



MS treatment in England: is access still a lottery?



Foreword

So much has changed in the past three years. More disease modifying therapies (DMTs) for relapsing forms of MS are available than ever before. Public policy and guidance about how to treat and manage MS have been substantially revised. And, crucially, we now know that starting treatment with a DMT close to diagnosis improves long-term outcomes for people with MS.



We conducted the first My MS My Needs survey in 2013. The results, which were published in our 'A lottery of treatment and care: MS services in the UK' report revealed shocking disparities in the services offered from one part of the country to another. Since then, the National Institute for Health and Care Excellence (NICE) has adopted several of the report's recommendations in its clinical guidance, including that people with MS should be offered a comprehensive review of their treatment and care that draws on expertise of the wider health and care professional team. So the question remains – is access to treatment and care still a lottery?

This year we undertook a second survey to find out. The results give us reason for both celebration and concern. I am extremely pleased to see that access to DMTs in the UK among those who could benefit has increased from 40% in 2013 to 56% in 2016. This is real progress. These treatments have been proven to be cost effective and improve health outcomes. As more treatments become available, we need to maintain and continue to improve access to these vital treatments.

Worryingly, there remains a minority who are missing out on treatments that could help them. As many as one in ten with relapsing MS haven't seen an MS nurse or neurologist for over a year. Among this

group, just 12% are taking a DMT, compared to 73% of those who saw both specialists within the last year.

People diagnosed with MS more than ten years ago are less likely to see an MS nurse when they need to compared with people diagnosed more recently. And access to DMTs is variable across England.

Personalisation of care and support is a key focus of health policy, yet the hallmarks of personalised health and care are lacking. Just 12% of people with MS have been offered a care plan or care plan review, and 17% believe their health and care professionals do not work well together at all.

These findings chime with recommendations from the Public Accounts Committee (PAC) for improving neurology services. The PAC's report makes it clear that services for people with neurological conditions such as MS are not consistently good enough.

So, the lottery continues, but is evolving. And more change is to come over the next three years. More medicines are expected to become available. Clinical Commissioning Groups (CCGs) may be required to take on more responsibility for a range of specialised services, including DMTs. The Neurosciences Clinical Reference Group is scheduled to develop a new service specification for neurological conditions, which should clarify commissioning responsibilities.

As these changes take hold, we must not allow the lottery of treatment and care to prevail. If we want the UK to be a place where people with MS are in control of their health and care, and live full, independent lives, I urge decision makers at a local and national level to act on this report's recommendations.

Michelle Mitchell
Chief Executive, MS Society

About MS

Over 100,000 of us in the UK have MS. It's unpredictable, and different for everyone.

It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel. But it doesn't have to be this way. We're driving research into more – and better – treatments. For everyone.

Together, we are strong enough to stop MS.

Strength in numbers

We conducted a survey of 11,024 people across the UK with MS between February and April 2016, making this the largest collection of patient-reported data from the UK MS community to date.

The initial survey was run in 2013. Together, the results of the My MS My Needs surveys provide an opportunity to understand in detail how people with MS feel about their treatment, care and support.

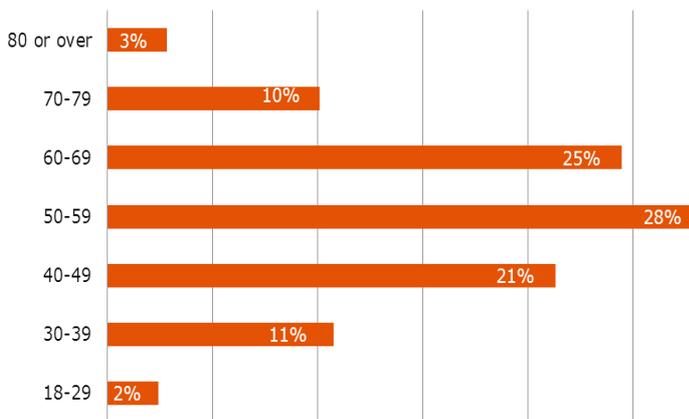
In 2016, 75% of respondents completed a paper-based survey, sent out to MS Society members, and 25% completed the survey through an email link, via the MS Register and Shift MS. Because of age and gender bias in our sample, the data has been weighted to be representative of the UK MS population.

