



# What should the future commissioning environment of **Multiple Sclerosis care** look like?

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*Next steps to delivering patient-centred and  
equitable access to services across England*



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# Forewords

## Foreword from Roy Lilley

I very much welcome this report.

Every person with MS deserves access to effective and efficient MS services which can provide the holistic care and support they require.

Yet due to the combination of a convoluted and opaque MS commissioning infrastructure alongside a growing number of over burdened services across the country, there are several challenges in providing access to this equitable, high quality care.

This report takes a welcome holistic view to address this situation head on. By concentrating on four key areas it provides a blueprint to evolve the commissioning and delivery of MS services to place MS patients at the heart of service delivery, which creates a refreshing patient-centred approach.

This paper is clever, innovative and, in my view, long over due. The important next step is to recognise its truths, implement its common sense, and use its wisdom to make a difference.

***Institute of Healthcare Management***

## Foreword from the MS Trust

The landscape of MS care in the UK has changed dramatically in recent years, largely prompted by the evolution of new treatment paradigms for relapsing remitting MS (RRMS), and the greater emphasis on earlier treatment and more rapid escalation of therapy where possible.

Whilst welcome, this greater focus on treatment coupled with the increasing range of disease modifying drugs (DMDs) available, and the time-consuming monitoring that go with them, has resulted in a situation which is stretching the capacity of already under-resourced MS specialist services – the burden falling particularly on MS specialist nurses.

At the MS Trust, we often hear from people with MS who are not eligible for a DMD, such as those with progressive MS. They often feel increasingly distant from their MS team due to these capacity pressures.

This situation presents an ongoing challenge for MS services: *how do they utilise their resources to support the drive for earlier and higher levels of DMD treatment, while still ensuring that everyone with a diagnosis of MS can receive appropriate, timely, high quality care?*

In an effort to address this challenge head-on, we launched MS Forward View (MSFV) in Autumn 2015 – an ambitious programme which set about addressing where there is greatest scope to use service capacity more effectively and use existing resources in new and different ways.

MSFV brought together the MS community to agree the priority actions needed to make MS care fair across the UK. The resulting nine consensus statements present a shared view of what is required to ensure every person with MS has equal access to effective and efficient MS services in order to receive the support and care they need.

Two years later, the MS community has made good progress in delivering against the statements set out within MSFV. For instance, work is well underway to increase resources via our Advanced MS Champions Programme and MS Specialist Nurse Funding Programme and the MSFV stakeholders are committed to continuing to work together to achieve change.

Yet there is still much to do. MSFV called for services for people with MS to be centred around their needs. It is time that there was an evolution in approach to the delivery of MS services. We need a person focussed approach to commissioning and provision of services, to ensure that the holistic needs of a growing number of people with MS are met.

This report highlights that action must still be taken to achieve this. We must come together as an MS community and focus on addressing this for the benefit of every person with MS.

**Jo Sopala**  
***Director of Health Professional Programmes at the MS Trust***

# 1. Report Context

**The MS commissioning landscape is in a period of flux.** The ongoing direction of policy from NHS England focuses on evolving commissioning frameworks to support the development of a more integrated and patient centred system of care.

This evolution includes the delegation of certain specialised commissioning responsibilities from NHS England to local organisations, with an increasingly population or ‘place-based’ approach to commissioning and greater joint working at a local level.

Adult specialised neurosciences services, which encompass certain services for patients with MS and disease modifying drugs (DMDs) have been identified by NHS England for the potential transfer of commissioning responsibilities to Sustainability and Transformation Partnership (STP) level commissioning in the near future.<sup>1</sup> This has caused a large degree of uncertainty amongst the MS community, concern about how this model will work for such a complex condition like MS, and what impact these changes could have on patients.

Yet, despite these potential landmark shifts, there is currently no consensus on how the delivery of services and DMDs should evolve to achieve greater benefit for both patients and MS services across England.

To address this, over the last 12 months Merck has hosted a series of events including two regional roundtable meetings in May and June 2018 to discuss the optimal future commissioning environment for MS services and DMD treatments. The roundtables brought together expert groups in the commissioning and delivery of services for patients with MS to ensure that discussions were across the entire MS care pathway, from primary care to the specialist acute MS service. Stakeholders that attended included patient groups, the acute MS service (neurologists, MS Nurses, neurosciences pharmacists and neurology service managers), primary care (GP), and local commissioners (STP planned care lead, CCG pharmacists, senior commissioning managers).

This report summarises the outputs and consensus arising from those roundtables and defines the next steps to implementing meaningful change. The intention is that the findings and recommendations will support the ongoing dialogue required to make change happen and to help evolve the MS commissioning environment to work better for both patients and MS services.

We invite feedback and welcome ongoing discussion with stakeholders across the MS community on the calls for action, recommendations and ideas laid out in this report.

*“As a neurosciences pharmacist, the commissioning of MS occupies a lot of my time. This report highlights the problems faced within MS services, but also provides some very easy wins to overcome them. I do believe if we work together as an MS community of clinicians and commissioners, we can solve the problems and share some good practice with other clinical specialities which face similar problems.”*

– Joela Mathews, Neurosciences Pharmacist, Royal London Hospital, Barts Health NHS Trust

*“This report is the beginning of a journey towards adequate and equitable care for patients. Now is the time when we should plan to have a national approach to managing patients with multiple sclerosis, with national leadership.”*

– Dr Abhijit Chaudhuri, Consultant Neurologist, Barking, Havering and Redbridge University Hospitals NHS Trust

*“This document provides a comprehensive report on the challenges and changes required for MS patients who require DMDs across England. However, more importantly, it also addresses the needs of those who are not on a DMD including secondary progressive MS and primary progressive MS, whose needs are just as important.”*

– Samantha Colhoun, Clinical Nurse Specialist in Multiple Sclerosis, University Hospitals Birmingham NHS Foundation Trust

# Summary of recommendations

This report calls for an evolution in approach to the delivery of MS services, which places MS patients at the heart of service delivery, so that the holistic needs of the growing number of people with MS can be better met. To achieve this, four core priority areas are identified for action:

## Call to Action 1: The commissioning environment of MS services should evolve to drive equitable access to patient-centred care

- Patient choice and experience should be integral to any future commissioning decisions. Funding flows need to enable equitable access to all the holistic services that MS patients require
- To maximise the value of scarce clinical expertise, NHSE should encourage best practice shared care arrangements between hub and spoke models that allow for greater local flexibility in the set-up of specialist spokes. A review of the geographic spread of hub services also needs to be considered
- The DMD drug budget should remain with NHS England to assure equity of access, however clarity on “who pays for what” for the administration and longer-term monitoring requirements is essential to support safe and effective prescribing
- To support the drive for further equity in access and reduce the capacity pressures on MS services, the commissioning of DMDs, and the service that wraps around them, need to be considered together

## Call to Action 2: A medicines optimisation framework for DMDs should be developed, and agreed by key stakeholders, to safeguard MS patients, improve clinical outcomes, and reduce impact on patient quality of life

- The framework should consider DMD administration and monitoring demands on the patient and the service to define an efficient treatment model as a basis for local decision-making
- To safeguard MS patients, the service should be able to provide, and patients be able to conveniently access, the required DMD administration, monitoring and follow up
- Accountability standards and responsibilities for DMD prescribing and monitoring should be outlined. This would also support implementation of new local spoke services
- Patients should be engaged and empowered to choose an effective treatment (drug, administration and monitoring) to suit their personal circumstances and lifestyle (e.g. work and ability to travel) to support informed shared-decision making

## Call to Action 3: A workforce skill-mix plan for MS services should be developed to enhance service efficiency

- The optimal workforce skill mix for MS services needs to be defined and the shortage of neurologists and MS specialist nurses needs to be addressed
- To help alleviate capacity pressures, training of alternative members of the multidisciplinary team – such as pharmacists and healthcare assistants – to play a more active role in the DMD pathway should be explored
- Building on this, training and support should be given to the broader MDT, including occupational therapists and physiotherapists, in order to support the holistic needs of all people with MS
- A national workforce plan for hospitals and community-based MS nurses is needed, to aid succession planning and meet the needs of an increasing number of people with MS

## Call to Action 4: Local data transfer challenges should be addressed so that data can travel, rather than the patient

- Local data transfer challenges should be addressed so that patients can have routine monitoring closer to home, and spend less time on frequent journeys to NHS sites
- Results from DMD monitoring should be accessible electronically to all healthcare professionals involved in the care of the patient
- A review of best practice and digital innovation around monitoring provision should be conducted. This would enable identification of digital solutions to support safe and efficient DMD monitoring.
- The role of Blueteq should be evolved to capture common data elements and deliver a more clinically meaningful national database for monitoring and improving clinical outcomes

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## 2. Background

### WHAT IS MS?

Multiple sclerosis (MS) is a chronic, neurodegenerative condition that affects the nerves in the brain and spinal cord, for which there is currently no cure.

