

The Forgotten Many:

A 2020 Vision for Secondary Progressive Multiple Sclerosis

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The following organisations have endorsed this report:

- Multiple Sclerosis Academy
- Multiple Sclerosis Trust
- Shift.ms
- UK Multiple Sclerosis Specialist Nurse Association
- UK Clinical Pharmacy Association Neurosciences Pharmacy Group

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Foreword

The 'forgotten many' is how people with secondary progressive multiple sclerosis (SPMS) describe themselves. SPMS has a significant impact upon those with the disease, their families, the NHS and society overall.

The lack of efficacy of many of the licensed treatments for the relapsing forms of MS has left people with SPMS with the impression they have a second, different, untreatable disease. Telling someone they have SPMS is not too dissimilar to telling someone they have a terminal illness. For this reason many healthcare professionals steer away from having this awkward conversation. For those people on a Disease Modifying Therapy (DMT) for relapsing MS, disease progression conjures up fear that a diagnosis of SPMS will mean them having to stop their treatment.

A further issue is that many people with SPMS are discharged from regular neurological follow-up to local community-based services and their general practitioners to manage any problems. This is despite emerging evidence that aggressive management of MS-related comorbidities and lifestyle interventions can improve MS outcomes. So many people with progressive MS are smouldering away in the community thinking they have an untreatable, but relentlessly progressive disease. This report challenges this assumption and makes the case for actively managing and treating people with SPMS. However, to do this there is an urgent need to expand MS services and to develop new MS centres to accommodate these forgotten patients.

The emergence of treatments to treat and modify the course of progressive MS will require a retooling of MS centres; an increase in MS neurologists and specialist nurses, more dedicated MRI time for monitoring patients and additional ancillary services to address the massive unmet need associated with patients who have greater disabilities and associated comorbidities.

This report touches on the many facets of managing SPMS and the forgotten many and how we need to find them and offer them a holistic service to improve their quality of life, improve their neurological outcomes and at the same time reduce unnecessary and preventable utilisation of healthcare services. This report is a call to arms for parliamentarians, policy makers, NHS Providers, commissioners as well as the MS community to think differently, work differently and to now reconnect with the forgotten many. No patient with secondary progressive MS should be left behind.



Professor Gavin Giovannoni

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Executive summary

Secondary progressive multiple sclerosis (SPMS) is a type of multiple sclerosis (MS) that the vast majority (about two in three) of those with a relapsing form of the condition will go on to develop. SPMS has a significant impact on those with the condition, which causes irreversible disability, cognitive decline, bladder dysfunction and considerably impaired mobility, among a range of other symptoms.

While there are management options to help people with SPMS deal with individual symptoms, there have historically been no available treatments to slow progression of the disease itself. There has also been a corresponding lack of focus on SPMS services across the NHS for a variety of reasons. This has led to considerable challenges in support for people with SPMS in general, as well as managing the transition from relapsing remitting forms of MS to the secondary progressive forms of the condition. Alongside this, there are limited data available on the impact of SPMS, compared to MS within the wider population.

This report has been developed in consultation with a group of MS experts who have provided insight into how services are managing people with SPMS. While good practice like the advanced MS champions programme is emerging, there is plenty of room for improvement and an urgency to prioritise and provide a greater focus and better support for people with SPMS.

A significant part of this document has, for the first time, made available prevalence data on the potential numbers of people living with SPMS in every clinical commissioning group (CCG) and health board across the UK. By using this information health economies could ensure improvements in care.

The expert panel agreed the most **urgent concerns** agreed for SPMS are:

- **Find the ‘forgotten many’**
Understand the scale of the SPMS population and use a population management approach to address quality and value.
- **Develop guidance for SPMS diagnosis**
Explicit guidance for SPMS would aid prompter diagnosis and help integrate psychological support.
- **Establish an integrated care pathway for all patients**
A national agreed SPMS integrated care pathway should be developed in consultation with patients and a wide range of professionals.
- **Use data better to understand patient need**
To undertake the urgent concerns above and address other priorities we must use data to better understand patient need.

The expert group also highlighted these **major priorities**:

- **Communication to people with MS**
Care must be centred on positive communication with patients and access to the right psychological support.
- **Workforce capacity and professional practice**
Services urgently need to understand and address capacity issues to ensure people with SPMS receive care and the professionals involved receive specific training to manage patients.
- **Establish care planning and annual reviews**
Ensure all patients access care planning and an annual review. In order to do this, exactly what constitutes a care plan must be clearly defined.
- **Focus on outcomes**
Agree on the outcomes that services for people with SPMS should focus on.
- **Clinical audit to highlight variations in care**
Clinical audit of services is essential at a national level to identify and address variations in care.

We want to make our vision a reality for everyone with SPMS in the UK. This report details the action improvement priorities our expert panel have identified. These need to be addressed by governments, policy makers, the NHS, healthcare professionals as well as people with MS themselves. We know that the problems facing MS services are acute and achieving our vision will not be easy. But the vision set out in this report is a cause for great optimism. By starting this conversation and setting out the case, we believe that we can lead the way to better and more effective care for people with SPMS.

Who needs to act on recommendations?

Urgent concerns

Find the ‘forgotten many’

- **NHS England** to lead an appropriate and targeted awareness campaign to increase understanding and awareness of SPMS.
- **Commissioners** responsible for neurology services populations to focus on system improvement opportunities which includes SPMS population identification and segmentation. Services need to be based on symptoms, function and need.
- **Specialist MS services** to work with their **neurology commissioners** to highlight their unseen numbers of people with SPMS.
- **MS charities** and stakeholder groups to be supported to engage with Local Healthwatch and Health and Wellbeing Boards to influence services locally.

Develop explicit guidance for SPMS diagnosis

- **Professional bodies, specialist professionals** and lay people to develop explicit guidance for SPMS, building on existing good practice.¹

Establish an integrated care pathway for people with SPMS

- **The National Neuro Advisory Group (NNAG)** to spearhead and coordinate a national programme which will agree and develop a template integrated care pathway to improve quality of care and patient outcomes in neurology patients including SPMS.
- **MS services, sustainability and transformation partnerships (STPs)** and **integrated care services (ICSSs)** to ensure annual reviews of integrated care plans for people with SPMS.

Use data to better understand patient need

- **The Neurology Intelligence Collaborative (NIC)** as part of the NNAG to work with Public Health England and NHS Trusts to ensure subtypes of MS are coded as part of Secondary Users Service (SUS) data so that more meaningful data can be established for Hospital Episode Statistics (HES) data.
- **MS teams** to record MS patient subtypes (RRMS, PPMS SPMS) as appropriate to ensure more accurate HES data reporting.
- **Commissioners** to make sure local health systems use granular HES data to focus on opportunities which have the potential to provide the greatest improvements for people with SPMS.
- **Commissioners** to work with **RightCare Delivery Partners** to address local care variations identified in the Progressive Neurological Conditions Focus Packs.²

Major priorities

Communication to people with MS

- **Healthcare professionals** to ensure that key conversations around MS progression are discussed so that people are more aware that their condition might progress ensuring less shock when they are told they have SPMS.
- **Commissioners** should ensure mental health service arrangements for neurological patients are clarified.
- **STPs** and **ICs** should consider the opportunities presented by integrated models of care and budgets for mental health and SPMS.
- Neurology health professionals' training should ensure they are equipped and confident in screening people's mental, cognitive and emotional health needs. The **MS Academy** should look towards provision of appropriate courses to equip this workforce.
- **MS charities** to work with clinical teams to support greater involvement of people with SPMS in their own care.

Workforce capacity and professional practice

- **NHS England** and **NHS Improvement** to commit to a National Neurology Plan which sets out how the workforce can deliver equitable services for people with neurological conditions including SPMS.
- **MS service managers** to address capacity issues and make greater use of the clinical expertise of MS specialists, nurses and allied health professionals in managing SPMS by establishing more diverse teams including sufficient administrative support.
- **MS Academy** to provide specialist MS training courses to support the new generation of MSologists for the future.

Ensure each person with SPMS has a care plan and annual review

- **Neurological Alliance** and **NNAG** to define and publish what constitutes a neurology care plan and produce a template plan for use in SPMS and other neurological conditions.
- **GPs, community teams** and **specialist MS services** to ensure each person with SPMS has a care plan and annual review.