There are an estimated 89,000 people living with MS in England.ⁱ The data presented in this report is from the 9,008 respondents who live in England.



3/4 of respondents were women

Figure 1: Age of respondents



75% of respondents were women, 25% men. The majority were aged between 50-59, and 66% were diagnosed more than 10 years ago. 44% of respondents had relapsing remitting MS.

This report focuses on the treatment, health and care aspects of the survey. Many of the figures cited are the proportion of people with a given need who said that this need was met, that is the

number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

Key findings

- ▶ In England, 56% of those who could potentially benefit from taking a DMT are doing so (an increase from 40% in 2013).
- ▶ Only a small number of respondents in England are taking symptom management treatments specifically licensed for MS. 2% are taking Sativex and 1% Fampyra. Botox's use as an SMT is higher (6%).
- ▶ Access to health professionals and the right information are key to access to a DMT – 81% of people who have access to MS specialists and the right information are taking a DMT. Just 10% of people who could benefit from these treatments but did not access any of these services are taking one.
- ▶ 86% of respondents had their need for access to a neurologist met (increase from 83% in 2013).
- ▶ 83% of respondents had not been offered a care plan or a care plan review for their health care.
- ▶ 17% of survey respondents answered "not at all" when asked if they felt that the professionals who help plan their care worked well together.
- ▶ The most common key contact for health care and support in relation to MS was a specialist nurse (45%). One in five identified their GP as their key contact for health care and support in relation to their MS.
- ▶ A quarter of respondents (26%) required support to remain physically active in the past 12 months but had not received any.
- ▶ One in five of respondents required emotional support but had not received this.

Treat Me Right

Our number one goal is to ensure people with MS have access to effective treatments. The MS Society believes that every person with MS should have access to the right treatment at the right time, no matter where they live.

Access to disease modifying therapies

In recent years, several new disease modifying therapies (DMTs) for MS have become available on the NHS. There are now 11 licensed DMTs for people with relapsing forms of MS. They can decrease the number and severity of relapses and slow the progression of disability. Added to this, there is now consensus among the MS and clinical community that early treatment with a DMT can improve long-term outcomes.ⁱⁱ

All figures related to DMTs are calculated among those who could benefit from these treatments (that is, those with relapsing remitting MS or secondary progressive with relapses).

Further treatments for MS are in development with some being considered for licensing and appraisal. It's possible there will be more DMTs available on the NHS from 2017 onwards.

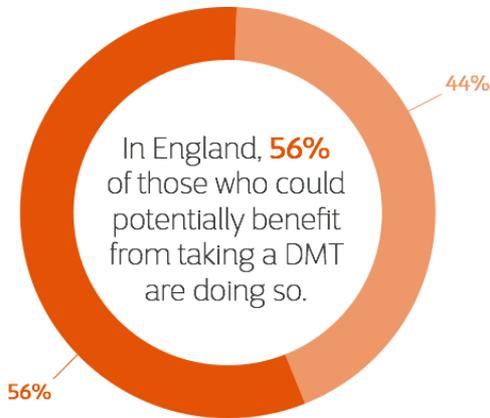
Daclizumab, for relapsing forms of MS, is being appraised for availability on the NHS. Two new treatments for primary progressive MS – biotin and ocrelizumab – are also being considered for appraisals by the National Institute for Health and Care Excellence (NICE). Were these treatments successfully appraised, they would be the first DMTs for people with progressive forms of MS available on the NHS.ⁱⁱⁱ

As well as these new DMTs, NICE are also reappraising beta interferons and glatiramer acetate. These were the first DMTs made available for treating MS, and have been available through the Risk Sharing Scheme since 2002. The scheme was set up to assess the long-term effectiveness of these treatments, with results so far indicating that they reduce disability progression and are cost effective for the NHS.