The condition is thought to affect around 89,000 people in England, the equivalent of roughly one in every 600 people, and roughly 4,100 people are newly diagnosed every year across the country.<sup>2</sup> MS is also the most common cause of serious physical disability in people of working age,<sup>3</sup> with many typically experiencing their first symptoms in their late 20s.

Around 85% of patients are diagnosed with relapsing–remitting MS (RRMS) which is defined by periods of stability (remission) followed by episodes when there are exacerbations of new or old symptoms (relapses).<sup>3</sup>

People with MS often experience a complex range of symptoms and disabilities, including visual and sensory disturbances, limb weakness, gait problems, and bladder and bowel symptoms.<sup>3</sup> However, MS has an unpredictable disease course, and everyone's MS is different, so no two people will have the same range and severity of symptoms. This makes it particularly challenging to manage.

Due to the variety of symptoms, people with MS can experience a significant impact on their ability to work, as well as an adverse and often highly debilitating effect on their quality of life and that of their families.<sup>3</sup>

### WHAT IS A DISEASE MODIFYING DRUG?

Although there is currently no cure for MS, there have been a number of advances in the care and services available to people with MS. One significant advance has been the introduction of

a class of medicines over the last 20 years, known as Disease Modifying Drugs (DMDs), which have changed the treatment landscape for people with RRMS.<sup>4</sup>

These medicines can reduce the number and severity of relapses, delay the progression of disability and slow the speed at which it happens.<sup>5</sup> Currently, there are over 13 DMDs<sup>6</sup> licensed and approved for use by the NHS for RRMS – compared to just 4 in 2002.<sup>7</sup> Each DMD has different efficacies, side effects, methods of administration and monitoring requirements.

### THE CURRENT MS SERVICE CHALLENGE

Whilst the introduction of these medicines has brought benefits for thousands of MS patients across the country, there is considerable evidence to show that MS services have evolved in a reactive way and MS teams are becoming increasingly overwhelmed by the workload associated with the provision of these DMDs.<sup>4</sup> This increasing pressure is due to a number of interlinked factors:

- The introduction of a growing number of DMDs, each with their own specific monitoring and administration requirements, has led MS teams to adapt and expand their DMD service each time a new DMD is approved for use. However, the prescribing and monitoring of this increasing number of medicines has evolved in a reactive way, with limited strategic oversight and planning. This has resulted in the operational evolution of different models of DMD service delivery around the country.
- The growth in the number of MS patients that are eligible for DMDs in recent years has not been met with a matching growth in the workforce and resources required to support these patients. There is a well-documented shortage of neurologists and MS nurses across England,<sup>4</sup> and the majority of MS specialist nurses in England are

working above the MS Trust's recommended "sustainable" caseload of 358 people per full-time MS nurse.<sup>8</sup>

- As the treatment landscape has evolved, with successive availability of new DMDs each with distinct monitoring requirements, so too has the role of the MS specialist nurse. It is widely recognised that due to capacity challenges, the focus of MS specialist nurses has narrowed.<sup>8</sup> As a result, nurses have struggled to provide the holistic supportive care required to meet the broader non-DMD related needs of people with MS, including for those patients who have a more progressive form of MS and are either not eligible, or are no longer eligible, for a DMD. Such support includes self-care, wheelchair use, falls prevention and managing urinary tract infections. This is particularly important for those who don't benefit from DMDs.
- On top of this, relevant professional bodies, such as the Association of British Neurologists in their 2015 DMD prescribing guidelines, recommend that DMDs should be started as soon as possible in eligible patients with the goal of increasing time to disability progression and improving long-term outcomes for people with MS.<sup>9</sup>

This myriad of factors is an obstacle to the delivery of the service outcomes outlined in the Adult Specialised Neurology service specification<sup>10</sup> such as improving the quality of patient experience; ensuring patients are monitored regularly to allow for early identification of changes in their disease progression. Indeed, some patients are carrying the burden personally

in terms of, often frequent and lengthy, journeys to the neuroscience centre for treatment administration and monitoring.

As the number of people with MS on DMDs is expected to grow and the number of DMDs available increases, there is consensus for action to be taken at both a national and local level to address the pressures on the MS service.

To address these challenges the MS Trust published the MS Forward View in Autumn 2016, an ambitious programme which set about agreeing where there is greatest scope to use service capacity more effectively and use existing resources in new and diverse ways.<sup>4</sup>

In particular, the MS Forward View developed nine consensus statements, which presented a shared view about the priority actions needed to make MS care fair across the UK. For example, the MSFV recommends that: services are centred around the needs of MS patients, and not around the organisation delivering the service; multidisciplinary teams should work together to share learning, agree standards and undertake joint audit to optimise care pathways, so that people with MS can experience seamless and integrated care; and, unwarranted variation in access to care needs addressing, in order to improve the patient experience.<sup>4</sup>

Two years later, whilst good progress has been made on delivering on these consensus statements, action still needs to be taken to enhance the delivery of patient-centred care and support the equitable access to services across England.

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### 3. Calls to action to enable patient-centred and equitable access to services across England

Every person with MS should have equal access to effective and efficient MS services to receive the support and care they need. This report calls for an evolution in approach to the delivery of MS services, which places MS patients at the heart of service delivery and allows for the holistic needs of a growing number of people with MS to be met.

In particular, it identifies four core areas that should be addressed as a priority in the short-term. These are:

1. Evolve the commissioning environment for MS services to drive equitable access to patient-centred care.
2. A medicines optimisation framework for DMD monitoring should be developed and agreed by key stakeholders to safeguard MS patients, improve clinical outcomes, and reduce the impact on patient quality of life.
3. A workforce skill-mix plan for MS services should be developed to enhance service efficiency.
4. Local data transfer challenges should be addressed so that data can travel, rather than the patient.

Underpinning each of these calls for action, are a number of key recommendations to deliver on each of these four priority areas.

The recommendations echo that of the MSFV,<sup>4</sup> which outlined a shared view about the priority actions needed to improve the equity, efficiency and effectiveness of MS services across the UK. Furthermore, the recommendations put forward should also help address the 'triple challenge' set out in the NHS Five Year Forward View – providing

better health, transformed quality of care delivery, and sustainable finance.

This report summarises the key recommendations from the two roundtable discussions and defines the next steps to implementing meaningful change. The intention is that these findings and recommendations will support the ongoing dialogue required to evolve the MS commissioning environment to work better for both patients and MS services.

#### 3.1 CALL TO ACTION 1

**The commissioning environment of MS services should evolve to drive equitable access to patient-centred care**

##### PATIENT-FOCUSED COMMISSIONING

Patient choice needs to be at the heart of treatment and service decisions. To achieve this, education is needed to empower patients to become active partners in decisions about their ongoing care and monitoring with their clinical team. Patients should be informed of the monitoring and administration burden associated with each DMD, so that they can make an educated decision as to which medicine best suits their personal circumstances and lifestyle.

Roundtable discussions also indicated that there is a need to provide a more patient-centred approach to commissioning decisions and funding flows, that addresses the whole patient pathway, and improves equitable access to services.