Focus on outcomes

- **MS clinical leaders** and the **Healthcare Quality Improvement Partnership (HQIP)** should meet and debate which SPMS outcome priorities should be a focus for local health systems.
- **Commissioners** should identify how they will implement MS condition-specific improvement priorities for SPMS in the RightCare Progressive Neurological Conditions Toolkit² and RightCare Community Rehabilitation Toolkit³.
- The **MS charities** and the **National Institute for Health Research (NIHR)** should work together to undertake new research into solutions for managing impairment and disability with relevance to SPMS.

Clinical audit to highlight variations in care

- **Clinical leaders** in partnership with the **MS charities** and **HQIP** should work together to audit and evaluate the outcome of MS services so that services for people with SPMS can be planned and delivered more effectively.

Chapter 1. Multiple sclerosis in context

The aim of this report is to increase awareness of the significant impact of SPMS in society today. It will identify, through quantitative and qualitative data, the impact of SPMS on patients, the NHS and wider society, and create an understanding of the issues that can support engagement with policy makers and stakeholders to help improve outcomes for people with SPMS.

Multiple sclerosis (MS) is a lifelong neurological condition affecting the central nervous system. The condition affects everyone differently with a wide range of possible symptoms, such as bladder and bowel problems, fatigue, pain and difficulties with walking, balance and coordination. Usually, some level of permanent disability develops.

Secondary progressive MS is a degenerative neurological condition that just under 75,000 people in the UK have or will go onto have.* People with SPMS become increasingly disabled over time and, with new treatments on the horizon, it is important that they are diagnosed as early as possible. Despite their wide range of health and care needs, there is a persistent lack of support for people with SPMS.

There are three main types of MS:⁴

- Relapsing remitting**
Relapsing remitting MS (RRMS) follows distinct attacks of symptoms, followed by recovery, either fully or partially.
- Primary progressive**
Primary progressive MS (PPMS) develops over time, with no periods of recovery from symptoms, and there is a gradual build-up of disability.
- Secondary progressive**
RRMS frequently becomes secondary progressive MS (SPMS), with the gradual build-up of disability.

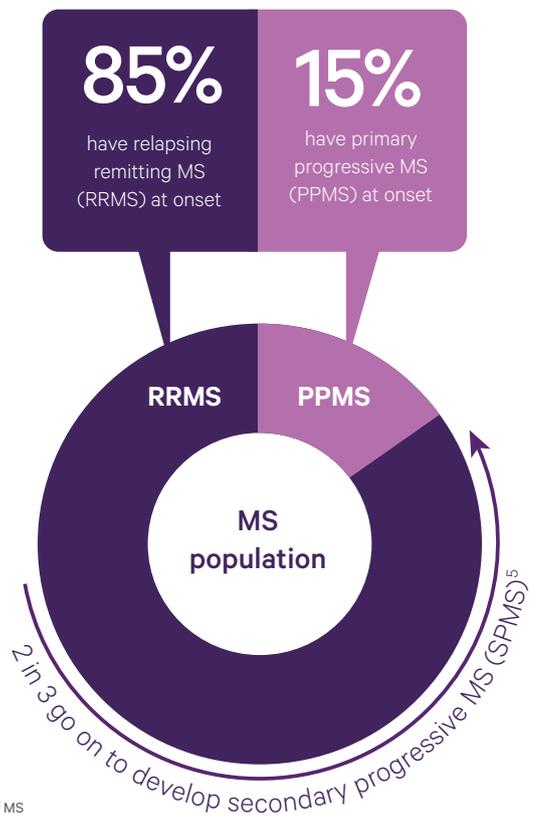


Figure 1
Types of MS

*Prevalence estimate based on THIN dataset and ONS population estimates; see Figure 9.

Secondary progressive MS

People with RRMS often go on to develop a progressive form of the condition – SPMS. Here the severity and frequency of relapses decreases or even stops altogether, but the level of permanent disability increases over time, moving from worsening in RRMS to being with progression in SPMS as depicted in Figure 2. This can be explained because there are two underlying processes:

- Inflammation around nerves which is associated with the RRMS pattern
- Destruction of nerve fibres, which is associated with progression.

2 in 3 people diagnosed with relapsing-remitting MS go on to develop secondary progressive MS⁵

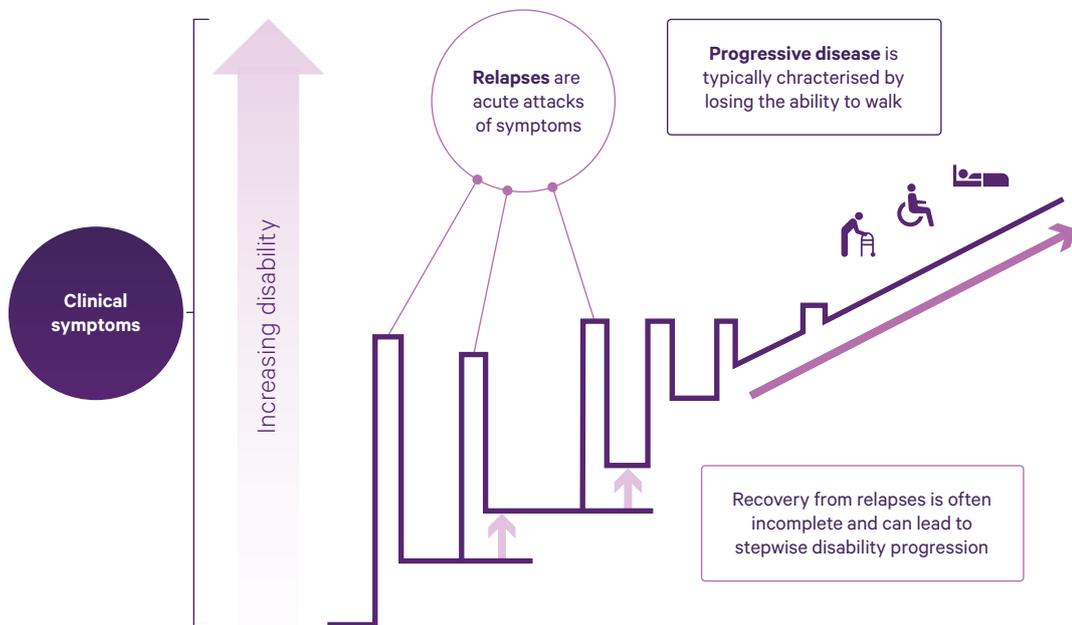


Figure 2
Disease course of SPMS

Source:
Adapted from
Giovannoni G
et al. (2015)
Brain Health:
Time matters
in multiple
sclerosis.

Identifying when MS has changed from a relapsing remitting to a progressive course of the condition is not straightforward because the change is not sudden but, typically, a gradual process where relapsing and progressive patterns overlap. Figure 3 illustrates the transition⁶. A small number of people may be diagnosed with SPMS from the very beginning. These, with hindsight, could have experienced relapses in the past but they may have been mild or their significance missed. Alternatively, there may have been lesions (small patches of damage caused by MS) in areas of the brain or spinal cord that did not give rise to any symptoms.

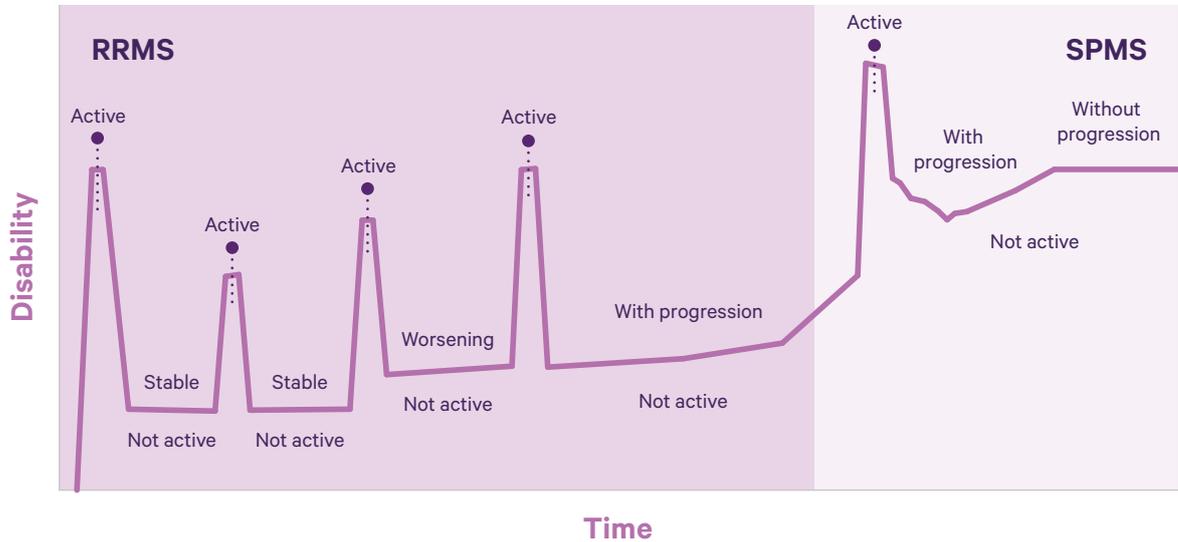


Figure 3
Transition
from RRMS
to SPMS

Source:
Adapted
from MS
Trust (2018)
Secondary
progressive
multiple
sclerosis.

