

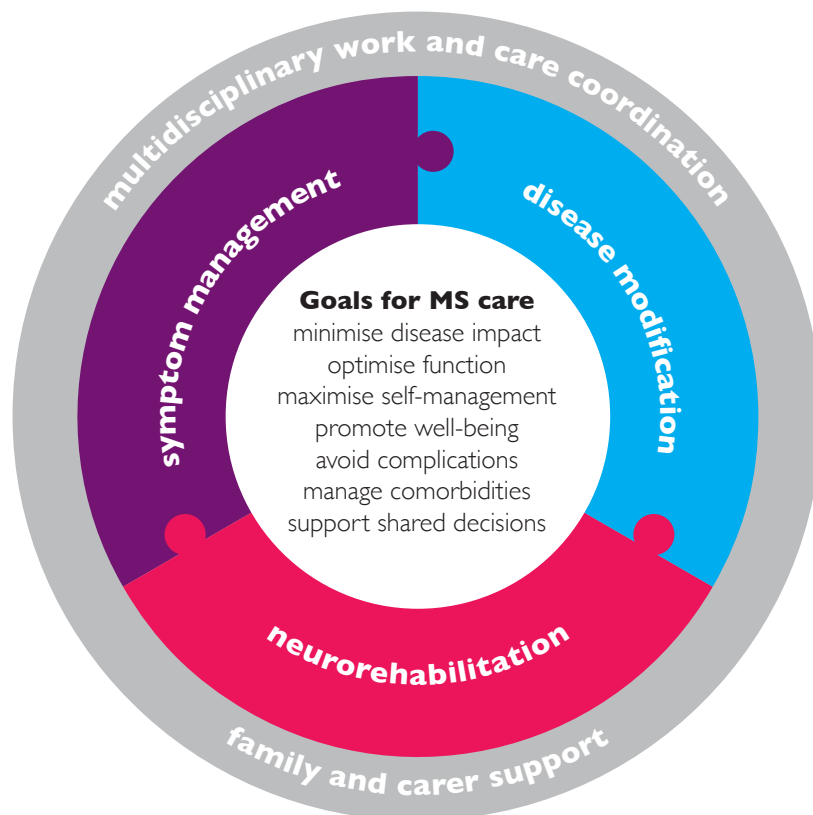


MS Forward View: a consensus for the future of MS services

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Amanda Croftⁱ, Geraldine Mynorsⁱⁱ, Megan Robertsⁱⁱⁱ, Daisy Doncaster^{iv}, Amy Bowen^v

A holistic model for MS care



ⁱ Policy Officer

ⁱⁱ GEMSS Programme Manager

ⁱⁱⁱ MS Specialist Nurse and Advanced Practice Advisor

^{iv} MS Forward View Project Coordinator

^v Director of Service Development



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MS Forward View: a consensus for the future of MS services

Foreword

As people living with MS, we are acutely aware of the differences in services people receive depending on where they live, and the type of MS that they have. For this reason, we were keen to become members of the MS Forward View project advisory group, to address some of the imbalances evident in access to MS services within the NHS.

The MS Forward View project continues the MS Trust's history of championing MS specialists and working closely with them to ensure high quality, fair and accessible services that are sustainable for the future, for everyone with MS.

At the heart of good services is a strong relationship between those of us living with MS and the health professionals who support us. Our voices as patients were, and continue to be, central to the entire project. The three of us attended the meetings and workshops but, uniquely, we were also supported by a wider forum of over 60 people from all over the country, which included individuals with different types of MS and several carers. This allowed for extensive conversation, the generation of exciting ideas, and ensured that the views of the MS population in the UK were represented.

The MS Forward View report calls for action to ensure that services for people with MS are equitable and efficient, whilst being flexible enough to reflect the extraordinary variation in individual needs. It recognises that all people with MS should be involved with an MS team signposting them to relevant services, in order to best manage their disease. It sets out a clear consensus about what the future of MS services should look like which will help the MS sector to be more focused and coordinated in our efforts to improve care for everyone with MS.

The project has generated much enthusiasm and positive thinking, from both health professionals and people with MS. The MS Trust will continue to work closely with all parties to ensure that the project has the impact it deserves, doing everything they can to put the messages of the project to commissioners, managers and health service leaders, the ultimate outcome being to support us all throughout our MS journey.

We are hopeful that practical projects will result from MS Forward View to help us move toward these goals.

Amy Mackelden
MS Forward View lay members*

Pia Reynolds

Caroline Smith

* Biographies of the MS Forward View lay members are available at www.ms-trust.org.uk/msfv-lay-members



A consensus for the future of MS services

This final report of MS ForwardView presents evidence for the scale of the challenge facing MS services and the opportunities to make care more efficient, effective and equitable for everyone with MS.

We want MS ForwardView to stimulate coordinated action on what MS services can do differently, now. That is why we have brought together our findings, summarised in this report, into these nine consensus statements.

The purpose of the MS ForwardView consensus is to present a shared view about the priority actions needed to improve the equity, efficiency and effectiveness of MS services across the UK. We developed these statements from the evidence collected during the project and from the views of our Lay Forum and the organisations and individuals from across the MS sector who were part of the project Advisory Group.*

These consensus statements set out our ambition for how we can make services work better for everyone with MS and deliver value to the NHS. They will help the MS sector to be more focussed and coordinated in our efforts to improve care for everyone with MS. They give us some common aims that we can work together to achieve. They will help us be more consistent in the messages we are communicating to those commissioning MS services and, most importantly, in how we talk with people with MS about what they should expect from their care.

1. MS is a fluctuating, variable, life-long condition. To live well, every person with MS needs an individually tailored, flexible blend of symptom management, disease modification and neurorehabilitation. To meet this need, they require good care coordination with access to a multidisciplinary team bringing skills from both MS specialist neurology and neurorehabilitation. This should be the basis of how services are designed, delivered and commissioned.
2. Services for people with MS should be centred around their needs and not around organisations. MS teams need to identify and connect with the wider neurospecialist, community and social care networks in their area. They should work together to develop pathways, share learning, agree standards and undertake joint audit, so that people with MS experience seamless and integrated care. It is important to people with MS that they know how to contact the service in between routine appointments.
3. Every person with MS should have an MS health professional who works with her or him to coordinate their care, especially at times of change. Good care coordination is an ongoing process that includes clinical assessment, helping people with MS set their goals and putting in place the support and care they need to achieve them. People's goals will not only be medical and MS services should recognise the importance of overall health and well-being.
4. Each year, MS teams should offer everyone with MS a comprehensive annual review with an appropriate health professional who has specialist expertise in MS. This is an opportunity to review and update the goals for care, making decisions together about the medical, emotional and social aspects of their health and well-being.
5. Every MS team should have a named professional lead for advanced MS. People with advanced MS and those who care for them have a particular need for coordinated care from a wide range of services. For some, this includes timely access to palliative care. The lead for advanced MS should be responsible for involving the wider network of services, developing care pathways and making sure people with advanced MS know what services are available to them.