As part of this, a more proactive approach to patient care between different centres is required. There should be better interaction between DGHs

and regional neurosciences centres, so that patients can seamlessly access the services they need. Above all, patients with MS should be able to access holistic care that meets their broader needs, beyond the requirement (or not) for a DMD, to improve outcomes and quality of life.

### THE NEED TO ADDRESS “WHO PAYS FOR WHAT”

**The current commissioning environment in MS is highly complex and is not fully understood by managers, clinicians, or even commissioners.** MS is a complex condition, and patients often need input from healthcare professionals spanning multiple disciplines, sectors and providers at different stages. However, funding for these services comes from a range of sources, can be confusing and the impact of the service on commissioners’ budgets is not transparent. The place of delivery, referral route, and the type of contract in place, also all affect how these services are paid for and therefore what is provided.

Currently, DMD acquisition costs are reimbursed by NHS England through specialised services, regardless of where they are prescribed. However, there is a lack of clarity regarding funding the costs associated with drug administration and the safety monitoring of DMDs. This includes activities such as phlebotomy, scheduling and carrying out MRI scans or other tests required by the treatment protocol, and interpretation and review of test results. These costs can be either funded by NHS England, absorbed by MS services, or paid for by the patients’ local CCG.<sup>12</sup>

The complexity associated with reimbursement has resulted in a lack of clarity about who pays for what. This is challenging, as currently the long-

term service impact of treatments, including the impact of administration and monitoring of DMDs on services, is not considered when treatment decisions are made.

### THE ROLE OF NATIONAL MS POLICIES IN DRIVING EQUITABLE ACCESS TO CARE

The uncertainty created by such a complex and fragmented funding system has been exacerbated in the past by the limited national strategic planning for MS services in England. The Adult Specialised Neurology Service Specification has not been updated since 2013, and there has not been a strategic review of whether this specification is delivering the optimal pathway for patients and services.

As a result, the location of neuroscience centres (Hubs) is not always aligned to the demands of the local population and patients travel long distances to have their treatments administered and monitored. This has resulted in the operational evolution of different models of service delivery around the country.

**Table: Location of neurosciences centres around England<sup>2</sup>**

Region	Neuroscience Centres
North	8
Midlands and East	5
London	6
South	5

The last year has seen the development of a number of forthcoming policies, which aim to provide this national direction. Namely, NHS England published an MS DMD Treatment Algorithm in September 2018 and work is

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*“If you ask any CCG, ‘what is your spend on MS in total?’  
 They haven’t got a clue.”*  
 – GP Commissioner  
 ”

underway to develop an updated national adult neurology service specification.

These initiatives are encouraging and provide a vital opportunity to establish the strategic oversight required to address the challenges being faced

### Recommendations:

- Patient choice and experience should be integral to any future commissioning decisions. Funding flows need to enable equitable access to all the holistic services that MS patients require
- Current system costs need to be mapped across the different parts of the care pathway (primary, secondary, tertiary and community) to develop a shared understanding of how different budget allocations impact each other and the overall service

equitable access could potentially cease if DMDs moved to being commissioned locally by STPs, or other regional footprints, due to local competing priorities with other disease areas for funding. Additionally, due to smaller patient numbers in MS, there was a general feeling that MS is unlikely to be a priority for STPs, when compared with other conditions that affect larger numbers of patients, such as diabetes, cardiovascular disease and respiratory disease. Consequently, there could be variability in access to DMDs across different STPs, which could result in a treatment “postcode lottery”.

- Responsibility for local commissioning of DMDs was last undertaken by primary care trusts, prior to the inception of NHS England and clinical commissioning groups in 2013. The commissioning and treatment landscape in MS has changed substantially since then, and there was general agreement that there is a lack of recent experience of commissioning DMDs at a local CCG level.

## COMMISSIONING OF DMDs TO ASSURE EQUITABLE ACCESS

DMD costs are currently funded nationally by NHS England’s specialised services. There was consensus throughout the roundtables that this supports the drive for equitable access to DMDs across the country, and therefore this should be continued.

The general opinion from both providers and commissioners was that the loss of national oversight and funding for DMD acquisition costs would be strongly opposed for several reasons:

- The MS budget is protected in NHS England specialised commissioning, with a nationally agreed level of spend. This provides equitable access to treatment, which helps to reduce unwarranted variation. This

*The current national approach to funding of DMDs by NHS England supports equitable access to treatment, and creates a fair and transparent process for patients*

- Many clinicians feel that current arrangements support their clinical decisions to prescribe, whilst commissioners suggested that the national approach by NHS England creates a fair and transparent process for patients.

### Recommendation:

- The DMD drug budget should remain with NHS England to assure equity of access, however clarity on “who pays for what” for the administration and longer-term monitoring requirements is essential to support safe and effective prescribing

### CURRENT MS SERVICE MODELS

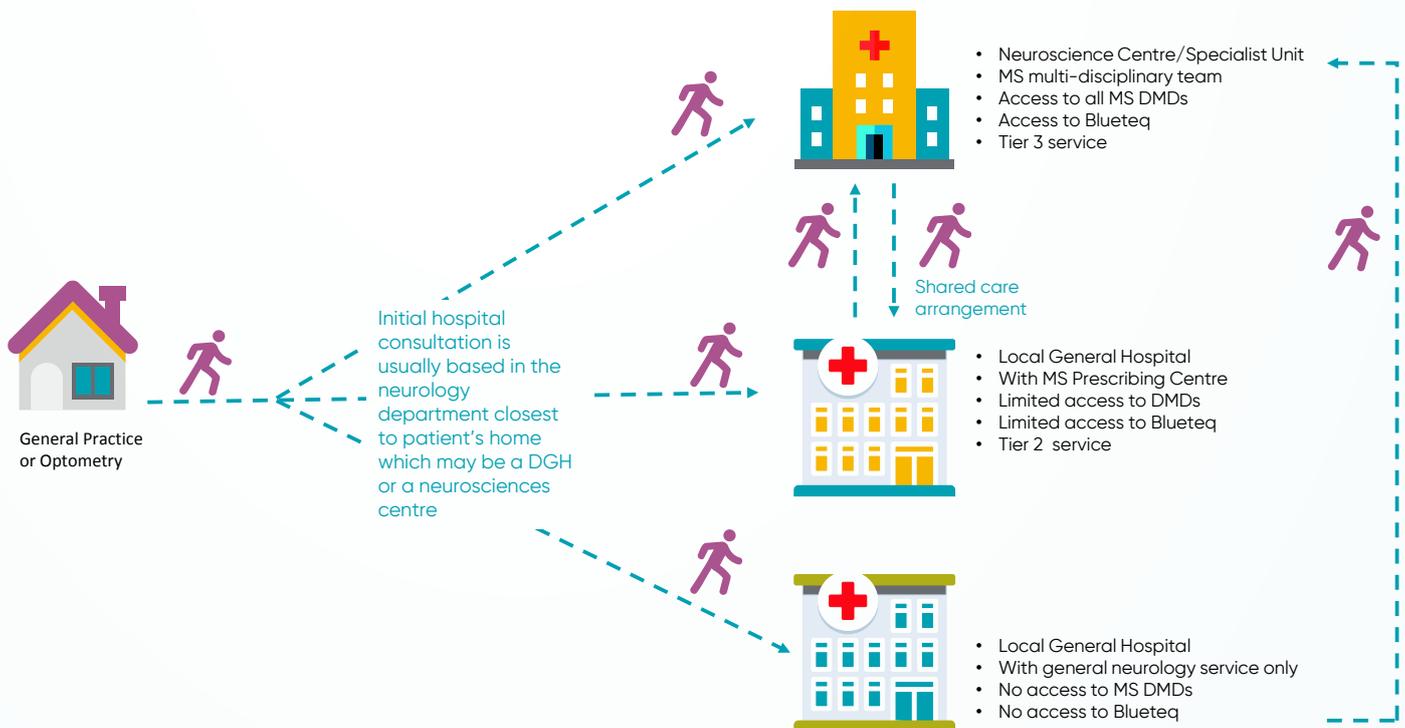
Experts at the roundtables described how the overall quality of care and access to treatment is currently being driven by the local geography, the distance the patient is willing or able to travel to access the service, an overall lack of staff capacity, and an ability to get timely access to specialist MS services.