There is no specific test to identify that an individual's MS is now SPMS. The diagnosis is made by looking back at changes across the continuum of the condition and the neurologist must decide if a sustained increase in disability has occurred and if this is due to the MS and not to other factors.

People with SPMS may have an occasional relapse but, generally speaking, relapses do not happen in SPMS. Although disability increases, the rate at which this happens varies from one person to another, and there may be times of improvement and times when symptoms stay the same. There is often a reluctance to speak about progression; however, this is a significant time as much can be done to help individuals stay independent, manage symptoms and improve wellbeing, and it is vital that the MS multidisciplinary team is involved in reassessment at the transition time.

Who is affected?

MS can affect anyone, although more women than men are affected, and globally it is more prevalent in higher income countries and those further away from the equator⁷. While it is possible to be diagnosed at any age, relapsing remitting MS is typically diagnosed between the ages of 20 and 40 years and primary progressive MS (PPMS) is more often diagnosed between the ages of 30 and 50⁸. The cause of MS is unknown, but a combination of genetic and environmental factors is thought to play a role⁹. A number of disease-modifying therapies (DMTs) are available for RRMS; whilst they are not a cure, they can reduce the number and severity of relapses and slow down the damage that RRMS builds up over time¹⁰. There is DMT available for the treatment of early PPMS and, in November 2019, the European Medicines Agency (EMA) also recommended a treatment for active SPMS¹¹. Until this time there have been no treatments available other than treatments for individual symptoms in SPMS; however, new treatments for SPMS are on the horizon in the UK¹⁰.

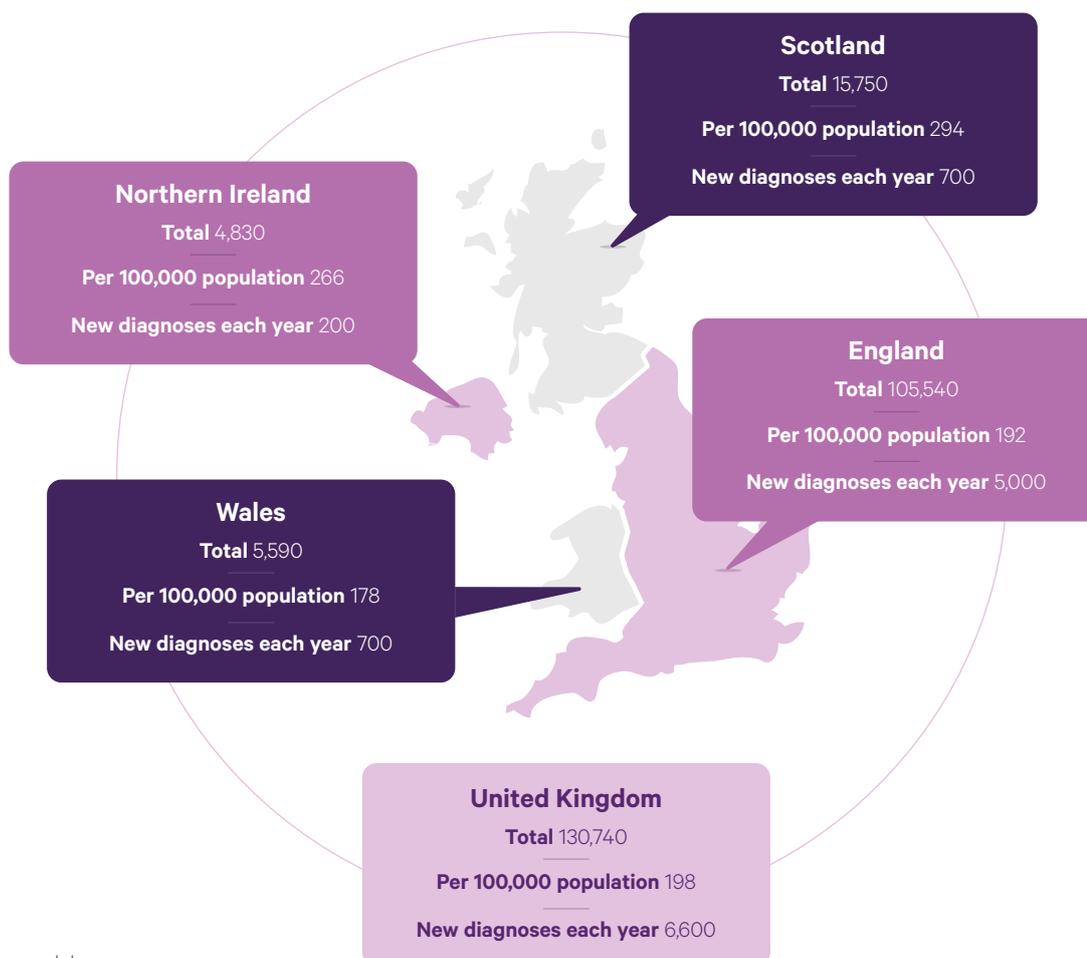
Prevalence

The prevalence of MS in the UK has been the subject of significant debate over many years. Since 2014, the prevalence used was provided by a study by Mackenzie et al (2014)¹². New estimates in 2019 use a primary care database called The Health Improvement Network (THIN)^{13, 14}. The THIN database is a system used by GPs to record patient information. The number of people with MS within the THIN dataset was applied to the total national population¹⁵ to estimate the number of people with MS in the general population and the number of new cases each year.

Figure 4 provides country-specific numbers of people with MS, which overall estimates show to be 130,740 UK wide, with an incidence of 198 per 100,000. This means that one in every 500 people is living with MS and almost 7,000 people are newly diagnosed each year in the UK. Scotland has the highest prevalence rate in the UK with 294 people living with MS per 100,000.^{13, 15}

Figure 4
Number of people with MS*

Sources:
Lumicisi B et al (2019); ONS Mid-Year Population Estimates.