* See page 8 for further details on how we involved the MS community. A list of advisory group members is included at Appendix I.



6. MS teams should make greater use of the clinical expertise of MS specialist nurses and allied health professionals with expertise in MS, strengthening their role as clinical leaders in MS. Establishing more diverse teams including sufficient administrative support will release them from time-consuming non-clinical tasks. This will help MS services get the best value out of specialist resources, making them more efficient and sustainable.
7. There is an urgent need to make disease modifying drug monitoring safer, more efficient, cost-effective and convenient for people with MS. MS teams need effective IT systems that talk to each other so they can review test results from across the area they serve and reduce the need for face-to-face appointments. MS services should take advantage of existing projects across the NHS to improve information sharing and develop a more systematic approach to monitoring.
8. There is a need to reduce unwarranted variation in access to and use of disease modifying drugs (DMDs) in MS and to ensure optimal value and outcomes from the DMD pathway as more treatments become available. A clinical consensus to review who should prescribe DMDs, to establish safe and practical monitoring regimes, to agree the content and intervals for reviews of disease activity, and to determine DMD stopping criteria as well as adequate provision for follow-on support, is called for.
9. MS services need to be able to plan services effectively, measure and reduce variation, and audit and evaluate the outcomes of service provision. We therefore need a better understanding of the number of people with MS in the UK, their need for and use of MS treatments and services and a comprehensive set of measurable standards. The development of a common dataset and register of people with MS, used by every MS team in the UK, should be a priority.

We are delighted that the following organisations have already joined the MS Trust in endorsing these statements:

MS Forward View lay forum
Association of British Neurologists MS Advisory Group
UK MS Specialist Nurse Association
Therapists in MS
UK Clinical Pharmacists Association
Royal College of Nursing
MS Society

We hope that more organisations will add their voice to this consensus in the months to come.



I. Introduction

The NHS is facing the greatest challenges in its history. Demand for healthcare, and the possibilities of what healthcare can achieve, are growing much faster than the resources available. Many services, particularly those for people with long term health conditions, are fragmented or disjointed, preventing the provision of seamless, high quality care. The accessibility and quality of services varies considerably across the country and what is true of the wider NHS is also true of care for people with multiple sclerosis (MS).

In October 2014, NHS England published its *Five Year Forward View*¹, setting out a vision of how the NHS needs to change in order to respond to the unprecedented pressures it is facing and deliver more efficient and effective care for those who need it. The *Five Year Forward View* identifies opportunities to secure better health, better patient outcomes and greater efficiency through radically upgrading the focus on prevention, organising care differently, tackling unwarranted variation in outcomes, delivering more care locally, and empowering patients to take greater control of their own care. Achieving the vision of the *Five Year Forward View* will require action on three priority areas: **demand, efficiency and funding**. Failing to address any one of them could result in a toxic combination of worsening services, fewer staff, budget deficits, and restrictions on new treatments.

The success of the *Five Year Forward View* relies on services rising to the challenge and finding ways to make its vision a reality in their own areas. Services for every condition need to address these issues, and MS is no exception. MS services need a clear vision for the future of MS care that helps them identify how they can deliver more efficient, effective and equitable care for everyone with MS. MS ForwardView is the MS Trust's response to this challenge, harnessing the expertise of the whole MS sector to drive the consensus needed to ensure that people living with MS are not losing out.

We know how dedicated MS health professionals are, and how determined they are to lead the world of MS care. They need help, support, and commitment from a charity like the MS Trust to tackle head on the pressures and challenges they are facing, and to secure the future of MS services that are fit for the evolving clinical and financial landscape. MS services need practical support and clear ideas about how to respond to these challenges and where they should focus to make the biggest difference to improving care.

The MS Trust is committed to supporting and developing MS specialist services in the UK because we believe that this will result in the best care for people living with MS. Access to specialist services, and in particular MS specialist nurses (MSSNs), is essential if people living with MS are to receive the full range of support they might need. That is why the MS Trust launched MS ForwardView, a one year project to identify the priority actions needed across the sector to deliver efficient, effective and equitable services for everyone with MS, regardless of the type of MS they have, or where they live. Our ambition is that MS ForwardView unites commissioners, providers, people with MS and MS health professionals to help ensure that everyone with MS gets the best possible care.



2. A 'forward view' for MS services

Multiple sclerosis (MS) is a lifelong condition that affects the central nervous system. Over 100,000 people in the UK are living with MS, and more than 100 people are diagnosed every week². MS is the most common cause of non-traumatic neurological disability in young adults³. For some, there are disease modifying drug treatments available, though everyone with MS lives with multiple symptoms which are often difficult to deal with. The range of symptoms and disabilities caused by MS, and the unpredictable course of the disease, make it particularly complex and challenging to manage.

Even without the impetus of the *Five Year Forward View*, the urgent need for concerted action to secure the future of MS services is clear. Previous MS Trust reports have found that MS services are struggling under the pressure of a changing clinical landscape⁴⁻⁶, with a growth in the range of disease modifying drugs available, more intensive monitoring regimes and a more complex decision-making process for people with MS (see box).

Disease Modifying Drugs for MS

Disease modifying drugs (DMDs) have changed the face of treatment for people with relapsing forms of multiple sclerosis over the past 20 years. They reduce the frequency of relapses and the accumulation of lesions in the brain detectable by MRI scanning, and some studies suggest that they can slow disability progression and improve long term outcomes^{7,8}. The number of DMD treatment options available on the NHS has grown from four in 2002 to 11 today, with more likely to be licensed and then appraised by the National Institute for Health and Care Excellence (NICE) in the next 12-24 months, including, for the first time, one for the treatment of primary progressive MS. The NICE clinical guideline on MS⁹ does not cover DMDs, but the Association of British Neurologists (ABN) prescribing guideline¹⁰ now recommends that treatment with DMDs should be started as soon as possible in eligible patients.

The demands of managing DMD treatment are placing a disproportionate burden on MS services. It is harder for services to meet the needs of people who don't benefit from DMDs, many of whom have advanced disability, or to deliver the holistic care that everyone with MS needs. Vital symptom management and multidisciplinary services are patchy or unavailable in many parts of the UK⁵, and many people cannot access the treatments and support they require. The majority of MS specialist nurses are working with unsustainable caseloads⁵ and there is a shortage of many of the other specialist health professionals people with MS rely on to manage their care.