Following referral by the patient’s GP (or optometrist) to secondary care for assessment

and diagnosis, the initial hospital consultation is usually based in the neurology department closest to patient’s home. Depending on where the patient lives, this may be a DGH or a neurosciences centre.

At present, only neurosciences centres are consistently able to prescribe the full range of DMDs via Blueteq (the computer system that is used to gain approval from NHS England to prescribe). Elsewhere, even with the expertise and capacity to do so, clinicians within some DGHs are not permitted to prescribe certain DMDs, as they do not have access to the medicine on the Blueteq system. These restrictions can further adversely affect capacity, waiting times and timely access to treatment, because a patient may need to be referred to a neurosciences centre in order to access a particular DMD treatment.

### Current pathways to accessing DMD prescription, administration and monitoring<sup>18</sup>



## HUB AND SPOKE MODELS

The opinion was that the 'Hub and Spoke' model of shared care facilitates improved access to treatments for patients. There is a service specification defined by NHS England for neurology specialised services,<sup>10</sup> which sets out that specialist care should be provided at a tertiary neurosciences centre acting as a 'Hub', which is fully equipped to carry out the full range of neuro-related procedures. Multidisciplinary specialist outreach clinics provided by the members of the multidisciplinary team visiting from the 'Hub' centres, constitute the subspecialist 'Spokes'.

*Hub and Spoke models of shared care between neurosciences centres and local hospitals should be expanded*

In addition to the 'Hub and Spoke' system, local community and primary care services (e.g. physiotherapy and community nursing), where skills can be developed with the assistance of specialist staff from the 'Hub' centres, aim to provide ongoing maintenance care for people with neurological conditions.

Currently there are administrative obstacles within the 'Hub and Spoke' infrastructure. Due to the limited access to DMD drugs on the Blueteq system at a DGH, the neurosciences centre may have to invoice and cross-charge to NHS England, the cost of drugs that are initiated and administered in a DGH spoke, for patients

that have never attended the neurosciences centre. This places an administrative burden on the neurosciences centre pharmacy team and impacts on their capacity to conduct patient-facing activities.

There was consensus that DMDs should be prescribed in both neurosciences centres (Hubs) and shared care centres (Spokes). Importantly, prescribing and monitoring should sit together, with the expertise in each location to do both. Addressing pathway efficiency and service capacity issues across different treatment centres in a 'Hub and Spoke' model of care delivery, should ensure that DMD monitoring and patient support is seamless between different providers.

## FUTURE MS SERVICE MODELS

There was consensus that the 'Hub and Spoke' model of shared care can positively impact on patient convenience, patient safety, service capacity, learning and development and team succession planning, and the model should therefore be expanded.

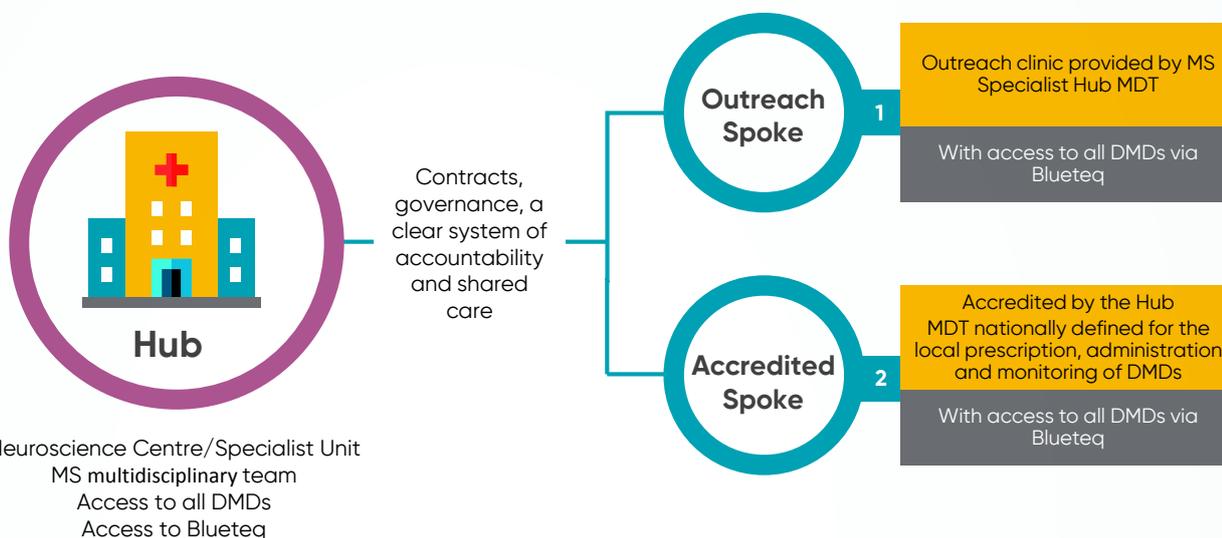
A key requirement would be robust governance arrangements for locally agreed shared care arrangements within 'Hub and Spoke' models of shared care between neurosciences centres and local neurology services. Co-operation between a range of clinicians and stakeholders will be essential to achieve this.

Where there is a service demand or capacity issue, there should be further development of local collaborative 'Hub and Spoke' shared care arrangements, in line with appropriate governance arrangements, to help improve service delivery, and minimise the distance patients have to travel in order to access these medicines. Virtual MDTs should be explored as a means of driving and establishing this shared care.

## Proposed pathway to accessing DMD prescription, administration and monitoring

### NHS England defined national strategy on commissioning neuroscience centres

'Local' team to design MS services to meet the needs of the local MS population



In addition to the hub outreach model, it was suggested that the service specification should evolve to give greater flexibility to support a spoke service, which could maximise the available skill mix, under the oversight of the hub.

More spoke-based services could allow for the MS specialist service to be delivered nearer to the patients, as opposed to the patient being required to travel to the neurosciences centre.

However, wherever MS services are commissioned in the future, there is a need for common standards and guidance on different national and local commissioning responsibilities within MS care, to drive a consistent quality of services, alongside equitable access to treatments.

#### Recommendations:

In conjunction with the NHS England treatment algorithm, the following need to be outlined nationally:

- Best practice shared care arrangements between hub and spoke models that allows for greater local flexibility in the set-up of specialist spokes.
- Clear communication on which sites are able to prescribe DMDs, who can prescribe these medicines, and under what circumstances.
- Hub and Spoke shared care agreements, which allow access to a full range of drugs on Blueteq at both types of centre.

*Further collaboration and work is needed to define the optimum population footprint for a collaborative commissioning arrangement in MS*

## WHAT IS THE APPROPRIATE POPULATION PLANNING FOOTPRINT FOR MS SERVICES?

There is current debate as to the population or organisational level at which MS services and DMDs should be commissioned in the future.

*Where there is a service demand or capacity issue, further develop local collaborative 'Hub and Spoke' shared care arrangements, in line with appropriate governance arrangements, to help improve service delivery, minimise the distance patients have to travel, and ensure there are no delays to patients gaining timely access to DMDs*

How should the 'local' service be defined for MS? It was suggested that CCG population footprints were much too small and an STP footprint size might also not be big enough for commissioning MS at a local level. However, it was also felt that the regional NHS England population footprints might be too large.

It was suggested that integrated care system (ICS) level commissioning or a 'MS needs-based' level commissioning could be implemented in the future.

### Recommendations:

- Further collaboration and work should be conducted to define the optimum geography and footprint for a collaborative commissioning arrangement in MS.
- Key stakeholders should be brought together to construct a "collaborative commissioning" framework template.