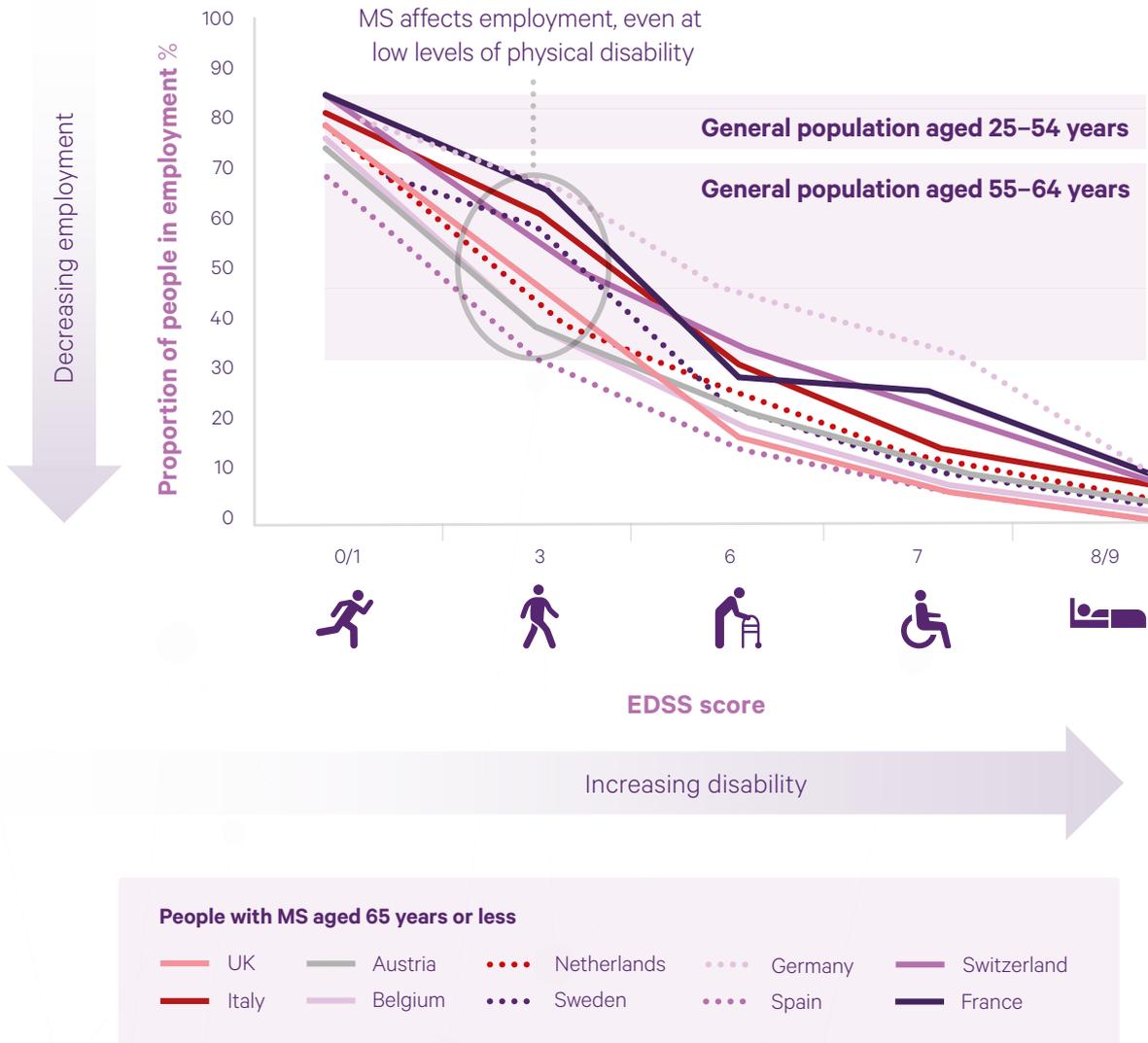
*Figures are rounded

Disability

It is important to diagnose the transition to SPMS promptly because people with SPMS who cannot access treatment accumulate a higher level of disability¹⁶. MS is the most common cause of disability in people of working age¹⁶ and reduced participation at work can start early in the disease (see Figure 5)¹⁷. With progression, problems such as fatigue, pain and cognitive issues will become an issue, as will participation in the general activities of daily life, such as employment¹⁶.

Figure 5
Effect of MS disability on employment

Source:
Giovannoni G et al. (2015) Brain Health: Time matters in multiple sclerosis.



MS affects employment significantly, even at low levels of physical disability on the Expanded Disability Status Scale (EDSS) rating scale¹⁶. Higher EDSS scores result in escalating informal care and a dramatic increase in indirect costs compared with medicine costs¹⁶.

An All-Party Parliamentary Group (APPG) on MS¹⁸ conducted a year-long review that examined the employment journeys of people with MS, including the experiences of individuals in employment, out of work and looking for work. While many of the obstacles identified relate to the progressive, unpredictable and neurological nature of MS, some

were found to be relevant to the employment situation of people with a range of other disabilities. The review found that on average, people with MS lose 19.4 working years (assumes average retirement at 65 years). People with RRMS are more likely to be in employment than people with PPMS or SPMS. People with SPMS are the least likely to be in employment; only 28% of people with SPMS are employed, compared to 69% of people with RRMS and 43% of people with PPMS.

Recommendations from the APPG were for improved provision of employment retention support, and to establish best practice for the transition out of employment for those who cannot work due to their health. This highlights that people with MS face significant challenges when it comes to employment, with those with SPMS the most highly affected.

Among other common symptoms experienced by people with MS (fatigue, pain, visual impairment, numbness, bladder and bowel problems, sensory symptoms, weakness, loss of balance, loss of mobility, spasticity and cognitive problems), depression was highlighted as being “of particular concern because depression affects psychosocial functioning and adherence to treatment”.

People with an EDSS score of 5 and above were reported to be most likely to leave work early, and also more likely to have depression.

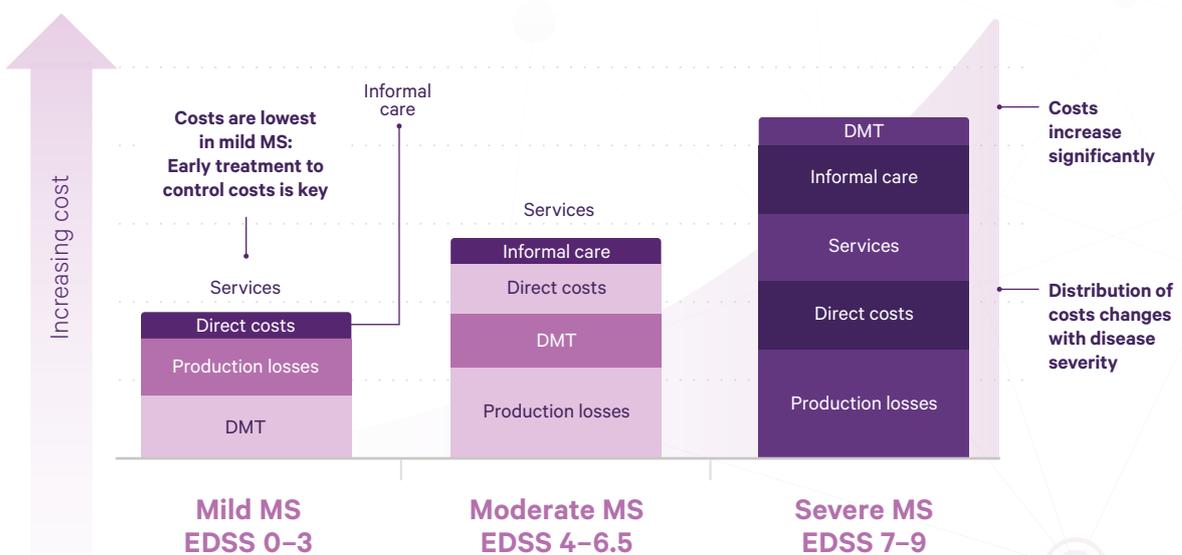
Economic burden

In terms of costs, the authors feel MS is one of the costliest neurological conditions due to its early onset, long duration and significant effects on work and daily activities. The annual mean cost of MS per patient in Europe was estimated as €22,800 for mild disease, €37,100 for moderate disease and €57,500 for severe disease¹⁹, which does not include welfare benefits. Mean annual costs in the UK were £11,400 for mild disease, £22,700 for moderate disease and £36,500 for severe disease²⁰.

Kobelt et al. (2017) highlight that costs and use of services for MS are highly correlated with disease severity, but resource consumption is also heavily influenced by healthcare systems organisation and availability of services¹⁹.

Figure 6
Relationship between MS disability and costs

Source:
Adapted from
Kobelt G et al.
(2017).



Figures 6 and 7 show how the mean total annual cost per patient by EDSS score escalates dramatically. As care costs rise with EDSS score, this is accompanied by a marked effect on the proportion of participants below retirement age in employment, which declined from 81.9% at EDSS 0 to 8.2% at EDSS 9, and amplifies the economic burden of advanced MS¹⁹.