These challenges are aggravated by a lack of clarity over commissioning responsibilities, unnecessarily complex funding arrangements, and systemic barriers to coordinating care across organisational boundaries¹¹.

Through MS ForwardView, the MS Trust brought together representatives from across the MS sector[†] to explore in detail how to meet these challenges and to facilitate a consensus across the MS sector about the future of MS care.

MS ForwardView aims to identify the priorities needed for the MS sector to deliver efficient, effective and equitable services for everyone with MS, regardless of the type of MS they have, or where they live.

[†] See section 3 for further details of the way we involved the MS community. A full list of advisory group members is included in Appendix 1.



MS Forward View examines MS services through the lens of the *Five Year Forward View*, setting out a vision for a service that is truly designed to serve everyone with MS, and which meets the goals of better health and better patient care, delivered more efficiently.

The objectives of the project were to:

- ▶ describe the barriers and enablers to appropriate and equitable provision of care, including the impact of current **funding flows** for MS services in England.
- ▶ identify key points along the MS pathway where there is greatest scope to use **service capacity** more effectively.
- ▶ scope the opportunity to **improve care** by using existing staff, skills and resources in new and different ways
- ▶ describe and benchmark **current provision** of MS services across the UK.
- ▶ propose pilot projects and education programmes to test and **evaluate new ways of working** to improve care for people with MS.



3. What we did

To achieve the aim of MS ForwardView, we focused on **four priority areas**:

- Mapping MS services
- Examining funding flows for MS services in England
- Understanding the needs of people with advanced MS
- Exploring the disease modifying drug pathway

This section provides a brief summary of what we did, the data we collected, and the individual outputs from each area of work.

Involving the MS community

To help us reach a consensus about the way forward for MS services we involved the MS community in every part of the project. We set up an advisory group representing the breadth of the MS sector; bringing together clinicians, specialised and local commissioners, professional bodies, experts in workforce planning, multidisciplinary educators, people with MS and patient organisations. Throughout the project, the advisory group acted as a sounding board for ongoing advice and input. A list of members of the advisory group is included in Appendix 1.

Input from people living with MS was central to our work. We recruited three lay members to sit on the advisory group and we set up a wider forum of people affected by MS to support them in their representative role. The forum was established to:

- represent the views and experiences of people with MS.
- help keep the project team focused on the needs and views of people with MS throughout.
- hold the project team accountable to ensure that the intended outcomes of the project are relevant to and resonate with people with MS.

The forum consists of approximately 60 people living with MS, including people with relapsing MS and progressive MS, as well as people caring for a loved one with MS. Our lay forum has helped us to develop a broad understanding of the issues and concerns of people living with MS, their carers and families.



3.1 Mapping MS services

To answer questions about how to use service capacity more effectively and improve care by using existing resources in new and different ways, it was first necessary to understand what resources are currently available. MS ForwardView set out to map the workforce of MSSNs and MS neurologists around the UK, building on and updating the previous work done for the 'Case for Equitable Provision' report in the summer of 2014¹². For the first time we have also mapped and presented DMD prescribing and treatment monitoring centres, and presented data at team level as well as by commissioning area.

People with MS rely on MSSNs for continuing, coordinated expert care, and consult their MS nurse more than any other health professional about their MS⁶. Neurologists with a special interest in MS, neurorehabilitation doctors, allied health professionals (AHPs) with expertise in MS, neuropharmacists and neuropsychologists are also all important members of the multidisciplinary team that people with MS need.

We focused on mapping MS specialist services because:

- ▶ **General availability of neurology services is variable across the country**, with more than half of neurology patients reporting problems accessing the services or treatment they need¹³ and neurology consultant provision well below the European average¹⁴.
- ▶ Previous work by the MS Trust has identified a **shortage of MS specialist health professionals** across the UK, with, for example, many MSSNs working with **unsustainable caseloads**¹². We wanted to update these data and provide a current picture of provision.
- ▶ Some multidisciplinary services involved in **MS care had not been systematically mapped before**. We wanted to get a more complete picture of provision, including neurologists, rehabilitation consultants and neuropharmacists, so we could consider how to use resources most efficiently and effectively and to identify any gaps or variations.

To build an up-to-date picture of MS services in the UK, from February to July 2016 we carried out four surveys of health professionals: MS specialist nurses, consultant neurologists, rehabilitation medicine consultants and neuropharmacists working in MS[‡]. We published our revised online [map of MS services](#) in September 2016.

3.2 Examining funding flows for MS services in England

People with MS live with a complex, variable and often unpredictable condition which can cause a wide range of symptoms. At different points in their disease trajectory they may need input from healthcare professionals spanning multiple disciplines, sectors and providers. In England, these services are funded in a number of different ways, with commissioning responsibility split between 'specialised' provision (funded by NHS England) and 'local' provision (funded by Clinical Commissioning Groups – also known as CCGs).

We chose to focus on funding flows for MS services in England because:

- ▶ Commissioning and funding arrangements are **particularly complex in England**
- ▶ Commissioning and funding arrangements are **poorly understood** by clinicians, managers and commissioners
- ▶ It is important for service providers to understand how services are funded when thinking about the **commissioning implications of service developments**

To better understand the issues we conducted interviews with MS specialist health professionals, commissioners, service managers, and representatives from NHS England from January to April 2016. We published a practical [guide](#) to funding for MS services in England in September 2016¹¹.

[‡] The reports of the neurologist, rehabilitation medicine and pharmacist surveys are available from the MS Trust on request.



3.3 Understanding the needs of people with advanced MS

'Advanced MS' describes the scale of burden that MS is having on an individual, rather than the type of MS they have. People with advanced MS have multiple, concurrent symptoms of MS which are ongoing, dependence on others for some or all care and support needs, and significant impairment of function.

We focused on advanced MS for three reasons:

- People with advanced MS make up a **significant proportion of the MS caseload**⁶
- People with advanced MS **incur greater costs** to the healthcare system¹⁵
- MS service **resources are being diverted away** from the care of people with advanced MS due to the demands of the DMD service⁶

To better understand the main issues we held a workshop with people with advanced MS, their informal carers and a range of health professionals providing the services people with advanced MS need.

We published our report, [*Improving services for people with advanced MS*](#)¹⁶, in November 2016.

3.4 Exploring the disease modifying drug pathway

The growing number of people living with MS, the rising proportion of people with MS taking DMDs, the availability of more DMD treatment options, and the greater intensity and complexity of DMD monitoring regimes are all increasing the burden associated with the provision of DMDs.