## ALIGNING SYSTEM PAYMENT MECHANISMS AND INCENTIVES

There is a need for the MS commissioning model to advance so that payment mechanisms and incentives for change are joined up with treatment choices. This may require new pricing and commissioning frameworks to help incentivise service redesign with the opportunity to release service capacity.

There was a strong view that the commissioning of DMDs, and the service that wraps around them, need to be considered together. However, there is currently no incentive within the system to change activity levels or prescribing habits. It is also important that any payment reform encourages efficiencies in the pathway, without adversely affecting income for providers.

New funding models should therefore be explored, and an incentive framework which is attractive to both commissioners and providers should be developed to facilitate improvements in service delivery.

*Key stakeholders should be brought together to evolve commissioning of MS services so that patient management and related payment mechanisms are joined up*

## SETTING UP A NEW DMD PRESCRIBING CENTRE AT A 'SPOKE' HOSPITAL (IMPERIAL COLLEGE HEALTHCARE NHS TRUST AND HILLINGDON HOSPITAL NHS TRUST, WEST LONDON)<sup>14</sup>

### BACKGROUND:

Due to a historical close working relationship, Hillingdon Hospital has for many years offered a DMD service (for a limited range of DMDs) as a 'spoke' of the neuroscience centre at Imperial College Healthcare NHS Trust. At that time, the Hillingdon service had one MS specialist nurse and an MS consultant, who also worked at Imperial, but the service was not recognised by NHS England as a prescribing centre. As a result, certain prescriptions had to be issued by Imperial as the 'hub', and Imperial claimed reimbursement for the drug costs from NHS England.

This required the Hillingdon MS Service to refer people starting DMDs to the MS nurses at Imperial so that the DMDs could be prescribed from there. Imperial retained

responsibility for ongoing reporting (through Blueteq) and prescribing for Hillingdon patients, and the safe monitoring of their DMDs, whilst having no direct clinical responsibility for their ongoing care.

Prior to implementing the change, the MS nurse at Hillingdon engaged with key stakeholders at the NHS Trust to explore the impact of the proposed change on the existing services and how it would cope with the additional demand.

The planning and implementation of the new service was led by the Clinical Commissioning Pharmacist at Imperial working jointly with the Hillingdon MS team.

### WHAT ARE THE BENEFITS OF WORKING IN THIS WAY?

The establishment of the new prescribing centre has streamlined the process of prescribing, monitoring and delivery of DMDs for people with MS in the area. This is in line with medicines optimisation goal of bringing services closer to patients' homes. It has ensured that clinical accountability is clearly defined and has reduced unnecessary communication between the teams.

## 3.2 CALL TO ACTION 2

**A Medicines Optimisation Framework for DMDs should be developed and agreed by key stakeholders to safeguard MS patients, improve clinical outcomes, standardise practice and reduce the impact on patient's quality of life**

### WHY IS THERE THE NEED FOR A NATIONAL FRAMEWORK?

Care for patients with MS has evolved in recent years as the number of available DMDs has increased. However, according to expert opinion, as the number of NICE approved medicines has grown, service changes to facilitate the prescribing and monitoring of these medicines have evolved in a reactive way. This has resulted in the evolution of different operational models of service delivery around the country, designed and implemented at a local level, with few opportunities to share good practice, learn from beacons of excellence, or be guided by an overall strategic service delivery plan.

The lack of a strategic implementation plan means that many people with MS struggle to

*A strategic review of service delivery to inform the optimal patient pathway to deliver medicines is required*

access the treatments and support they require in a timely manner. This can lead to substantial delays between the decision to prescribe a DMD and initiating the medicine.

This challenge is also set to increase. NHS England has predicted that the number of approved treatments will increase from 10,600 in 2016/17 to 20,000 three years after the MS Treatment Algorithm's publication<sup>2</sup>. To meet this increasing demand and deliver equitable access to a growing number of patients, it is crucial that there is a strategic delivery plan to manage the impact on specialist services.

Given the reactive evolution of MS services to the influx of new medicines, and the expected increase in demand for these DMDs, there is an urgent need to ensure DMD monitoring is safe, efficient, cost-effective and convenient for people with MS. A national medicines optimisation framework which considers DMD administration and monitoring demands on the patient and the service, could define an efficient treatment model and ensure the NHS achieves greater value for money invested in medicines.

### THE FRAMEWORK SHOULD AIM TO ACHIEVE THE FOLLOWING:

- 1. Clarify responsibilities for DMD provision to safeguard patients.** The framework should set national guidance and reinforce that responsibility and accountability for DMD prescribing. Prescribing and monitoring should sit with the specialist team in the first instance. Abnormal results from routine monitoring tests should be addressed by the specialist clinical team, but appropriate ongoing communication with the patient's GP is key.

“  
“With the suite of drugs for MS  
increasing, it is becoming more  
complex to manage.”  
– Consultant Neurologist  
”

- 2. Minimise the distance patients have to travel.** There should be enhanced interaction between DGHs and regional neurosciences units, so that patients can seamlessly move between centres. Where possible, phlebotomy should take place as close to the patient’s home as possible, provided that the pathology systems allow for the DMD prescribing team to access, interpret and act on the results by the prescribing centre.
- 3. Enhance patient engagement and empowerment to self-care and choose the treatment, its administration and monitoring.** There is scope for people with MS to be more informed about the monitoring requirements for DMDs when they make the decision with their neurologist or MS specialist nurse to start treatment, and to take greater ownership for ensuring that monitoring happens when needed. To achieve this, education is needed to empower patients to become active partners in decisions about their care and ongoing monitoring to ensure it fits in with their personal circumstances and lifestyle.

## **BUILDING ON THE FOUNDATIONS OF THE MS TREATMENT ALGORITHM**

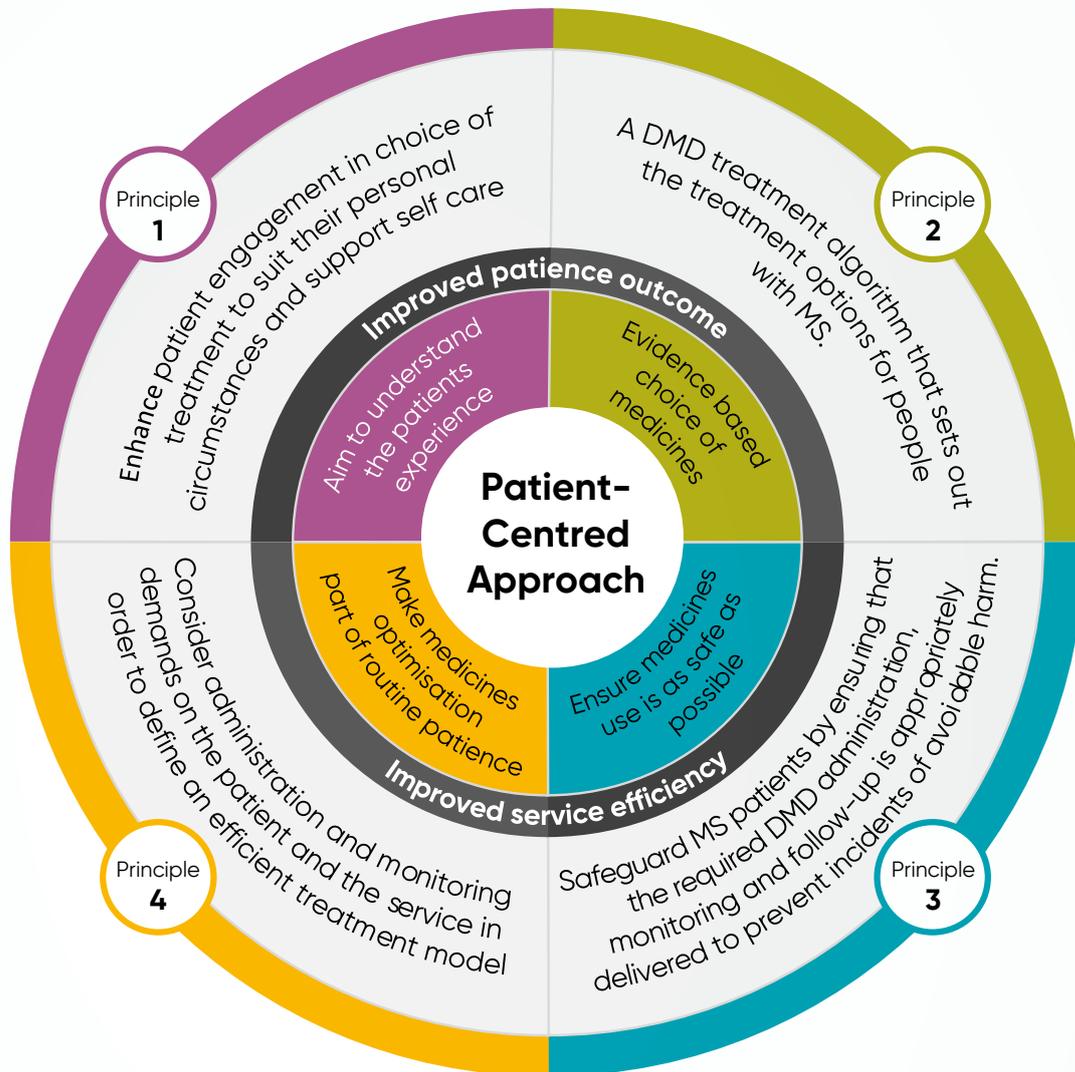
NHS England and the Association of British Neurologists, with input from other organisations, have developed a MS DMD treatment algorithm which sets out the treatment options for people with relapsing multiple sclerosis.<sup>13</sup> NHS England published the algorithm in September 2018, following a public consultation on the document in May 2018.