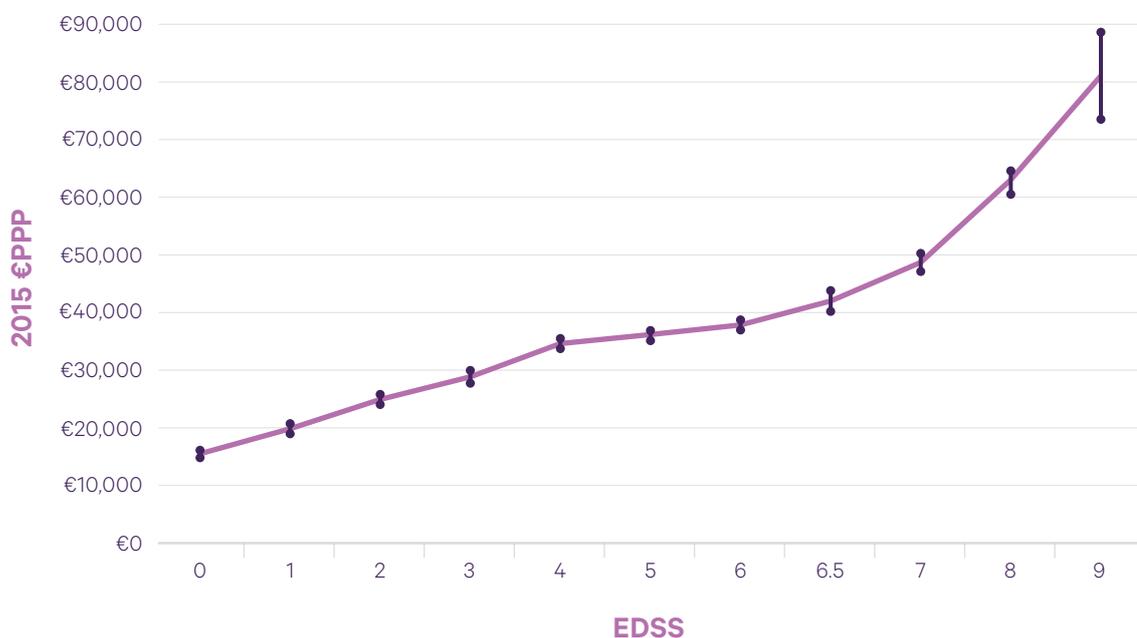


Figure 7
Mean total annual cost per patient by EDSS score

Source:
Kobelt, G et al. (2017).

Treatment options, care and support

In November 2019, the European Medicines Agency (EMA) also recommended a treatment for active SPMS¹¹. Until this time there have been no treatments available other than treatments for individual symptoms in SPMS. However, despite the large number of people who could benefit from these treatments, there is a persistent lack of support available to this patient group. Treatments that target common symptoms include:

- Drug treatments for spasticity and spasms, bladder and bowel problems, fatigue, pain and sensory symptoms, depression and mobility issues
- Therapies, such as physiotherapy or cognitive behavioural therapy
- Management techniques, e.g. to minimise fatigue
- Rehabilitation to achieve personal goals.

To access these treatment options, people with SPMS need to receive regular review appointments to monitor their symptoms and assess which treatments they could benefit from. It is therefore important that patients are actively reviewed and assessed at regular intervals.

For treatment to be effective, patients must also be provided with the appropriate support to manage their symptoms and other health issues that arise from or exacerbate their MS. Ideally, people with SPMS should receive a holistic approach to care, which considers all aspects of their health, and healthcare professionals should be equipped with a good understanding of SPMS and the ability to accurately identify MS patients with secondary progressive disease. Not all SPMS patients are given a diagnosis, which is a hurdle to receiving recommended treatment and support. Furthermore, staff need training about when to consider and initiate treatment for SPMS.

Chapter 2. The benefits of data

Although there is an abundance of data within the health service it is only in recent years it is being meaningfully used to address variations in healthcare provision. HES data contains around 1 billion records of patients who have been treated in hospital trusts in England. This includes inpatient, outpatient, A&E and critical care activity. The inpatient data splits out elective activity (planned care) and non-elective (non-planned care). All hospital activity is recorded but not always as accurately as it could be. Inpatient activity is recorded by ICD-10 code (International Classification of Diseases Version 10) and OPCS-4 (Office of Population Censuses & Surveys, classification of procedures and interventions version 4). Code and outpatient activity is recorded as either a first outpatient or follow up appointment.

HES data is a cleaned and audited version of SUS data. HES and SUS data start from the same source, the NHS trusts episode of care data; this is all consolidated in the SUS warehouse from Patient Administration Systems (PAS). Extracts from the SUS warehouse, the raw input data, form HES data. SUS data is only available to the NHS as it contains patient identifiable data and clinician sensitive data. This can be accessed daily by the trust. HES data is still available at patient record level but the identifiable fields have been pseudonymised.

ICD-10 codes are used to classify diseases and other health problems in secondary care. Patients can have both a primary and secondary diagnosis (up to 20). The primary diagnosis is the main condition treated or investigated during the relevant episode of healthcare (reason for admission does not constitute primary diagnosis). Secondary diagnoses are defined as conditions or complaints either coexisting with the primary diagnosis or arising during the episode of patient care. The provider will enter only the number of codes necessary to describe and manage the patient's condition. MS has the ICD10 code of G35.

It is essential that MS services and CCGs have a clear understanding of the local MS population for whom they are delivering services so that services can be planned to meet the differing needs of their MS patients, especially the complex needs of the SPMS population. Data can give a firm footing for a population management approach.

Since 2014 the prevalence used to estimate the numbers of people with MS was provided by a study by Mackenzie et al (2014)¹². New estimates in 2019¹³ use a primary care data base called The Health Improvement Network (THIN)¹⁴. The THIN database is a system used by GPs to record patient information. The number of people with MS within the THIN data set was applied to the whole nation population to estimate the number of people with MS in the general population and the number of new cases each year.

Figure 8 shows an example of prevalence estimates for a typical CCG in England, NHS Doncaster; it highlights the potential numbers of patients within each of the subtypes of MS. By comparing patients on active caseloads within this CCG, the MS team can establish if there are 'lost patients' who are not being seen.

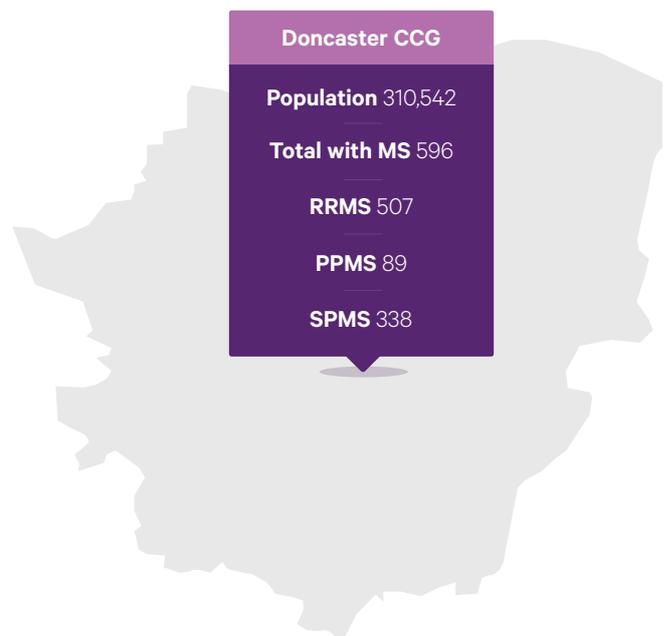


Figure 8
Example
CCG
prevalence
estimate

For the first time this report publishes by individual CCG and Health Board an estimation of the numbers of people living with MS including sub types of MS; RRMS, PPMS and SPMS.

Sources:
Lumicisi
B et al
(2019); ONS
Mid-Year
Population
Estimates.

Figure 9
Prevalence estimate of MS diagnoses

Sources:
Lumicisi B et al (2019); ONS Mid-Year Population Estimates.

Figure 9 shows the national prevalence estimates for MS diagnoses in the UK^{13, 15}. Services should not just be seeing patients on active treatment but also manage their total population of MS within a locality or MS network. Many individuals with progressive forms of MS may only be seen when a complication arises, so services should be planned to take this segment of the patient population into account.

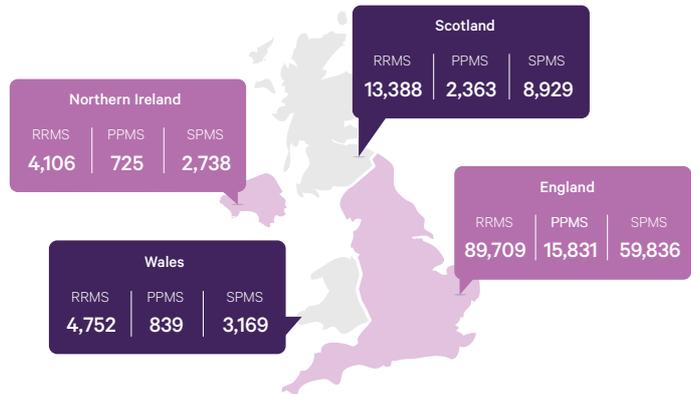


Figure 10
Emergency admissions in MS

Sources:
Hospital Episode Statistics (2019).