We chose to focus on exploring how the DMD pathway could be made more efficient because:

- MS teams have become **increasingly overwhelmed by the workload** associated with DMD provision
- The demands of DMD provision are **compromising the ability** of MS services **to meet the needs of people with progressive forms of MS**, for whom there are currently no DMDs available
- The demands of DMD provision are **compromising the ability** of MS services **to meet the non-DMD related needs of everyone living with MS**

To explore the issues surrounding DMD provision we used the results from our surveys of health professionals (see section 2.1) and held a one-day workshop attended by clinicians and people with MS. We also modelled different scenarios to identify the inputs required by an MS caseload under different assumptions about treatment rates going forward, and the associated workforce requirements.

We published our report, [*Improving the efficiency of disease modifying drug provision*](#)¹⁷, in November 2016.

The outputs of the project, in addition to this overall summary report, are available on the MS Trust website and listed (with hyperlinks) in the following table.



Figure 1: table of outputs

Output	Publication date	Format
Map of availability of MS services	September 2016	Online interactive map
MS Specialist Nursing in the UK 2016: Report on progress towards equitable provision	September 2016	PDF report
Funding flows for MS services in England: a practical guide	September 2016	PDF report
Improving services for people with advanced MS	November 2016	PDF report
Improving the efficiency of disease modifying drug provision	November 2016	PDF report
Findings of the MSFV survey of consultant neurologists working in MS	Powerpoint reports available from the MS Trust GEMSS team on request	
Findings of the MSFV survey of rehabilitation medicine consultants		
Findings of the MSFV survey of neuro-specialist pharmacists		



4. Key findings: the challenges facing MS services

The data we collected highlighted that MS health professionals are dedicated to providing the best possible service and support for people with MS, but that they face a consistent set of challenges:

- People living with MS have **diverse and fluctuating needs** that change over time.
- People with MS need **access to a range of specialist health professionals** to maximise the effectiveness of their care.
- MS services need to **get the best value out of specialist resources**.
- MS services face **systemic challenges to improving service quality and efficiency**.

The challenges we have identified are not new or surprising: they will be immediately recognisable to people with MS and those working in MS services. However, MS Forward View provides the strongest evidence base to date showing how these challenges are affecting services, why the predominant service model needs to change, and the ways in which MS services can improve.

If not tackled, these challenges will result in services that are:

- Increasingly **reactive**
- **Fragmented** and unable to deal with whole episodes of care
- Variable and **inequitable**
- **Inefficient and expensive** for the NHS
- **Inconvenient** for people with MS

This section sets out the evidence we gathered and our key findings under the headings of the four key challenges.

4.1 People living with MS have diverse and fluctuating needs that change over time

MS is a fluctuating, variable, life-long condition. Most, if not all, people with MS deal with a very individual set of difficult, ongoing symptoms that can affect every aspect of their lives. People with MS who took part in our workshops and forum discussions described a need for multidisciplinary support to help them deal with the range of symptoms and to help them manage their condition as independently as possible. We also heard about the importance of maintaining control over their life and choices, especially as disability increases.

The people with MS and MS specialist health professionals who took part in the MS Forward View project agree that, **to live well, every person with MS needs an individually tailored, flexible blend of:**

- **Symptom management:** Interventions which aim to alleviate the symptoms of MS, prevent complications, manage comorbidities and manage side effects from medications. This includes palliative care for those who need it.
- **Disease modification:** Drug treatments which lessen the impact of the disease course for individuals with active disease.
- **Neurorehabilitation:** A process of assessment, treatment, management and evaluation by which the individual with MS and their family and/or carers are supported to achieve and maintain their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of life¹⁸.

The balance of each of these elements will change, depending on the individual's needs at any one point in time.



A multidisciplinary model for holistic MS care

Throughout MS Forward View, we asked whether there is an ideal service model to deliver this holistic MS care. Based on what we have learned, service configuration is less important than the characteristics of the service. We have defined the essential characteristics of a multidisciplinary model of MS care that can deliver the flexible blend of services that everyone living with MS requires.

A multidisciplinary model for holistic MS care has the following characteristics:

- People with MS receive **personalised care and support centred around a set of outcome-focused service goals** that support them to live well with their condition.
- Everyone with MS has access to **a multidisciplinary team bringing skills from both MS specialist neurology and neurorehabilitation**, as required. The need for skills and experience from both disciplines reflects the diverse, inter-related and fluctuating needs of people with MS throughout their disease course. The service aims should therefore drive early involvement of rehabilitation and **a proactive multidisciplinary culture**.
- **People with MS experience seamless and integrated care** that helps them maximise their overall health and well-being. They are partners in their **care coordination**, working with an MS specialist health professional to help them set their health and well-being goals and to secure the support and care they need to achieve them.

Figure 2: A multidisciplinary model for MS care



The ability of MS services to deliver all three components of this holistic model, in the right balance, is being compromised by the increasing demands of managing just one of them: disease modification.



The growing demands of disease modification

Demands on MS services are rising: there is a growing population of people with MS; a greater range of DMD options; and a move to earlier initiation of treatment and switching or escalating to achieve optimum treatment response. Our report, *Improving the efficiency of disease modifying drug provision*, sets out the evidence to show that MS teams are becoming increasingly overwhelmed by the workload associated with DMD provision. MS services are already struggling to keep pace with increasing DMD treatment rates and the complexity of monitoring regimes. MS nurses in particular are struggling with the monitoring requirements¹⁷.

The workload associated with DMD management is set to intensify over the next five years as the proportion of people with MS on DMDs grows. Our model of future DMD activity predicts that the number of people on DMDs within a typical MS caseload will increase by more than 50% by 2020, even without the introduction of new treatments.

This increase in workload will be challenging or impossible for MS teams to deal with unless they work differently – particularly given that research by the MS Trust shows that the majority of teams are starting with caseloads well in excess of the recommended 'sustainable' level¹⁵.

The equity impact

In the context of rising demand associated with DMD management, many MS teams are finding it increasingly difficult to provide an equitable service for their whole caseload. There is no doubt that DMD administration and management is a critical element of any MS service. However, those eligible for DMDs only make up around half of an MS nurse caseload⁶. The rising pressure of managing a DMD service means that many MS teams are struggling to meet the symptom management and rehabilitation needs of people with MS. While this affects everyone with MS, it has a particular impact on those who are not taking or are not eligible for DMDs. Most worryingly, those for whom MS has already had the most significant impact often struggle to get the care they need, and some even report feeling abandoned by MS services⁴.