With an increasing number of treatments available, it's even more important that people with MS are able to talk to an MS specialist about their options as soon as is appropriate after diagnosis. This is now agreed best practice – NICE recommend that, at the time of diagnosis, people with MS are offered written and oral information on a range of topics, including DMTs.^{iv} The Association of British Neurologists recommend that decisions about treatment should be jointly taken by the person with MS and their neurologist, with treatment starting as early as possible.^v

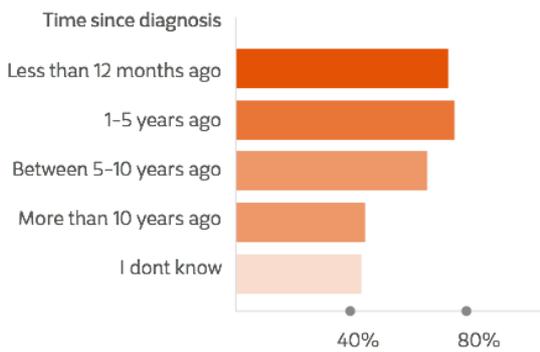
In England, 56% of those who could potentially benefit^{vi} from taking a DMT are doing so. This has increased significantly since our last survey in 2013 (40%). This is likely to be linked to the newer treatments that have become available on the NHS, which are judged to be effective and easier to take.

Figure 2: Access to DMTs in England



People diagnosed recently are more likely to be taking a DMT than those who were diagnosed some years ago – 74% of those diagnosed within the past 12 months who could benefit from taking a DMT are taking one, compared with only 44% diagnosed more than 10 years ago.

Figure 3: Access to DMTs by time since diagnosis



There are several drivers that make it more likely that a person will be taking a DMT. Access to health professionals and the right information are key – 81% of people who have access to a neurologist, MS nurse and the right information are taking one. Just 10% of people who did not access any of these services are taking a DMT.

Increasing and evolving treatment options, each with different support and infrastructure requirements, have a profound effect on service models and delivery. This paints a complex, challenging picture when considered in light of the financial constraints of the NHS and professional caseloads already exceeding their optimum levels.^{vii}

There are, of course, many examples of excellent MS treatment, care and support throughout the UK and beyond – we must learn from these and spread good practice if we are to meet these challenges.

Access to symptom management therapies

There are several symptom management therapies (SMTs) specifically licensed to treat MS, which can make a significant difference to the day-to-day lives of some people with MS. They can help with problems such as spasticity and walking or an overactive bladder. Licensed SMTs for MS include Sativex, Fampyra and Botox. Botox

received a positive recommendation in the 2014 NICE guidelines for MS, whereas Sativex and Fampyra both received negative recommendations.

Only a small number of respondents in England are receiving Sativex (2%) and Fampyra (1%). This reflects the difficulty many people have in trying to obtain these SMTs through the NHS, due to the 2014 NICE guideline. Botox's use as an SMT was higher (6%). This is probably because Botox received a positive recommendation in the NICE guidelines. We believe that all licensed MS treatments should be made available through the NHS.

Recommendations

- ▶ Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
- ▶ All licensed treatments for MS should be made available on the NHS in England.

Access to the right support

People with MS require access to professionals from all parts of the health and social care systems to best manage their condition. We believe that people with MS should have timely access to professionals and be at the centre of decision-making about their care.

Published earlier in 2016, the NICE Quality Standard for MS recommends that people with MS have access to care from a multidisciplinary team with expertise in MS, and access to a comprehensive review of their treatment and care annually.^{viii} This team should consist of a range of professionals including neurologists, MS specialist nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dietitians, social care, continence specialists and GPs.

Respondents to our survey were asked to indicate their need for and access to support from various professionals over the past 12 months.

MS nurses

MS specialist nurses play a crucial role in the care and support of people with MS. Their role and responsibilities can be wide-ranging and varied. Typically, these include providing information and support on how to best manage MS and on DMTs, initiating and monitoring treatment for people with relapsing forms of MS, providing psychological support and co-ordinating care. People with MS regularly cite their MS nurse as their key contact for treatment, care and support.

86% of people who needed to see an MS nurse were able to in the past 12 months. Just over one in 10 (11%) had not seen a specialist nurse but felt they had needed to. This is particularly concerning - it is vital that the system has capacity to respond effectively to the needs of people living with MS.