Complications leading to emergency admission

The complications associated with sub-optimally managed MS create an under-recognised burden on NHS services and budgets (see Figure 10). In 2018/19 there was a total of 30,310 emergency admissions for people with MS at a cost of over £86 million. Prescribing and admissions related to MS comorbidities is often a hidden, yet increasing, cost which CCGs have to pay. The most common reasons for emergency MS admission are often preventable such as infections (urinary tract and respiratory) and bowel problems, including constipation. Figure 11 shows the scale and increasing burden of MS comorbidities²¹.

Figure 11
Common primary reasons for emergency admissions regarding patients with MS

Source:
Hospital Episode Statistics 2016/17 to 2018/19.

	2016/17	2017/18	2018/19
Respiratory issues: emergency admissions cost	£13,709,092	£13,438,573	£15,074,191
UTI: % of emergency admissions	15.3%	9.2%	9.9%
UTI: cost per emergency admission	£2,898	£2,415	£2,697
Bladder and bowel: emergency admission cost	£12,609,388	£7,188,608	£9,192,762
Bladder and bowel: cost per emergency admission	£2,775	£2,268	£2,558

*Full data tables for all CCGs and health boards in the UK are listed at the back of this report^{13, 14, 15}.

Chapter 3. Healthcare policy and guidance

There has been a range of policy relating to neurology and MS over the last decade, including:

Guidelines and quality standards

- National Institute for Health and Care Excellence (NICE)
- International Quality Standards

NHS Improvement, NHS England and Public Health England

- MS treatment algorithm and Blueteq
- Getting It Right First Time (GIRFT) and RightCare
- Long-term conditions, population management and service models
- Workforce crisis

Disease modifying therapy

- Treatment algorithm

Devolved nations policy

In summary the literature review identifies very little policy or guidance specifically related to SPMS. Historically, the most relevant item is the National Service Framework for Long Term Conditions²², which addressed many of the Quality Requirements relevant to SPMS; however, this document is now obsolete. The NHS RightCare Progressive Neurological Conditions Toolkit² and other emerging policy could support this patient group but at the moment none specifically refers to SPMS. Guidance that explicitly addresses the needs of people with SPMS should be developed and a concerted effort is required to lobby Government and policy makers to ensure this focus in emerging policy.

For people with SPMS, increasing impairment and disability seriously impacts quality of life. Without targeted monitoring and support, when problems arise this will have serious consequences, not only for the person but for the NHS.

You can find full detail of the literature review in the Appendix.

Chapter 4. Professional perspectives:

The current reality of having SPMS

Aim

Our healthcare profession survey sought to understand:

- Professional views on the current management of SPMS.
- What they considered as priorities for management, which would inform an action improvement plan for SPMS.

Methods

Recruitment to the survey was based on the following criteria:

- Multidisciplinary professionals who were currently, or have in the recent past, been responsible for the care of people with SPMS.
- Senior and/or policy representatives from MS charities and MS educational providers.

We invited eligible respondents to participate in a one-hour telephone interview scheduled in January and February 2020.

- All those interviewed used a pre-defined questionnaire.
- Following the interviews key emerging themes were identified from qualitative responses.
- All responses were anonymised.
- Respondents gave informed consent to participate and could withdraw at any time from the interviews.

Results

Ten respondents were successfully recruited and interviewed; these included the following disciplines:

- MS specialist neurologist
- MS specialist nurse
- Occupational therapist
- Physiotherapist and rehabilitationist
- Neuro-pharmacist
- MS charity CEO and policy representative
- Person with MS
- MS educational provider

Key emerging themes

The MS expert group highlighted a range of what they consider urgent and major issues for people with SPMS. Recommendations from this research now outline improvement recommendations for a range of organisations and people including government, policy makers, healthcare professionals, commissioners, educationalists and service users. By working together, many of these recommendations could be achieved to improve the overall care people with SPMS now receive.

Urgent concerns

Finding the ‘forgotten many’

Trusts are not identifying patients with MS by subtype, other than RRMS, so there is no actual understanding of the total population of patients. All respondents acknowledged that individuals with SPMS are seen less in clinic compared to patients with RRMS, creating inequitable care for this group. Many patients are discharged from management within specialist units because of capacity issues, but their needs are often greater as their disability increases. Patients who have SPMS who are no longer in contact with specialist services should be identified.

A multiplicity of issues such as service demand and a skilled workforce to manage all patients who have MS results in insufficient service capacity to cope. This is however a strategic service planning issue and unless commissioners and service managers recognise the need to address these issues nothing will change.

There is no more money within the system so the NHS needs to look at value. It is important to understand the total MS population including subtypes of MS so that the numbers and needs of these patients are explicit to commissioners. A population management approach was suggested to highlight this need.

There is also a need to confirm an SPMS diagnosis to patients. Our stakeholders said there is a “nationwide problem for people with advanced MS who are often abandoned once they reach progressive stages”. The uncertainty of diagnosis was highlighted alongside the fact that giving this diagnosis is often very difficult. Comments were that it may be beneficial for neurologists and MS teams to have breaking bad news training refreshers.

Developing guidance for SPMS diagnosis

The majority of respondents acknowledged that there is significant uncertainty in identifying SPMS, with an approximate 2–5-year range to formal identification. As a result, many patients are still recorded as having RRMS, although they have transitioned to a progressive form of the disease. Guidance may support diagnosis but this needs to be done in a positive way.

Establishing an integrated care pathway for all patients

All respondents spoke of the need for multidisciplinary care in management of people with SPMS and gave good examples of how this was working (or not working) in their area. Development of a nationally recognised integrated care pathway for SPMS was highlighted. Some centres have multiple care pathways for patients, which creates confusion and lacks continuity between professionals.

Using data to better understand patient need

Although a range of data is available to understand performance, and organisations such as RightCare advocate using this, clinical staff have limited access to data and often need support in understanding how beneficial this can be for their service. It was felt data should be available routinely, through open access sources, so that issues of variation in care could be addressed.

Major priorities

Communication to people with MS

The language used for a diagnosis of SPMS can feel like bad news and whilst a new label does not alter reality, the mindset around it can be changed. For many patients, their SPMS diagnosis comes out of the blue. Health professionals need to make patients more aware that their condition might progress so that SPMS does not come as such a shock.

The multidisciplinary care that patients need can also create problems for them (see Care planning). Without adequate care plans and joined-up communication between professionals, patients have to repeat their story every time they see a different professional. Patients who have had MS for a long time can be challenged by cognitive symptoms and this needs to be acknowledged.

Workforce capacity and professional practice

There are significant workforce issues in neurology. Services are often stretched to capacity, which means that only patients on active treatment are seen – this to the detriment of people with SPMS.

The wider involvement of other professionals is required to manage people with SPMS.

Discharge is common from specialist services, with patients seen more frequently in primary care rather than secondary or tertiary care. These shifts in healthcare provision necessitate training of new professionals, such as GPs, practice and community nurses and pharmacists.

Succession planning for MS specialist services is also essential so that a new cohort of MS professionals is available.

The expansion of the role of advanced MS champions was seen as positive by all.

Establish care planning and annual reviews

People with SPMS should have a care plan and at least an annual review to ensure their needs are identified and met; however, this is not happening for a large number of people and complications are not being identified. There was concern from five of the ten respondents that the term 'care plan' meant different things to different people. All agreed that people with SPMS who are likely to have the most impairment and disability should have a care plan.

Focus on outcomes

Respondents felt that outcomes that were meaningful to people with SPMS were not used and recording of care given was very much a tick box exercise rather than focusing on how interventions provided benefit to patients. There was a need to agree which outcomes services should be striving towards. This could also inform the research agenda but should be done in partnership with patients, not clinically led.

Clinical audit to highlight variations in care

There is a need for a national audit of MS care to inform and address variation. Local audits are useful for individual services, but the benefit of outlining the national picture can be a powerful lever for service change. Specifically, within an audit the needs of individuals with SPMS should be acknowledged.

Chapter 5. Summary

SPMS is a progressive stage of MS that has a considerable impact on those affected. Around 2 in 3 of those who are initially diagnosed with the relapsing form of MS will go on to develop SPMS within 15 to 20 years. In many cases this will lead to irreversible disability, including cognitive decline, bladder dysfunction and greatly impaired mobility, among a range of other symptoms. Despite the significant challenges that people living with SPMS face, there is currently a lack of well-developed specialist services for the condition available across the NHS, and while MS services have developed significantly over the past 20 years, they are often geared towards people with the earlier stages of the condition, creating difficulties for those managing the transition to SPMS.