People with more advanced MS are often not aware of what services are available to them. Participants in our advanced MS workshop told us they did not have information about what their MS service offers people with their needs. Many described being unclear about whether they were still 'part of' the MS service or not and feeling that any service for advanced MS was, in effect, 'bolted on' to an MS service for those on DMDs and wasn't suited to their needs¹⁶.

As their condition becomes more advanced, people with MS report that contact with their neurologist may reduce or stop altogether¹⁹. The results of our *Is MS Care Fair?* survey, conducted earlier in 2016, showed that people with progressive MS are much less likely to have seen either a consultant neurologist (55% vs 79%) or an MS nurse (60% vs 79%) than people with relapsing MS in the previous 12 months⁴. They were also twice as likely not to have seen any MS specialist healthcare professionals. Some people with advanced MS who are not followed up by a neurologist may be discharged only to the care of their GP²⁰. This is not appropriate for anyone with MS. It means that people with advanced MS can become disconnected from or even lost to MS services and risks leaving people to manage multiple MS-related symptoms without access to specialist input.



Key findings

1. People with MS need a service offering the expertise of MS specialist neurology and neurorehabilitation in order to receive a flexible blend of symptom management, disease modification and neurorehabilitation. They need teams that have a culture of multidisciplinary working and everyone with MS should have an MS specialist health professional who works with them to coordinate their care, typically an MS nurse or, in some cases, an AHP with expertise in MS.
2. Current MS service provision is skewed disproportionately toward the needs of people on DMDs. Many MS services are struggling to meet the symptom management and neurorehabilitation needs of everyone with MS, particularly those who are not on DMDs. The needs of both people on DMDs and those who are not need to be addressed.
3. People with advanced MS are particularly vulnerable to becoming disconnected from specialist MS services, partly because hospital-based services can be so difficult for them to access, and there is an opportunity to make them more aware of what specialist input can offer them.

4.2 People with MS need access to a range of specialist health professionals to maximise the effectiveness of their care

Achieving the flexible blend of symptom management, neurorehabilitation and disease modification that everyone with MS requires is dependent on the availability of services within a local area, and how well those services work together.

Our research shows that there is a shortage of the specialist health professionals people with MS need, meaning that some people with MS:

- receive less input from their MSSN than they really need.
- travel long distances to reach services.
- may not be able to access the full range of disease modifying drugs.
- do not have access to the symptom management and neurorehabilitation services they need to live as well as possible.

MS specialist nurses are the health professional people with MS turn to the most⁶. They work across the whole disease trajectory, providing expert information and decision support as well as proactive case management to respond to acute deteriorations and relapses. Their interventions prevent secondary complications which can be disabling or life threatening and result in unscheduled care²¹.

Despite a welcome increase in the number of MSSN posts since 2014, our survey of MSSN teams found there is still significant variation across the UK in the caseloads of MSSNs. Our report, *MS Specialist Nursing in the UK 2016*⁵, highlights that **64% of people with MS live in areas where MSSNs have caseloads in excess of the MS Trust 'sustainable' caseload** of 358 people with MS per whole time equivalent MSSN. Nearly a quarter of people with MS, more than 25,000 individuals, live in areas where caseloads are more than twice the sustainable level. This may mean that a proportion of people in those areas are not known to their nearest MSSN service at all, or are receiving much less input than they really need. This may equate to a less proactive service, less able to prevent or respond to complications and acute deteriorations of MS symptoms. In some areas, despite adequate provision, **people with MS may still have to travel significant distances to reach services**. This is notable in areas such as central Wales and Northern Ireland.



People with MS may need input from a wide range of specialist health professionals during the course of their disease. The MS specialist working with each person with MS to help coordinate her or his care (typically an MSSN or an AHP with expertise in MS), needs to be able to consult with and make referrals to these professionals when needed. This includes being able to access the expertise of neurologists and neurorehabilitation physicians, as well as a range of AHPs including physiotherapists, occupational therapists, speech and language therapists, and psychologists. Much of the input of these health professionals is based on individual need and delivered in discrete episodes to address a specific issue. Our research shows that **availability of the majority of these multidisciplinary services is patchy at best, with some vital services such as neuropsychology absent in many places⁵.**

The number of neurology consultants in the UK is less than a third of the European average, and the Association of British Neurologists (ABN) has estimated that the UK needs a further 279 neurologists to meet demand²². A key factor in whether someone with MS can access the full range of DMDs for which they are eligible is whether they are under the care of an MS specialist neurologist. We found that not all people with MS who are potentially eligible for DMDs have an MS specialist neurologist to advise them on treatment options and prescribe^a. Our survey of neurologists found that less than a third of non-specialist neurologists prescribe DMDs compared to 100% of neurologists who defined themselves as providing a specialist MS service. Those non-specialists who said they do prescribe DMDs prescribe only a limited range (typically, though not always, excluding the 'highly effective' category DMDs administered by IV infusion). Although most neurologists refer on to colleagues within their team or at another centre for access to DMDs they don't prescribe, **in a number of cases it is unclear whether people with MS are being offered the full range of DMD treatments, and this is a cause for concern.**

Neurorehabilitation physicians are an even scarcer resource than neurologists with only a third of MS specialist nurse team leads reporting 'good' availability in their area⁵. This **lack of capacity is a barrier to neurorehabilitation physicians becoming more involved in the care of people with MS**, something many of those who responded to our survey expressed a clear wish to do.

Other neurorehabilitation specialists are also in short supply⁵. On average, fewer than half of MSSN team leads answering our survey rated the availability of neurospecialist physiotherapy in their area as 'good'. Only slightly more than a third of MSSNs rated the availability of neurospecialist occupational therapy as 'good'. **There appears to be a particular shortage of psychological services**, including cognitive assessment, neuropsychology and counselling services. The lack of specialist services to help people maintain physical and cognitive function and confidence can impact on the individual's ability to maintain employment and social activities, which are key drivers of overall well-being. The absence of these vital services will inevitably place a greater burden on already overstretched MSSNs.