Concern has been voiced that the algorithm does not address DMD monitoring in enough detail. It was felt that there should be a whole pathway approach to the commissioning of DMDs, which considers both the administration and longer-term monitoring requirements for different DMDs in treatment decisions.

The Royal Pharmaceutical Society advocates medicines optimisation due to the focus on improved outcomes for patients and to ensure that both patients and the NHS get better value from the investment in medicines.<sup>15</sup> Four guiding principles are described which are consistent with existing national and good practice guidance. Currently the MS treatment algorithm would support implementation of one of these four principles.

## Medicines Optimisation Framework for DMDs

(Adapted from Royal Pharmaceutical Society Medicines Optimisation<sup>15</sup>)



### THE 4 PRINCIPLES OF MEDICINES OPTIMISATION FOR DMDs

To help deliver effective medicines optimisation of MS DMDs, all four principles should be implemented. These are as follows:

#### Principle 1: Aim to understand the patient's experience

There was a general view that an informed,

shared decision-making approach between the prescriber and the patient is essential when choosing which DMD to prescribe. This is because the choice of DMD will impact on patients' quality of life. For example, long journeys to access frequent monitoring tests will impact a patient's ability to work.

To achieve this, enhanced education and support is needed to empower patients to become active

partners in decisions about their care. Patients should be informed of the administration and monitoring burden associated with each DMD, so that they can make an educated decision as to which DMD best suits their personal circumstances and lifestyle. This will, in turn, help inform their treatment choices.

There is also the potential for people with MS to be more involved in their care and to take a greater role in managing their disease and ownership of the requirements for DMD treatment and monitoring.

### Principle 2: Evidence based choice of medicines

NHS England's proposed treatment algorithm for MS DMDs supports the implementation of principle 2.

Mixed opinions were expressed about the impact the algorithm will have on local clinical practice. Whilst some clinicians feel that it will not change routine practice, others have suggested that it may limit switching between drugs, and that the application of the 'stopping criteria' will result in discontinuation of therapy in some patients.

### Principle 3: Ensure medicines use is as safe as possible

The MS service should be able to provide, and patients be able to access, the required administration, monitoring and follow up to prevent incidents of avoidable harm from DMDs. However, due to the pressures on the service and the challenges for the patient in accessing the service, concern was raised that patients may not get the follow up they need.

### Recommendations:

NHS England should bring together key stakeholders to establish a Medicines Optimisation Framework for DMDs. This framework should aim to:

- Outline a 'best practice' model for DMD monitoring, that aims to eliminate potential safety issues and deliver an efficient and effective patient pathway
- Encourage patient empowerment and education on the impact of monitoring to support informed shared-decision making on treatment decisions

### Addressing the burden of monitoring responsibilities on MS teams

To support the drive for further equity in access, and to reduce capacity pressures on MS services, the commissioning of DMDs, and the service that wraps around them, need to be considered together. This is so that the overall impact of a treatment decision on a patient and their MS service can be considered. Decisions must take into account the administration and monitoring burden of DMDs, rather than just the cost of the medicine, to provide the best 'value' for outcomes.

Whilst there was consensus that, in order to maintain patient safety, the prescribing team should be responsible for monitoring and interpretation of results, many were conscious that this monitoring requirement places an additional burden on already stretched neurosciences centres and MS specialist nurses.

With this in mind, to support these MS teams, there is the need for guidance that considers

the workload involved with DMD administration and monitoring through a medicines optimisation framework for DMDs. Such a framework could safeguard MS patients, improve patient outcomes, and reduce the impact on patient's quality of life, whilst also improve the efficiency of DMD provision.

### Recommendations:

- To support the drive for further equity in access and reduce the capacity pressures on MS services, the commissioning of DMDs, and the service that wraps around them, need to be considered together
- Accountability standards and responsibilities for DMD prescribing and monitoring should be outlined. This should be overseen by the same team, with engagement of multidisciplinary team members with a different skill mix to cover the range of tasks involved.
- There is a need for guidance that considers the workload involved with DMD administration and monitoring through a medicines optimisation framework for DMDs
- Treatment decisions for any DMD should ensure that both patient choice and service capacity pressures are carefully balanced

### "SHOULD WHOEVER PAYS FOR THE DRUG ALSO PAY FOR THE MONITORING?"

Due to the uncertainty around funding flows and lack of clarity surrounding the responsibility for monitoring of DMDs, the role of primary care in MS patient monitoring is complex. Typically, a CCG will only pay for blood tests carried out in a primary care

setting if this has been specifically commissioned by the CCG, for example via an enhanced service. Otherwise any monitoring in primary care is absorbed as part of GP workload, with no additional reimbursement.

As a result, some GP practices do not monitor hospital-only high cost drugs, whilst others refuse to carry out blood test monitoring for clinical governance reasons. This has resulted in a model where there is variability in the provision of monitoring arrangements and responsibilities across the country, which is becoming increasingly difficult to manage.

A key question therefore raised is 'should whoever pays for the drug, also pay for the monitoring?' Throughout the roundtables, many felt this was an essential requirement for several reasons:

- If this is not the case, the overall monitoring burden for the patient and service may not be properly considered.
- Governance concerns and potential safety issues can arise when the prescribing and monitoring of DMDs are split across different clinical teams and different locations. This can cause a lack of clarity from primary and secondary care about who is responsible and accountable for delivering the correct

*The overall quality of care and access to treatment is being driven by the local geography, the location of the patient, staff capacity, and timely access to monitoring results and services in neurosciences centres*

monitoring and actioning blood test results. This confusion can put patients at risk due to potential adverse drug reactions being missed, overlooked or inappropriately managed.

- Critically, there is also a lack of knowledge and expertise in primary care to conduct DMD monitoring and to liaise effectively with secondary care. GPs have limited experience of DMDs in MS and may therefore not feel confident to make judgments about DMD blood monitoring results. There is a risk that treatment could be stopped unnecessarily or, conversely, that adverse incidents might be missed.