There are also limited data available on the impact that SPMS has on individuals, the NHS and the wider economy, when compared to other MS subsets. This has led to a belief that those with SPMS are often poorly served, and there is an unmet need which should be addressed as a matter of urgency. This has been the view from the literature and those specialists who have participated in this research.

We have outlined a vision for action improvement within this report. We want to make that vision a reality for everyone with SPMS in the UK.

If people across governments, the NHS, healthcare professionals and policy makers support our plan, many of these actions could be implemented easily, without the need for investment. We just need action for the benefit of people with SPMS.

Chapter 6. Urgent concerns and major priorities

1. Find the ‘forgotten many’

Few of our stakeholders were aware of the total numbers and individual subtypes of people with MS in their own areas. They felt this was detrimental to the care of people with SPMS because of inequitable care provision. A ‘population management approach’ was suggested to address quality and value.

Population management is the means by which everyone within a locality with MS would have access to specialist services. Not everyone will need to use services at the same time but it is a means of ensuring that those who have most need will be seen as well as those receiving active treatment. This might mean reducing the number of people seen by that service directly or by introducing new models of care management, such as IT solutions for healthcare. Services need to be planned and commissioned on a complete picture of the needs of the whole MS population. Services would be responsive and tailored to local need – drastically improving the experiences of people with SPMS.

Our stakeholders said there is a ‘nationwide problem for people with advanced MS, who are often abandoned once they reach progressive stages’.

Many people with advanced MS are losing contact with MS specialist services as their condition gets worse. They have to rely on informal care from family and friends, and sometimes have to manage their condition alone.

Professional key points

Our stakeholders said many MS services only have the capacity to see people with MS who are currently on active treatments, but people with progressive MS have needs too.

Clarity around the total number of people with MS in the population could support capacity assessment to inform strategic planning. Most MS services are not recording MS subtypes and thus service planners are unaware of the true scale – and needs – of their SPMS population.

A significant proportion of MS caseloads are patients whose MS has become progressive but have not yet received an SPMS diagnosis.

Many patients with SPMS have been discharged from caseloads and are therefore ‘lost to the system’.

Giving the diagnosis is difficult.

The 'Forgotten Many' need a diagnosis and active follow-up. It was acknowledged that diagnosis is difficult and often done over a period of time, but a watch-and-wait approach can be problematic for patients and most patients know their condition is getting worse. Our stakeholders said the biggest challenges to diagnosing SPMS is that it is considered bad news because to date as there have been no treatments for SPMS, confirming this as a diagnosis might precipitate discontinuation of a DMTs and involve a difficult conversation which many may want to avoid. Stakeholders commented that "giving the diagnosis of SPMS is often worse than giving the initial diagnosis of MS", and "there is a reluctance to talk about progress in the disease" by doctors and patients – feelings of failure, disappointment and fear of going on to the next stage is considered a 'downward spiral'.

Ensuring specialists provide diagnostic and support services rather than a watch-and-wait approach would be beneficial.

For those patients who have slipped out of the system, case finding should be undertaken and support given to help them manage their condition and symptoms effectively. This will require greater liaison with GPs and primary care professionals, as well as the wider multidisciplinary, multi-agency teams involved in health and social care.

People with SPMS are more likely to maintain a high quality of life and less likely to need health services if they are informed.

Action improvement plan

- The variation in access to services by people with SPMS should be highlighted to policy makers.
- Clinicians and commissioners should identify the total population of people with MS in each health economy and record who is being seen within that population.
- Differing subtypes of MS should be recorded where possible.
- Illustrating the value of anticipatory and preventative care to prevent emergency use of services by people with SPMS should be a focus for primary care..
- Services should identify patients who are not on active caseloads to ensure regular assessment and diagnostic status.
- Liaison with GPs and primary care professionals could support case finding of patients so that more proactive care could be given.
- Breaking bad news training refresher courses may be beneficial.

Good practice

The MS Trust Advanced MS Nurse Champions act as expert navigators who try to get people back into MS services and signpost them to other services and expert advice that they need, such as therapists, counselling, speaking language services and dietary services. The Champions scheme saves about £250,000 each year by sending patients to the right place¹.

2. Develop guidance for SPMS diagnosis

All of our stakeholders spoke of the negative perceptions that a diagnosis of SPMS gives.

Some had reservations about the term ‘transition’ because of its negative connotations, but said the focus on advancement of the condition must be acknowledged and communicated earlier on and in a better way.

Stakeholders commented:

“A key part of conversations in MS is how ‘progression’ is talked about (not SPMS or PPMS); there is a need for people to be more aware that their condition might progress so it is less of a shock when they are told they have SPMS.”

“We need to encourage earlier referral (people with SPMS) – not leave it to a time when they’re disabled, but get in early to promote health interventions and to help slow progression.”

In the giving of the SPMS diagnosis it is important that the person (with SPMS) is given a clear idea of what the future will be.

“To know in advance what the potential pathway looks like as the condition progresses – different options, times and management. To understand how the diagnosis will impact work and home life, particularly relationships; to understand what support is available to them, particularly their mental well-being.”

Professional key points

The importance of delivering the diagnosis and explaining the progressive nature of the disease is critical but this needs to happen in a positive way.

Management guidance in SPMS may help support diagnosis.

Breaking bad news training may be useful.

Action improvement plan

- Development of explicit guidance to aid diagnosis.
- Greater focus on psychological support.

3. Establish an integrated care pathway for all patients

Care for people with SPMS needs to be integrated across disciplines, services and agencies. It is particularly important that individuals with SPMS have an integrated care pathway which is available to everybody involved in care delivery as well as to patients themselves.

It is important for patients to know in advance what their care pathway might look like. Healthcare professionals need a more detailed view of what is best practice for different cohorts of patients. Subtype of MS is not always indicative of need.

Some MS centres have multiple pathways for differing elements of care, but how these integrate needs to be clarified. Care pathways should map out how the multidisciplinary team, primary care professionals, as well as social care and the voluntary sector, are involved in patient care.

One stakeholder provided the example of a specialist MS multidisciplinary team that has a close working relationship with the community team of district nurses and GPs. The GPs provide annual reviews for patients with all neurological conditions and liaise with the specialist team for advice and support as needed.

Our stakeholders felt that integrated care pathways are much needed and this would help to introduce more uniform care across the country for people with SPMS. They also felt that currently the voluntary sector is an untapped resource to support care planning.

Professional key points

Not all services have a formal care pathway in place that details what the patient journey will be and the touch points along that journey.

Professionals need a clear roadmap for best practice in SPMS.

Action improvement plan

- A national agreed SPMS integrated care pathway should be developed in consultation with patients and a wide range of professionals.

Good practice

- Some services already have a formal SPMS care pathway in place.
- The Walton Centre in Liverpool provides a comprehensive multi-disciplinary service aiming to assess health needs of people with MS within a clearly defined integrated care pathway. It provides a full range of hospital-based treatments, with referral to community services for non-specialist management.

4. Use data to better understand patient need

Our discussions highlighted that the use of data to inform practice is patchy and rarely deployed to best effect. Data are powerful and can be used to understand practice, prescribing patterns and to target unwarranted variation in services, but accessing reliable data was an issue for everyone. Interpreting meaning for service improvements was also challenging.

Stakeholders felt comprehensive, robust and granular MS data could allow services to be planned and commissioned on a complete picture of the needs of the MS population including people with SPMS.

Data collected by healthcare providers, for example Hospital Episode Statistics (HES data), and through sources such as the MS Register, are becoming easier to collect electronically, share and link together. This offers opportunities to better understand MS patients at a local level, including the symptoms they are experiencing, the types of services they are using and how well those services are performing.

Local areas could use these data to take informed investment decisions and make sure they are providing the right level of coordinated support for people with SPMS.

Currently this information is not used to its full potential. In SPMS a large range of professionals and services are involved in care, but the data held often sit in the respective organisations and are rarely shared with other care providers. Very few people have oversight of the data held by different organisations and how they could benefit patients.

Data sharing is key to allow services to respond to key issues affecting people with MS and to support research into how patients might be better supported.

Professional key points

Availability of MS data is patchy and where it exists it is rarely used to best effect.

Data-sharing to improve services would be beneficial.

Action improvement plan

- Data should be routinely available to all services.
- Variation between services should be explicit.
- Services should be keeping up-to-date records of the MS subtypes in their population.
- Granular data should be used to inform practice and service delivery, shared between professionals and used to encourage research into new care systems and technology that could improve patient care.