^a Through our mapping work, we have identified 380 consultant neurologists who regularly see people with MS (most work in more than one hospital). Of the 95 who answered our survey, 79 of these described themselves as MS specialists



Key findings

4. There remains a substantial shortfall in the number of MS specialist nurses in many areas of the UK. Nearly a quarter of people with MS live in CCGs or Health Boards where there are more than twice the 'sustainable' number.
5. Not everyone with MS who is potentially eligible for DMDs has an MS specialist neurologist to advise them on treatment options and prescribe. Whilst the majority of centres offer the full range of DMDs, others offer only a limited range. Some centres have clear referral pathways in place for all DMDs which are not provided locally, but others do not. However, in a number of cases it is unclear whether people with MS are being offered the full range of DMD treatment, and this is a cause for concern. Regional networks and protocols are needed to ensure people with MS have equitable access to the whole range of DMDs, no matter where they live.
6. The rates of prescribing DMDs, and the types of DMD used, vary widely, and the reasons for this – including the relationship to MS specialist neurology provision – need to be more fully understood. This will require comprehensively mapping MS specialist and generalist neurology provision across the UK.
7. There is patchy or insufficient availability of key neurospecialist AHPs, particularly psychologists and occupational therapists, in many parts of the UK.
8. Early involvement of neurorehabilitation physicians is rare, partly due to limited availability, but neurorehabilitation physicians are keen to play a larger and earlier role in MS care. Better pathways and protocols to trigger timely involvement of neurorehabilitation would help people with MS achieve many of their goals, including optimising function, maintaining independence and preventing complications.

4.3 MS services need to get the best value out of specialist resources

The *Five Year Forward View*, which sets the current strategic direction for the NHS, challenges all NHS services to deliver better patient outcomes and greater efficiency¹. The draft specialised services framework published by NHS England in May 2016 also signals a clear intention to exercise tight control over the specialised commissioning budget²⁵. Value is the current watchword within the NHS, and this means that MS services must be able to show that they are delivering value for people with MS and working as efficiently as possible.

The MS Trust GEMSS (Generating Evidence in MS Services) evaluation project found that the productivity of MSSN teams, in terms of patient contacts per year, is highly variable⁶. Some of this can be explained by factors relating to caseload and geography, such as having a high proportion of people with advanced MS who require home visits on the caseload, especially where the service covers a highly rural area. However, GEMSS identified a number of levers which can improve the productivity of all MSSNs to the level of the best. Through MS Forward View we explored a number of these in more detail, and have identified several **opportunities to get the best value out of specialist resources**:

- Ensure MS teams have **sufficient non-clinical administrative support**
- Embed more formal **multidisciplinary working** in MS teams
- Build a **clinical consensus** to improve the efficiency of the DMD pathway

Non-clinical administrative support

The MS Trust GEMSS report identified that having sufficient administrative support is an essential enabler to maximise MSSN productivity and effectiveness⁵. Our MS Forward View survey revealed that more than a quarter of MSSNs have no administrative support at all within their teams, and a further third have less than a day a week of support per whole time equivalent nurse⁵. **More than three quarters of MSSNs feel they do not have sufficient administrative support to enable them to focus on clinical tasks.**



Based on our analysis, we recommend that each whole time MS nurse needs around 3 days a week of administrative support. This would enable them to focus on clinical tasks requiring their specialist expertise, such as managing whole episodes of care, leading particular aspects of the pathway, and providing leadership and strategic development of the service, allowing them to deliver more effective services and to reduce the workload of other health professionals, particularly neurologists. Our reports on advanced MS and the DMD pathway outline some of the ways this can be achieved, for example by each team having a DMD coordinator to schedule and track DMD monitoring, liaise with homecare companies, resolve non clinical queries and maintain records.

Our report on the DMD pathway identifies two further areas where making better use of the clinical expertise of MSSNs could make services more efficient and provide a better experience for people with MS:

- ▶ DMD monitoring could be made more efficient if MS nurses were empowered to **order MRI scans** in advance of neurology reviews so that these could be ready and available for the consultation.
- ▶ Services should also consider whether **independent prescribing of symptomatic treatments by MS specialist nurses and/or AHPs**, supported by clear protocols, would improve services for people with MS.

Multidisciplinary working

Our research also indicates that establishing more formal multidisciplinary working would help to get the best out of specialist resources by ensuring that the right members of the multidisciplinary team are involved at the optimal time.

As described in section 4.1, holistic MS care relies on a mix of disease modification, symptom management and neurorehabilitation. These services are currently delivered across multiple specialities and providers, which can present a barrier to multidisciplinary working. To deliver a seamless experience, services should endeavour to break down these barriers and establish formal ways of different professionals and different teams interacting, especially if they are not co-located.

Joint working between MS nurses and neurologists is widespread and well-established. Our MS nurse survey shows that around two thirds of MS nurses regularly meet with neurologists and at least one other MS health professional. Some MS teams have regular, scheduled joint meetings of the wider multidisciplinary team¹⁶. While this is encouraging, **widespread use of joint meetings or formalised arrangements for multidisciplinary working is often not present within MS teams.**

Our surveys of MS specialists found that, while the majority of MS services have good networks with other service providers in their locality, these networks are largely informal and often rely on goodwill between individual healthcare professionals rather than more robust, formalised care pathways and protocols¹⁶. In particular, our survey of neurorehabilitation physicians reveals that although more than three quarters of neurorehabilitation physicians report working with neurology colleagues on an informal basis, only 3% report holding joint MDT meetings and less than a fifth work to a formalised pathway. A recent study which mapped integration between neurology and palliative care services for different diseases found that this was the most limited in MS, with just two out of eight sites studied having regular, joint meetings²³.

Building a clinical consensus to improve the efficiency of the DMD pathway

There are a number of areas where a clinical consensus would help to improve the efficiency of DMD provision and ensure that specialist resources are being used to the best effect.

Monitoring requirements of different DMDs are currently set by pharmaceutical companies based on clinical trial protocols. **A consensus view of MS neurologists is needed to establish monitoring regimes for each DMD which are safe but practical within a real-world clinical environment.**



DMD treatment rates and options are increasing, with new drugs (including the possibility of DMDs for progressive MS) on the horizon. In October 2016, NHS England announced its intention to introduce standardised drug continuation criteria for people with MS. **A consensus view of MS neurologists is needed to ensure that any changes to criteria for starting, switching or stopping DMDs reflect the needs of people with MS and appropriate clinical practice.**

There is currently considerable variation in who prescribes DMDs, and which DMDs they prescribe. In section 4.2 we highlighted the variation in prescribing practice between MS specialist neurologists and non-specialist neurologists, and the impact this has on whether people with MS can access the full range of DMDs. Our survey of MS specialist nurses also found different approaches to nurse prescribing. Around one third of MS nurse prescribers (7% of all MS specialist nurses) currently prescribe repeat DMDs. Our survey of neurologists revealed that 70% of MS specialist neurologists 'agreed' or 'strongly agreed' with the statement that MS nurses, with appropriate training, could undertake repeat DMD prescribing. There is scope for more widespread nurse prescribing to improve both the efficiency of the DMD management process and the convenience to people with MS, but clearly this will require careful planning, training and depend on locally available staffing. The participants in our DMD workshop also agreed that pharmacists could play a much greater role in designing the DMD pathway and DMD monitoring, and potentially undertake repeat prescribing between neurologist reviews. These issues are explored in more detail in our DMD report¹⁷. **There is a need for national consensus on who can prescribe DMDs, incorporating both specialist and non-specialist neurologists and also MS specialist nurses and pharmacists undertaking repeat prescribing.**

