This programme of work will move beyond the historical approach of service development at a local level which has further exacerbated variance, difference in service provision and led to sub-optimal care. Despite best endeavours, despite strong clinical need, and solid “business” justifications, service development has been piecemeal and generally unsuccessful. We propose a strategic, coordinated, inclusive, collective and collaborative approach to service development, with a patient outcomes framework at its core. We believe this approach is fundamental to ensure equitable and sustainable UK wide MS services.

#### Priority action:

To fund and appoint a UK-wide strategic transformation team to work on behalf of the MS community and key stakeholders. The team will have the skills and experience to develop and initiate an agreed strategy for delivering sustainable funding models<sup>17</sup> for national service development. The strategic team will collaborate with commissioners including ICS leads to propose and instigate pilot work using MS as an exemplar for chronic disease health care transformation, based upon the development of a patient outcomes framework. We anticipate this team might need to be funded, at least in part by an MS pharma alliance in the first instance with a view to longer term self-sustained funding. This team will need to be led by a senior individual with a track record in influencing change, aligning different sectors and funding acquisition, supported by a core clinical multidisciplinary team representing the MS community.

#### Examples of anticipated benefits:

- Builds upon established engagement with key stakeholders and their interest in creating fit for purpose services;
- Has potential to provide clear nationally endorsed roadmaps for mandate-able optimal service delivery;
- Creates a momentum for change, not reliant on local teams allowing them to concentrate on care delivery.

### 2. Maximising work efficiency and building MS team resilience

This programme of work recognises that most MS teams report significant difficulty coping with current workloads. This will be compounded by expanding DMT eligibility, expanding caseloads and lowering thresholds for referrals. Theoretic staffing shortfalls are not resolvable realistically and the national level change highlighted above will take time to deliver. As a result, MS teams require support strategies to help manage their current and increasing workloads, maximise their efficiency and use of existing personnel, work differently to deliver care, build resilience and sustainability by attracting, educating, supporting and retaining the next generation of

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<sup>16</sup> These include charitable organisations, professional groups, pharmaceutical industry, Neuroscience Clinical Reference Group (CRG) representatives, commissioners, NHSE.

<sup>17</sup> Maximise funding opportunities from charitable organisations, project grants, fellowships and sponsorship.

MS professionals, and ultimately make MS an attractive work speciality and career opportunity. Aligned to this, and central to these developments, is clarification of exactly what PLwMS expect from their MS service and what their service expects of them in terms of engagement and self-management. This recognises that issues of engagement and self-management vary across individuals and services need to be flexible: an individualised therapeutic partnership.

Priority action:

To support MS teams to maximise their efficiency and coping, by collating and making available, via a web-based repository, exemplars of best practice in service design and delivery to include newly developed strategies and business cases. To develop and implement a Patient Experience Outcomes Framework and facilitate, promote and publicise patient self-management initiatives, enabling MS teams to benchmark their services specifically to leverage service development. These activities can not only enhance service quality and efficiency in the short term by focussing resources on those PLwMS less able to manage themselves but also develop clinician and administrative role frameworks for all within the MS team. This will enable people to work at the top of their license, delegate responsibilities and actions to the most appropriate, effective and efficient team member. These changes can then be supported with defined personal development pathways.

Examples of anticipated benefits:

- Creates a central repository of existing and new resources, and support that is currently not available. This could have a massive difference in delivering short to mid-term change in services currently under critical pressure.
- Creates efficiencies in service developmental business cases, by learning from other colleague's success, failures and experiences.
- Shares routine and best practice in a much more effective way that allows services to select areas for change which could impact on their service
- All the above will lead to demonstrable improvements in efficiency, quality and safety of care.

### **3. Maximising the insights gained from routinely collected data**

This programme of work recognises that large variation exists in the breadth, depth and quality of patient, service impact, outcome and prescribing data readily available to MS teams. Routinely collected data are under-utilised. If methods and processes of day-to-day data collection are stream-lined, aligned and refined, for example presenting data outputs in a visually impactful form, they would aid MS team's clinical decision making and improve service efficiency. These data, if harnessed regionally and nationally, could provide powerful support and guidance for specific change.

Priority action:

Support MS teams and individual team members to improve their data maturity and data culture locally (service and regional levels), by providing training in digital literacy and appropriate IT infrastructure (equipment and clinical systems including access to CDSS). This can be done through sharing models of good practice nationally and through the routine use of and appropriate interpretation, of hospital episodic statistics (HES) and prescribing dashboards.

Examples of anticipated benefits:

- Facilitating individual patient day-to-day care and decision making
- Facilitating improved safety and remote monitoring of patients

- By utilising HES data, identifying problem areas that could be improved.
- Facilitating continuity in, and quality of, care

## **Conclusions**

This audit and report has sought to identify, quantify, qualify and clarify challenges facing MS care, and simplify the recommendations and methods required which can help rectify the situation. The current baseline is that MS teams manage large caseloads, typically with suboptimal data support mechanisms. MS team compositions, roles and responsibilities vary. MS coordinators and pharmacists, despite their reported value, are rare. There is widespread skillset misuse. MS teams are stretched and coping poorly, and the services they provide are precarious, with notable concerns about patient safety, care quality and inequality, neuroradiology access and MRI reporting, and staff retention. Theoretic staffing shortfalls are huge with no short-term fix available. Historically, local MS teams have had poor influence on service development. Eagerness seems inversely related to experience.

We think there are 3 main priority areas, each with a priority action:

- Maximise influence
- Maximise efficiency
- Maximise data usage.

Central to these is a collaborative and strategy national-level approach to change. If the MS community collectively decides this is a way forward we need to maintain momentum by aligning and working together to implement the main recommendations. We believe this is a genuine opportunity to effect meaningful and long-lasting change. Now the work begins.

## **Next steps**

Consolidate and formalise support for these recommendations from the MS community and then wider stakeholders.

If consensus is achieved, to maintain meaningful momentum by obtaining funding for an interim strategic team.

## Abbreviations

ABN	Association of British Neurologists
AHPs	Allied Healthcare Professionals
CDSS	Clinical Decision Support System
CRG	Clinical Reference Group
DCC	Direct Clinical Care
DMT	Disease Modifying Treatment
EPR	Electronic Patient Record
FTE	Full-time Equivalent
HCPs	Health Care Professionals
HES	Hospital Episodic Statistics
ICS	Integrated Care Systems
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
NHS	National Health Service
NHSEI	NHS England and NHS Improvement
PA	Programmed Activity
PLwMS	People Living with MS
R&D	Research and Development
RMS	Relapsing MS
RtB4MS	Raising the Bar For Multiple Sclerosis
SPMS	Secondary Progressive MS
SpRs	Specialist training Registrars