Overwhelmingly people saw MS nurses in a specialist clinic in a hospital setting (72%). A smaller number saw a nurse in a community setting (13%). With the stated policy intention of NHS England (NHS) being to move more services into the community, discussed in more detail on page 12, there is much for those who commission and provide services for people with MS to consider.

Our survey data shows that the more recently a person with MS was diagnosed, the more likely they are to have seen a specialist nurse in the past 12 months – those diagnosed within the past 12 months are the most likely to have seen a specialist nurse (89%), compared with 62% of those diagnosed 10 years ago or more.

In view of the traditional role MS specialist nurses play in initiating and monitoring treatment with DMTs, it is not surprising that access to specialist nurses and whether someone is on a DMT follow a broadly similar trend. People with more recent diagnoses are more likely to have seen a nurse or be on a DMT than those diagnosed some years ago.

Neurologists

NICE recommend that everyone with MS should be offered a comprehensive review of their care at least once a year.^{ix} This review can be led by a neurologist but should draw on expertise from professionals across a multidisciplinary team. It should be tailored to the needs of the person with MS and cover symptoms, the disease course, general health, social activity, care needs and carers.^x If a person is on a treatment, a comprehensive review could also be used to assess how that is working, typically including an MRI scan.^{xi}

Just under two-thirds of respondents had seen a neurologist in the past 12 months (64%). A quarter (25%) had not, but felt they did not need to. One in 10 (10%) had not seen a neurologist but felt they needed to.

That one in 10 people with MS are not able to see a neurologist when they need to is much the same as the figure for MS specialist nurses. This may be an indication of a limited number of neurologists practicing in parts of England and the resulting service pressures.

There is no short-term fix to boost the numbers of neurologists in the system. But, given service and resource pressures across the whole NHS, there is a need to consider the skill mix across the wider multidisciplinary team. If other professionals can support people with MS, this could free up some capacity for both neurologists and MS nurses.

Professionals across the team

Survey respondents were asked about their access to other types of support – physiotherapists, support to remain physically active, continence professionals, and emotional support. Building capacity across a multidisciplinary team is also a way of ensuring that people with MS can access the support they need.

Continence advice and support

Many people with MS experience bladder and urinary problems, including incontinence and infections. Continence advisers can provide people with MS with information, for example about products and treatments for bladder problems, and confidential advice.

In England, 73% of respondents to our survey who had required specialist continence advice had received it. However, more than one in 10 felt they required this support but did not receive it.

MS treatments in England: is access still a lottery?

In 2013-14, there were 23,665 non-elective hospital admissions for people living with MS in England, costing the NHS £43 million. Urinary tract infections accounted for 14% of emergency admissions.^{xii}

A 2015 report by NHIS Commissioning Excellence and the MS Trust notes that a greater focus on anticipatory care, identifying at-risk patients and addressing issues before crisis point, could prevent many costly admissions and improve quality of life for many people living with MS.^{xiii} Therefore it is both important for people with MS to receive specialist support when they need it, and potentially cost effective to provide such support to prevent emergency admissions further down the line.



23,665

non-elective hospital admissions cost the NHS

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Physical wellbeing

Services that support people with MS to remain physically active help people remain healthy and independent in their day-to-day lives. Research suggests that support to remain physically active has also resulted in a decrease in GP and hospital consultant visits and reduced hospital bed days for people with MS.^{xiv}

A quarter of respondents (26%) required support to remain physically active in the past 12 months but had not received any. For those who did receive support, the sources of this support varied – 8% of all respondents received support from the NHS, 2% from their local council, 11% from a charity or voluntary organisation and 10% from somewhere else. This suggests that statutory services could do more to support people with MS to remain physically active.

 in the last 12 months
1/4 of respondents



required support to remain physically active

...but had not received any

Sources of support from a physiotherapist also varied, with the largest number of people receiving support from the NHS (31% of respondents). 7% received physiotherapy through private health care, another 7% through a charity or voluntary organisation and 1% through another source. 39% had not seen a physiotherapist in the past 12 months but indicated they did not need to. 17% had not seen a physiotherapist and felt they had needed to. As with support to remain physically active, this suggests a significant unmet need for people with MS.