Key findings

9. With the right support in place, there are opportunities for MS nurses and AHPs to work more consistently to their advanced practitioner clinical expertise, managing whole episodes of care and leading particular aspects of the pathway, such as relapse management. This would free up scarce neurologist time. Few MS nurses are independent prescribers, which may be a barrier to more efficient services and a better experience for people with MS. This applies to repeat prescriptions for DMDs and prescribing symptomatic treatments.
10. MS neurologists and MS nurses work closely together. However, broader multidisciplinary working is not always well established in many MS teams with few formally defined pathways and limited use of joint meetings.
11. There are opportunities to improve the efficiency of DMD provision by building a clinical consensus about the safe monitoring requirements for each of the DMDs, more formal criteria for when DMDs should be stopped, and the role of MS specialist nurses in prescribing DMDs. This would enable DMD prescribing centres to more accurately model their workload and establish patient pathways and protocols for each DMD that make the best use of the specialist resources within the team.

4.4 MS services face systemic challenges to improving service quality and efficiency

The data we collected consistently highlighted a number of systemic challenges to improving service quality and efficiency relating to:

- Role diversity and skill mix within MS teams
- Information and administrative systems
- Availability of reliable prevalence and local caseload data
- Overly complex funding arrangements



MS teams would benefit from greater role diversity and better systems

Our DMD report highlights **greater role diversity** within MS teams as one of the main opportunities to ensure efficient and effective delivery of care along the whole DMD pathway. MS teams need to be resourced appropriately with the right skill mix. This will depend on the size of the team and the makeup of the caseload, but there is scope for DMD or therapies nurses and neuropharmacists to play a greater role. Our DMD report recommends that:

- ▶ **Every MS team that is prescribing or monitoring DMDs should include a non-clinical DMD coordinator to manage the process.** In smaller teams, this function could be combined with the wider administration role which is required by all MS teams.
- ▶ **In larger teams, efficiencies can be gained by including a DMD or therapies nurse within the team.** These roles (which of themselves are unlikely to be sufficient to add up to a whole post in all but the very largest centres) could be combined with a responsibility for administering IV DMDs on an infusion suite or ward.
- ▶ **All MS teams who prescribe DMDs should include a pharmacist within the MDT** and involve them as much as possible in the development and design of processes and pathways for DMD care, including setting up and managing agreements with home care companies.

Further compounding the lack of sufficient administrative support discussed in section 3.3, many MS teams currently lack the underpinning systems that would help make DMD provision more efficient. Our DMD report highlights four areas where there are opportunities to improve the efficiency of DMD provision by implementing better systems:

- ▶ **Information systems for planning and monitoring care are lacking.** Our nurse survey found that three quarters of MS specialist teams do not have a system for managing the monitoring of DMDs across their caseload.
- ▶ **Systems are not integrated between providers to allow easy access to pathology results or other relevant clinical information.** This means that, where care is shared between more than one MS team or where blood monitoring is carried out by GPs or community services, MS teams are often unable to view the results directly. In many cases, the informatics-related barriers to phlebotomy being available locally are so insurmountable that people with MS have to travel many miles to a neuroscience centre simply to have blood taken.
- ▶ People with MS and MS specialist nurses report **difficulties with home care delivery.** People with MS on self-injected and oral medications have these delivered by homecare delivery companies. The choice of company is limited by whichever of the six pharmaceutical companies is supplying the drug. The ability of hospitals to explore different delivery options (such as patients collecting their medication from a local community pharmacy) is limited by VAT regulations, which mean that delivery via homecare costs less to the NHS.
- ▶ Our analysis has shown that **there may be scope to cut down on routine face-to-face appointments with people on DMDs without compromising safety.** Our MS nurse survey showed that only 32 out of 148 (22%) prescribing and monitoring centres reported that they were able to schedule blood tests without the need for an MS specialist nurse or neurologist appointment (with the results available at a later date).



Better data is needed to enable service planning

There is a lack of reliable data, either nationally or locally, on the true prevalence of MS, the characteristics of the MS population, and the use of health services by people with MS. A recent large scale study of MS using the General Practice Research Database showed that MS prevalence is increasing by an estimated 2.4% per year; and suggests a variation in prevalence of up to 50% between regions in England²⁴. However, this gives only a partial picture and the findings have been questioned². MS registers exist at both UK and Scotland level, but the UK MS Register uses self-reported data from people with MS and is very far from being comprehensive^{**}, and the Scottish MS register currently measures only MS incidence^{††}. **Better data at national and local level is essential to ensure that services can be properly planned and resourced.**

The 16 teams who participated in the MS Trust GEMSS project have, in many cases, identified that their caseloads fall short of the estimated number of people with MS in their local area, but it is currently impossible to know whether this is due to people with MS being lost to follow up, data error or other reasons. A national register and common dataset would provide MS teams with better prevalence data to compare against their service caseload data, helping them to assess the extent to which people with MS in their area might be out of contact with services and to compare performance on areas such as the rate of unscheduled admissions for people with MS.

Complex funding arrangements hinder service improvement

In England, MS care is the responsibility of a variety of different commissioning bodies, with most services funded via a mix of specialised provision commissioned by NHS England and local services commissioned by CCGs. We explore the challenges of MS funding in England and its impact on service development in a separate guide¹¹. In developing this guide we found that the detail of these arrangements is often not well understood by clinicians, managers or even commissioners, making it difficult for services to identify the economic implications of business cases for service development or improvement. **The complex mix of funding creates barriers when MS teams want to develop or reconfigure their services to make them more efficient, effective or service user oriented.**

This lack of clarity over funding does account, at least in part, for the variety of service models we see, as well as some of the operational challenges evident in making services seamless and efficient. For the other UK countries, while the challenges of commissioning don't apply in quite the same way, overall funding pressures are similar, as is the need to make service provision more seamless.

The uncertainty created by such a complex system of funding is exacerbated by the lack of a clear national service specification for neurology services in England. **There is an opportunity to simplify and clarify responsibilities around a comprehensive service specification.** The newly reformed Clinical Reference Group should address this as a matter of urgency. This is particularly important as the commissioning environment continues to change, with neuroscience services identified as being suitable for commissioning by Sustainability and Transformation Plan areas from 2019²⁶. It is vital that, wherever MS services are commissioned, there are strong national standards to ensure the consistency and quality of services.