#### Principle 4: Make medicines optimisation part of routine practice

The framework should consider DMD administration and monitoring demands on the patient and the service, to define an efficient treatment model. It should provide a basis for healthcare professionals to routinely discuss with each other, and with patients, how to get the best outcomes from medicines throughout the patient's care and achieve greater value for money invested in medicines



- 'Beacons of excellence' where governance, safety and shared care issues have already been addressed should also be identified. These should be modelled for national adoption, to improve the efficiency of DMD provision and patient outcomes.
- Learnings from other specialist services that have already implemented monitoring services for biologic drugs should be identified and encouraged. The feasibility of setting up and consulting a local 'board' for cross-specialty solutions for monitoring hospital-only specialist drugs, which pool commonalities around prescribing issues such as rheumatology, gastroenterology and hepatitis, should be explored.

## TREATMENT AGREEMENTS FOR PEOPLE ON DISEASE MODIFYING DRUGS, FRIMLEY HEALTH MS NURSE TEAM (BASED AT FRIMLEY PARK HOSPITAL)<sup>14</sup>

### BACKGROUND:

The Frimley Health MS nurse team has implemented a formal 'agreement' between the individual starting a new DMD and the MS nurse conducting the consultation.

### HOW IT WORKS:

The documents cover the following aspects:

- Brief introduction to the DMD: how it is administered – the risks and benefits
- Monitoring requirements
- Potential side effects
- An agreement of the individual to adhere to the monitoring requirements and maintain regular contact with the MS nurse service, alerting them to any potential problems.

During the initial consultation prior to starting a new DMD, the MS nurse provides information and education about the treatment and risk benefit and emphasises the fundamental importance of monitoring. Once both parties have confirmed their understanding, the individual starting the DMD and MS nurse sign the document, and the patient receives their own copy and a scanned copy is saved to the individual's electronic patient record.

### WHAT ARE THE BENEFITS OF WORKING IN THIS WAY?

People have a good understanding of the DMD they are taking, the potential risks/side effects, and take greater responsibility and an increased role in the management of their MS and their medication. This promotes a trusting, collaborative partnership approach between people with MS and the MS nurse team. The team uses a 'no bloods, no drugs' mantra, resulting in a high adherence rate.

### 3.3 CALL TO ACTION 3

**A workforce skill-mix plan for MS services should be developed to enhance service efficiency**

#### WORKFORCE SHORTAGES

There was extensive discussion regarding the well documented workforce shortages in MS services, and the importance of multidisciplinary working within and between different providers, to optimise efficiencies within the patient pathway.

The shortage of consultant neurologists and MS specialist nurses across England needs to be addressed.

In particular, due to the lack of successful strategic workforce planning for the MS specialist nurse role,<sup>3</sup>

the community is now facing "succession planning" issues, as experienced MS nurses begin to retire. This inadequate workforce succession planning has seen some services close when the MS nurse leaves or retires. A national workforce plan for hospital and community-based MS nurses is needed, to aid succession planning

*Holistic care is needed for all patients with MS, not just those who are eligible for DMDs, to improve outcomes and quality of life*

and meet the needs of an increasing number of people with MS.

#### THE NEED FOR MULTIDISCIPLINARY WORKING

As the treatment landscape has evolved, with successive availability of new DMDs, so too has the role of the MS specialist nurse. Due to capacity issues and workforce shortages, the focus of MS specialist nurses has increasingly narrowed, to focus on the administration and monitoring of these medicines.

Currently, MS specialist nurses are undertaking the majority, or in some cases all, tasks along the DMD pathway. This includes leading many non-clinical elements of DMD co-ordination and monitoring, such as scheduling review appointments and chasing routine results. This is

not an effective use of their expertise but, due to a lack of other staff to delegate tasks to, they are continuing to have to take on this responsibility.

As a result, MS specialist nurses are struggling to provide the holistic

care required to meet the wider non-DMD related needs of people with MS, including for those patients who have a more progressive disease and are not eligible or no longer eligible for a DMD. This includes supporting self-care, wheelchair use, falls prevention and managing urinary tract infections.

*"With all these new drugs, it's great that we can offer more treatment choices, but often what is not put in place, is the infrastructure that goes with that to offer treatments safely. And then the primary progressive and secondary progressive patients get pushed aside, and these are the ones that end up in hospital, because nobody is monitoring them."*

– MS Nurse

This situation is likely to be exacerbated with the increasing demand for DMDs. As the number of patients on DMDs increases, so too will the workload to administer and monitor these treatments. This will be a challenge for MS teams, unless they work differently. The optimal workforce skill mix for MS services needs to be defined and the shortage of neurologists and MS specialist nurses needs to be addressed.

There was a suggestion that experienced hospital-based MS nurses should also be encouraged to become independent non-medical prescribers, to support service development and capacity issues, with the proviso that they are supported to do so as part of a multidisciplinary team. Caveats to this were the need to ensure formal clinical supervision, peer review and governance, and the avoidance of 'lone practitioner hazard'.

***Multidisciplinary working and delegation of certain tasks, could release the MS specialist nurse to work at a more specialist level and provide more holistic care for the MS patient***

Examples of multidisciplinary working beyond the hospital-based MS neurologist and MS specialist nurse include:

- Healthcare assistants to support with blood pressure and urine testing
- Community MS nurses to support with managing complications and co-morbidities

- Physiotherapists to support falls prevention
- Continence nurses to support bladder problems
- Occupational therapists to support fatigue management, home adaptations and access to work
- Neurosciences pharmacists to support DMD prescribing and monitoring

To help alleviate capacity pressures, training of alternative members of the multidisciplinary team – such as pharmacists and healthcare assistants – to play a more active role in the DMD pathway should be explored.

#### **Recommendations:**

- The optimal workforce skill mix for MS services should be defined and the shortage of neurologists and MS specialist nurses needs to be addressed
- To help alleviate capacity pressures, training of alternative members of the multidisciplinary team – such as pharmacists and healthcare assistants – to play a more active role in the DMD pathway should be explored
- Building on this, training and support should be given to the broader MDT, including occupational therapists and physiotherapists, in order to support the holistic needs of all people with MS
- A national workforce plan for hospitals and community-based MS should be developed to aid succession planning and meet the needs of an increasing number of people with MS

## TWO COMMUNITY MS SPECIALISTS EACH DEDICATED TO DIFFERENT AREAS OF CARE, (MS CLINICAL SPECIALISTS COMMUNITY TEAM, NEUROLOGICAL CLINICAL SPECIALIST TEAM, MILTON KEYNES COMMUNITY HEALTH SERVICES)<sup>14</sup>

### BACKGROUND:

Two MS specialists – an MS nurse and an occupational therapist (OT) in an MS nurse/clinical specialist role – make up the community MS team in Milton Keynes. The MS nurse sees people with relapsing remitting MS (both those who are on DMDs and those who are not), and the OT sees people with progressive MS. The pair work solely on MS, but are based within a team of neurology clinical specialists, who cover various conditions.

### HOW IT WORKS:

The MS nurse provides monitoring and support for people being prescribed a DMD, and symptom management to people with relapsing remitting MS, while the OT provides care to people with progressive forms of MS, who often require more support with mobility, cognition and balance.

People with MS who meet the relevant criteria are prescribed DMDs at the Oxford regional centre. The MS nurse attends consultations and works alongside their neurologist and MS nurse team in joint clinics. Both clinical specialists work alongside the local neurologists, liaise with GPs and work closely with other relevant services. Initial appointments following diagnosis are conducted at the person's home, with their consent. Most patients will only see their local neurologist when required, and are usually able to book appointments quickly.

The pair also conduct joint transition clinics for people recently diagnosed with secondary progressive MS, before their care is then managed solely by the MS nurse. People on their caseload are reviewed regularly on a needs-led basis. These reviews may be annual, six-monthly, or more frequent, depending on the patient's needs. Email contact is actively encouraged in between appointments.

In addition to home visits and clinic appointments, the pair jointly run an 8-week course on fatigue management twice a year, with the local Neuro Rehab Service occupational therapists. Joint assessments and joint working are also conducted with the neuro-rehab service and specialist continence nurse team. They also hold an annual education, information and support day for people with MS who are experiencing bladder, bowel and sexual problems.