Emotional support

Half of people with MS experience anxiety and half experience depression, with many experiencing both.^{xv} Moreover, there is a strong link between mental and physical health – in 2012, £1 in every £8 spent on long-term conditions was linked to poor mental health.^{xvi} Ensuring people living with MS can access emotional support is vital.

As with support to remain physically active and physiotherapy, people with MS received emotional support from various sources, with 17% of respondents receiving it from the NHS. 3% received support from a charity or voluntary sector organisation, 2% through a private organisation and 3% from somewhere else. While 54% indicated that they had not accessed emotional support and felt they did not need to, one in five (20%) had not accessed support and felt they needed to. In view of the strong links between mental and physical health, it is important that people with MS are able to access such services when they need them.

Enabling comprehensive care pathways

Outpatient figures from the Neurology Intelligence Network show that access to neurology services tends to vary significantly depending on geographical location, with a concentration of services around 27 specialist centres.^{xvii} This can mean that required services are not available locally, resulting in people travelling long distances for treatment, which can be difficult for people with a neurological condition, or not receiving treatment at all.

The current service specification for neurological services is too defined by where care is provided, in particular those specialist centres, rather than who should provide it or what care is being provided. This has led to confusion around commissioning responsibilities for MS. Any new definition of specialised services should result in a designation of services that is clear and easily interpreted by commissioners across the whole pathway. This, in turn, would allow for specialised commissioning to be placed within an integrated process of commissioning.

We expect that NHS England's new Strategic Framework for Specialised Services will clarify commissioning responsibilities for neurological conditions such as MS. It could also be the start of a process to integrate care pathways for people with MS – ensuring they can access the specialist support they need and other kinds of care closer to home. This strategic shift will mean that local commissioners will have increased responsibility for commissioning elements of MS care. Added to the services they are already responsible for at a local level, they will have the opportunity to consider the whole MS care pathway and how best to integrate services around those who require them.

Recommendations

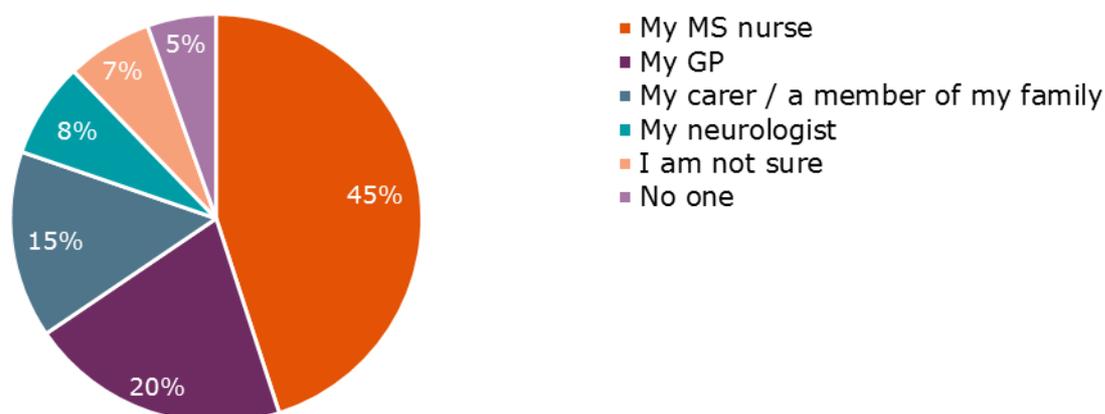
- ▶ People with MS should be offered a comprehensive review of their care at least once a year that draws on expertise from a multidisciplinary team.
- ▶ People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
- ▶ People with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.
- ▶ A revised Neurosciences Service Specification should be developed and clearly set out commissioning responsibilities for MS care and treatment.
- ▶ NHS England's Strategic Framework for Specialised Services should clarify Clinical Commissioning Group and NHS England commissioning responsibilities for MS.