** See www.ukmsregister.org

†† See www.msregister.scot.nhs.uk



Key findings

12. There are opportunities to improve the efficiency of DMD provision by implementing better systems and increasing role diversity. Whilst phlebotomy should be carried out as close to home as possible, reviewing and acting on blood results are the responsibility of the prescriber and cannot be devolved to primary care without shared care protocols and training which are difficult to establish and fund. Many MS teams do not have a system for managing the monitoring of DMDs across their caseload. Limitations in integration of IT systems means that people with MS often have to travel long distances for blood tests. In many teams, the burden of non-clinical coordination of monitoring falls disproportionately to MS nurses. With better systems and more role diversity within teams, MS specialist nurse time could be freed up for other aspects of care.
13. MS teams are operating without good prevalence data about the population of people with MS they serve. A single comprehensive UK register of people with MS is needed, that is used by all clinical teams and linked to their service-level data. Amongst other benefits, this would help prevent services losing touch with vulnerable groups.
14. Funding arrangements for MS services in England are very complex. This is highly problematic for teams when trying to undertake service development. There is an opportunity to simplify and clarify responsibilities around a comprehensive service specification.



5. The way forward: a consensus for action

Through MS ForwardView we have been able to evidence the scale of the challenge facing MS services. We have also been able to identify a number of opportunities to make care more efficient, effective and equitable for everyone with MS.

Our reports, *Improving services for people with advanced MS*, *Improving the efficiency of disease modifying drug provision*, and *MS Specialist Nursing in the UK 2016: report on progress towards equitable provision* set out detailed recommendations for MS services, commissioners, managers and national bodies.

However, as a community, we wanted to identify the priority actions that will help MS services respond to the challenges they are facing. We have focused our recommendations into one consensus on nine priority areas that will make the biggest difference to improving care for everyone with MS and delivering greater value to the MS. The consensus statements are presented on pages 4 and 5 of this document.

We are delighted to have succeeded in building a consensus supported by the whole MS community that we brought together in MS ForwardView. However, the consensus is not an end in itself. As an MS community, we are committed to continuing to work together to deliver on the ambitions in these consensus statements. There is much to do to, but we are determined to make sure that everyone with MS gets the best possible care. We are committed to working individually and collectively to achieve that ambition.



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Appendix I: MS Forward View advisory group membership

Name	Role	Organisation
Pam Bostock	Consultant Occupational Therapist and Co-chair of Therapists in MS (TiMS)	Virgin Care, Adult Ability Team, Staffordshire
Robert Brenner <i>(from June 2016)</i>	Consultant neurologist and member of the ABN MS advisory group	Association of British Neurologists
Georgina Carr <i>(from June 2016)</i>	External Relations Manager	MS Society
Amanda Cheesley	Professional Lead for Long Term Conditions and End of Life Care	Royal College of Nursing (RCN)
Samantha Colhoun	MS Clinical Nurse Specialist and Co-chair UK MS Specialist Nurses Association (UKMSSNA)	University Hospitals Birmingham NHS Foundation Trust
Sameena Conning	Head of Public Affairs	Biogen
Sonia Devereux	Speciality Doctor in Neurology (GPwSI multiple sclerosis)	NHS Tayside
Rachel Dorsey-Campbell	Senior Lead Pharmacist Neurosciences and NHSE Clinical Commissioning	Imperial College Healthcare NHS Trust
John Etherington	Consultant in Rheumatology and Rehabilitation	Defence Medical Rehabilitation Centre
Liz Fenton	Nurse Advisor	Health Education England
Steve Ferguson	National Public Affairs and Policy Manager	Merck
Sally Hughes <i>(October 2015 – June 2016)</i>	Programme Director – Policy and External Relations	MS Society
Louise Jarrett	MS Clinical Nurse Specialist	Royal Devon and Exeter Hospital NHS Foundation Trust
Christopher Kipps	Consultant neurologist, Clinical Director for the Strategic Clinical Network at NHS England (Wessex) and clinical lead for the Clinical Research Network (Wessex) for Mental Health, Dementia and Neurological conditions	University Hospital Southampton NHS Foundation Trust, Wessex Strategic Clinical Network and Clinical Research Network Wessex
Pam Macfarlane	Chief Executive	MS Trust
Amy Mackelden	MS Forward View lay member	MS Trust
Emma Murphy	Consultant in Rehabilitation Medicine	Royal Bournemouth Hospital



Name	Role	Organisation
Diane Playford	Professor of Neurological Rehabilitation and President-Elect of the British Society of Rehabilitation Medicine	Warwick University and the British Society of Rehabilitation Medicine
James Porter	Business Franchise Head, neuroscience	Novartis
Siân Price	Consultant neurologist and member of the ABN MS advisory group	Association of British Neurologists
Pia Reynolds	MS Forward View lay member	MS Trust
Eli Silber	Consultant neurologist	King's College Hospital
Caroline Smith	MS Forward View lay member	MS Trust
David Thomas	Public Affairs Manager	Roche
Laura Thompson	Patient Services Manager, UK	Teva
Joe Wildy	Public Affairs and Advocacy Lead, MS	Sanofi Genzyme
Sue Woodward	Interim Director of Clinical Education	Florence Nightingale Faculty of Nursing and Midwifery at King's College

The MS Forward View project team

Amy Bowen, Director of Service Development

Amanda Croft, Policy Officer

Daisy Doncaster, Project Coordinator

Geraldine Mynors, GEMSS Programme Manager

Megan Roberts, Specialist Nurse and Advanced Practice Adviser



About the MS Trust

The MS Trust is a charity which works to make a difference today for the more than 100,000 people living with MS in the UK.

We work to make sure everyone affected by MS can access good quality, specialist care. We do this by providing high quality education and professional development support to MS specialist health professionals so they can deliver an even better service. We support health professionals with online information, publications and updates on the latest research.

Through our innovative GEMSS programme, we support evidence-based service improvement in MS care. Our approach is always to work in partnership with health professionals to improve MS services now and in the future.

We also produce practical, reliable information for people living with MS. Our information is available online and in print, and we offer a telephone and email enquiry service to anyone who needs to know more about MS. Our materials are widely used by MS services across the UK.

We receive no government funding so we rely on donations to fund our vital services.

To find out more about our work, how we can help you and how you can get involved

Visit www.mstrust.org.uk

Call 01462 476700

Or email info@mstrust.org.uk



Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T. 01462 476700
T. 0800 032 3839
E. info@mstrust.org.uk
www.mstrust.org.uk

Registered charity no. 1088353