## 3.4 CALL TO ACTION 4:

**Local data transfer challenges should be addressed so that data can travel, rather than the patient**

### TECHNOLOGY AS AN ENABLER

Experts felt that many of the issues raised in this report could be addressed by better joined-up IT systems or better data collection. Communication of data electronically between different providers is needed to facilitate system efficiencies, to address any potential medicines safety issues, and to improve the patient experience. Outcomes data are also required to underpin future service developments.

### THE NEED TO ADDRESS LOCAL DATA TRANSFER CHALLENGES

Many MS patients are currently having to travel long distances for routine blood tests due to the difficulties healthcare teams from different providers experience accessing their results.

Routine monitoring of patients on DMDs has been made problematic due to shortcomings in the IT infrastructures, and difficulties in transferring electronic information between providers.

Currently there is no one-stop electronic system to record or access patient data across all providers. In some geographies, the IT-related barriers healthcare teams face accessing patient records and phlebotomy results are extremely challenging. This can lead to situations where patients who require routine blood monitoring

are frequently having to travel many miles to a neurosciences centre, rather than a local DGH, simply to have blood taken. This time spent travelling for blood tests can be very onerous and interfere with a person's day to day life.

For example, some hospitals in London and the South East cannot access primary care blood results as it is not possible for GP practices to transmit blood tests results electronically to the neurosciences centre. This means that patients must travel further to the neurosciences centre for routine DMD monitoring. Elsewhere, some localities do have a single electronic system between primary and secondary care, so that all clinicians can view test results. For example, in South Yorkshire, blood results can be accessed across the region e.g. results from a test done in Barnsley can be seen in a Sheffield hospital.

There was consensus that local data transfer challenges should be considered and addressed, so that patients can have routine monitoring closer to home and spend less time on frequent journeys to NHS sites. Patients should be offered alternatives to hospital phlebotomy at a neurosciences centre, with their results linked up to the DMD prescribing team.

### INEFFICIENT SYSTEMS ARE PLACING PATIENT SAFETY AT RISK

Even in cases where routine tests are conducted closer to the patient, communication of test results is problematic and may need to be faxed, because access to patient information and pathology systems is not shared between providers.

For instance, in cases where care is shared between MS teams, or a GP has taken on responsibility for phlebotomy for blood monitoring within their surgeries, many MS centres are unable to view the results if the surgery is outside their local area and uses a different laboratory.

*Drug monitoring is problematic due to shortcomings in IT infrastructures and transfer of electronic information between different parts of the service. Results from DMD monitoring should be accessible electronically to all healthcare professionals (HCPs) involved in the care of the patient, and appropriate communication with the patient's GP is key*

MS teams at prescribing centres are therefore spending a significant amount of time chasing up results from other teams and professionals. This is putting patient safety at risk, due to the

possibility of potential adverse drug reactions being missed, overlooked or inappropriately managed. Experts expressed the view that results from DMD monitoring should be accessible electronically to all healthcare professionals involved in the care of the patient.

NHS IT systems should allow DMD monitoring results to be electronically communicated to all healthcare professionals (HCPs) involved in the care of the patient across different centres

and organisations. This would make monitoring and review much more convenient and efficient for both the person with MS and the MS teams.

### **Recommendations:**

A review of best practice and digital innovation around monitoring provision should be conducted. This would enable identification of digital solutions to support safe and efficient DMD monitoring. The following should be explored:

- The use of digital innovation such as electronic patient records that could be accessed by different providers, and a Patient Passport which displays drug results such as those used in diabetes.
- The feasibility of digital 'Advice and Guidance' sessions between primary and secondary care clinicians when dealing with abnormal results.
- Patient held records, apps, and patient passports, as avenues to communicate and store test results.

## ACCESS TO CLINICALLY MEANINGFUL DATA

Currently the lack of data on service and treatment outcomes is a huge frustration to all involved in the commissioning and delivery of MS care. Existing data quality is poor, and there is firm agreement that measuring “real world” outcomes and capturing data in a meaningful way is a challenge. It was felt that this was important to improving MS services in the future.

Therefore, there was a recognised need for an electronic tool to capture “real world” outcomes and clinically meaningful data, to interpret the impact of treatments and to track clinical outcomes. Whilst MSBase is established as a key international database, the UK does not systematically contribute. The UK MS Register hosted in Swansea is another option, but not all MS treatment centres have access to it.

There are frustrations that whilst a lot of data is entered into Blueteq, it is not possible to extract the data and analyse the impact of DMDs on patient outcomes and care delivery. Many felt that Blueteq should be evolved to capture real world evidence and yield clinically meaningful information, rather than being used solely as a “commissioner tool”.

Potentially useful metrics and outcomes were discussed, including the percentage of patients

taking a drug, annualised relapse rates, adherence, staff time spent supporting patients with their therapy, and the number of appointments required for administration, drug monitoring, MRI, etc.

In 2017, the European Medicines Agency (EMA) organised a workshop on multiple sclerosis registries, which included representatives from the European MS Platform (EMSP) and its EUREMS group, the “Big MS Data” group, national MS registries, marketing authorisation holders, health technology assessment and reimbursement bodies, patients, national competent authorities, and the EMA. One of the workshop objectives was to agree on implementable recommendations on the ‘core data elements’ to be collected in registries for MS.<sup>16,17</sup> This has outlined the ideal dataset for use in MS but has yet to be implemented. National uniform access to a patient registry would be welcomed, with a clinical champion leading the implementation.

### Recommendations:

The role of Blueteq should be evolved to capture common data elements and deliver a more clinically meaningful national database for monitoring and improving clinical outcomes

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## 4. Next Steps:

In the move towards place-based commissioning, NHS England has identified a number of specialised services that could be transferred to STP footprint commissioning in the near future. Adult specialist neurosciences services, which covers certain services for multiple sclerosis, is one of those identified services.

Central to achieving place-based commissioning, will be maintaining national service standards, outcomes and accountability for specialised services, while providing local flexibility to design and deliver services. Evolution of collaborative commissioning of MS services could potentially act as a model for population health commissioning.

### LEADERSHIP:

To drive and oversee the future development of MS service standards, NHS England should consider supporting a national approach to commissioning MS services to address unwarranted variation.

There is an opportunity to bring together key stakeholders and patient representatives at a summit to define what good care looks like in MS and allocate main responsibilities and actions. Development of a subsequent action plan will support effective commissioning across a clearly defined and relatively small patient population, to ensure appropriate management of the financial risk associated with MS service delivery. This could act as a model for collaborative commissioning of other specialised services.

Suggested actions:

### 1. A population health approach to MS care

**Step 1:** Define the population health approach and the size of the STP/multi-STP footprint for commissioning MS services. This would need to take into account local and regional nuances to MS care.

**Step 2:** Map the end-to-end cost of the current MS pathway, from primary care through to

specialised services and provide clarity on who pays for what.

**Step 3:** Outline what needs to be achieved in order to be able to measure 'what good looks like' alongside outlining which standards and outcomes should be evaluated.

**Step 4:** Overlay what new models or improvements should deliver, scenario plan, and align with NICE quality standards. Resources should then be allocated to optimise the patient pathway and reduce regional variation. The use of a patient registry should then be adopted to generate the data, in order to measure service improvements.

### 2. Evolving the current MS service specification

A new MS pathway which ensures that interventions and resources are allocated, as needed, should be designed and implemented.

This should encompass all stages of disease, and all tiers of service delivery. Community services should be aligned with the full primary, secondary and tertiary services pathway, to consider more holistic management of patients at all stages of disease, not just those eligible for DMDs.

### 3. Patient activation, education, empowerment and choice

A jointly managed approach to care planning, in partnership with the patient, that facilitates shared-decision making, and makes the patient an active partner in their treatment and care plan should be implemented. One aim is to improve a patient's likelihood of adhering to DMD therapy, but this approach should also encompass the full range of management options for MS and its co-morbidities, not just drug management.

Patient activation should be embedded within normal clinical practice, in order to facilitate a more proactive approach to self-care and self-management, so that patients are empowered to mitigate and manage complications and co-morbidities that they experience.

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