Care planning

Care planning and care coordination has a vital role to play in ensuring that people with MS can access the full suite of support they require to best manage their condition. NICE's Quality Standard for MS states that people with MS should have a single point of contact who then co-ordinates access to care across a multidisciplinary team.

For our respondents, the most common key contact for health care and support in relation to MS was a specialist nurse (45%), perhaps unsurprisingly given the typical functions of their role, followed by a GP (20%).

Figure 4: Key contact for health care and support



People who listed their primary contact as a specialist nurse are most likely to feel they had their information needs met. This demonstrates the critical role that specialist nurses can play in helping people with MS make decisions about their care and treatment.

Worryingly, 5% of people said that no one currently co-ordinates their care, while 15% said it was a carer or member of their family – in this case, the degree to which that carer or family member has support from NHS professionals is unknown. NHS commissioners should consider whether bespoke care coordination roles in their areas would allow more people with MS to have a key contact to help coordinate their care, while also relieving administrative pressures from specialist nurses.

Respondents were also asked whether they felt the professionals who helped plan their care worked well together. The most common response was "to some extent" (36%), while 17% responded "not at all". 13% responded "completely".

NHS England's Five Year Forward View acknowledges that caring for people with long-term conditions, such as MS, requires a partnership approach involving people in their care as opposed to providing single, unconnected 'episodes' of care. Personalised care and support planning is subsequently designed to help support people to gain greater control over their own care. This is part of a movement from a reactive service,

responding when problems arise, to a proactive service centred on the needs of the individual.^{xviii}

Despite this desire at a national level for personalised care and support, our survey found that, overwhelmingly, people living with MS in England had not been offered a care plan or care plan review in the past 12 months (83%). Only 7% of respondents had been offered a care plan and 5% a review of their care plan.

Personal Health Budgets (PHBs) are an initiative designed to help empower people to shape and manage their own care. Under PHBs, an individual is expected to agree their health and wellbeing priorities with NHS staff through a care plan and is then allocated an amount of money which can be spent on services or items designed to meet these needs. In its Mandate to the NHS, the Government set out its ambition to extend access to PHBs and integrated personal budgets to at least 50-100,000 people by 2020.^{xix}

PHBs are, however, just one element of personalised care – it is critical that people with MS are offered a care plan and supported to take control of their treatment, care and support within a multidisciplinary team.

Recommendations

- ▶ People with MS should be offered a care plan or care plan review – this presents a key opportunity to involve people in their care.
- ▶ People with MS should have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.

Recommendations

These results reinforce the need for concerted action to make sure that people with MS are able to access the right treatment at the right time, no matter who they are or where they live.

We ask that decision-makers take heed of our recommendations and work with the MS community to make them a reality:

1. Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis within six weeks and again within six months.
2. All licensed treatments for MS should be made available on the NHS in England.
3. People with MS should be offered a comprehensive review of their care at least once a year that draws on expertise across a multidisciplinary team.
4. People with MS should be offered information and support at diagnosis to understand their condition and how it can be best managed. Their information and support needs should be reviewed regularly.
5. People with MS should be offered support from a multidisciplinary team, including emotional support, continence advice and support to remain physically active.
6. A revised Neurosciences Service Specification should be developed and clearly set out commissioning responsibilities for MS care and treatment.
7. NHS England's Strategic Framework for Specialised Services should clarify Clinical Commissioning Group and NHS England commissioning responsibilities for MS.
8. People with MS should be offered a care plan or care plan review – this presents a key opportunity to involve people in their care.
9. People with MS should have a single point of contact for their care, who coordinates care across a wider multidisciplinary team.

Our commitment

We will use evidence and insight and work with others to support implementation of these recommendations by:

- ▶ Providing reliable information and support to enable people with MS to take control of their lives.
- ▶ Supporting people with MS to connect with other people with the condition.
- ▶ Funding the best, most relevant research to enable new treatments to reach people with MS as quickly as possible.
- ▶ Campaigning for fair and appropriate access to treatment, care and support for every person with MS.



References

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We're the MS Society.

Our community is here for you through the highs, lows and everything in between.
We understand what life's like with MS.

Together, we are strong enough to stop MS.



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 **Let's stop MS together**