Good practice

The MS Society has produced *Improving Care for People with MS: the potential of Data and Technology* which further highlights the benefits of using data to benefit people with MS²³.

5. Communication to people with MS

By improving communication from the moment of diagnosis, we can better support people to manage their condition. Stakeholders commented that “A diagnosis of SPMS is often worse for patients than the initial MS diagnosis.” It can rule out hope and options for some patients so it is important to consider how the message is delivered. Part of this is the language used; a diagnosis of SPMS can feel like bad news. While a new label does not alter reality, the mindset around it can be changed.

For many patients, their SPMS diagnosis comes out of the blue. Health professionals need to make patients more aware that their condition might progress so that SPMS does not come as such a shock.

Our stakeholders said a significant number of people with SPMS lack psychological support; they feel daunted, abandoned and alone. Signposting to further support, tools and information is key.

Good practice

Use of the MS Passport in the Western Isles Hospital has given patients a personal handheld document to take to all their appointments and admissions to hospital. This has evidenced empowerment and incorporated regular self-management into their journey with MS.²⁴

My Medical Record (MyMR) is a digital platform (patient held record) available to patients of the University Hospital of Southampton (UHS). It has been developed by the trust to provide access to information for patients, and acute and community teams 24/7. It enables co-production of health goals and outcomes from both clinical and patient perspectives. It also provides a research evidence base for improving care planning through outcome measures, health questionnaires and research studies.²⁵

Professional key points

The progressive nature of MS needs to be communicated to patients at an early stage, so that SPMS does not come as a ‘second diagnosis’, which can often be devastating news.

Communication should also be ongoing and easily accessible. IT solutions should support face-to-face interactions.

People with MS need to know in advance what the potential pathway looks like as the condition progresses, and the different options and management avenues.

Patients also need to understand how the diagnosis will impact work and home life, particularly relationships, and they need to receive psychological support to help them accept their diagnosis.

Action improvement plan

- Access to psychological and mental health support should have greater availability.
- Everybody involved in SPMS care needs awareness of the specific communication needs of this patient group.
- Communication with patients should be built into the heart of all care pathways and care planning.
- Key worker systems should be implemented.

6. Workforce capacity and professional practice

Our stakeholders highlighted that workforce is a major issue in MS care. There is a need to ensure there are sufficient numbers of specialist MS neurologists, nurses and allied health professionals to manage patients, but this goes wider into the generalist workforce and into patient activation to help individuals with MS and SPMS manage their own health better.

Stakeholder comments:

“It is important that people with SPMS still have access to MS specialists but... pressure of demands on MS teams often means that this patient group have been ignored.”

“Workforce is not just about hiring new people, but succession planning and dealing with burnout – there is a need to keep the existing workforce motivated.”

To increase service capacity, a wider range of professionals and services needs to be involved. Education in MS and SPMS is needed for a range of professionals and services. Delays in diagnosis of MS are often brought about by lack of knowledge among non-specialist staff managing people with MS.

“Newer MS nurse specialists need ‘back to basics’ training, including breaking bad news, advanced care planning, and management of issues such as bladder and bowel problems and spasticity.”

“Currently much of the management that nurses provide is on DMT support.”

The MS Academy is providing education and training to equip existing and new specialists in MS care²⁶.

Good practice

The MS Trust runs a development module which is an educational course that most MS HCPs have attended. This has been running for several years and encompasses all aspects of MS care.

The MS Academy Masterclasses: Basecamp, foundation and advanced training programmes are developing the skills of professionals involved in MS and SPMS to give professionals the expertise needed to meet the needs of these patients²⁷.

Professional key points

There is insufficient capacity within the workforce to manage the needs of people with SPMS.

The demands placed on the MS workforce are currently inequitable across the UK.

Succession planning for the specialist MS workforce must be a serious consideration.

Links with primary care networks need to be made to address issues around poverty/social issues through social prescribing.

GPs need training to understand their role in earlier referral, anticipatory care and shared care, as the complexity of the condition increases.

District and community nurses need training to understand the common problems experienced with SPMS.

Action improvement plan

- Capacity planning in services is urgently needed.
- Training should be provided for the range of professionals involved in SPMS care.
- Succession planning is essential to develop new MSologists and supportive roles, e.g. neuro-pharmacists and social prescribers.

7. Establish care planning and annual reviews

Multiple professionals and services should be involved in the care of people with SPMS and this can be coordinated through the use of a shared care plan, ideally a digital plan that patients can also access. MS services should ensure all individuals with SPMS have a care plan that is updated annually.

The stakeholder group told us that not all SPMS patients are uniformly receiving an annual review and likewise have a care plan in place. Part of the problem is that many SPMS patients are not on active caseloads so they are not seen for review. Often, where patients are offered a review, clinics are so overbooked that these can slip from 12-monthly to 18-monthly reviews.

Stakeholder comments:

“Care planning means different things for different people.” What actually constitutes a care plan is currently not clear. This needs to be defined nationally.

Many services do not have a dedicated document that could be called a care plan, nor is this information easily accessible to patients (or patients may not be aware of it).

Some stakeholders were aware of online portals (or ‘care information exchange’) but felt these were in a minority and directed at individuals who are on treatment.

“We need to define what we mean by care plan and what goes in it.”

Professional key points

Care planning is currently underused and what constitutes a care plan is unclear.

Action improvement plan

- Ensure all patients access care planning and annual review.
- A care plan and what this should contain should be defined nationally.
- There should be a national call for people with MS and SPMS to have a care plan and this should be reviewed at least annually.

Good practice

Some services have developed a template form for annual reviews to ensure a uniform process regardless of who carries out the review.

The MS Trust has published research on helping people to establish the issues that they want to talk about in their annual review/consultation.

8. Focus on outcomes

Stakeholders felt that currently there is more focus on the care people with SPMS are receiving than on the outcomes of that care. This does not provide insight into which services might better support people and help delay the progression of disability or prevent problems from occurring. Neither does it identify patients who might benefit from treatments as they become available. The stakeholders felt that quality of life and outcomes for people with SPMS could really be improved with the support of a range of services such as:

- Access to transition/SPMS clinics that address complex symptoms
- Symptom-based clinics rather than MS subtype clinics, e.g. acute management clinics
- Neuro-rehabilitation
- Psychology assessment
- Social care and vocational support.

Our stakeholders said that a local service may be meeting the 'tick box' requirements of patient access to a therapist, but they asked whether in practice these activities were of value. Services should enable co-production of health goals and outcomes from both clinical and patient perspectives, as well as providing a research evidence base for improving care planning through outcome measures, health questionnaires and research studies.

Research into newer technologies and adoption of these might improve outcomes.

Having staff capacity to focus on outcomes, however, is a challenge, and technology needs to be explored to support this.

Professional key points

Outcomes for care in SPMS, including eligibility for treatment, social care and employment, need to be agreed.

Service users should be involved in discussions about which outcomes are important to them.

A focus on research into technologies and treatments for SPMS needs to be addressed. SPMS is a good example of a condition that shows that new types of drugs are possible. Wider research funding should be unlocked.

Technology could support outcome measurement.

Action improvement plan

- Debate and agree which outcomes services for people with SPMS should focus on.
- Use outcome data to support service delivery and inform the research agenda.
- Ensure solutions for managing impairment and disability with relevance to SPMS are used (e.g. bowel management).

Good practice

My Medical Record (MyMR) is a digital platform (patient held record) available to patients of the University Hospital of Southampton (UHS). It has been developed by the trust to provide access to information for patients, and acute and community teams 24/7.²⁵

Constipation and uncertainty about timely bowel evacuation can be a real issue for people with advanced MS. Transanal irrigation has been shown to improve outcomes, yet it is not universally used. Improved quality of life can result from greater certainty on bowel movements through social participation and retention of employment.²⁸

9. Clinical audit to highlight variations in care

In order to drive improvement in MS service provision, a UK clinical audit of MS services should be undertaken regularly. There is currently no clear strategy from the NHS on how to support MS teams to deliver care for the whole MS population, which includes people with SPMS. Local audits are beneficial to understand practice, for example one of our stakeholders stated their service had carried out an audit of referral to therapy services. They found that only 25% of people with MS were getting referred to physiotherapy, despite having EDSS levels around 6, and only 14% of people were referred to occupational therapy. This is significant for individuals with SPMS.

Our stakeholders told us that many services are not recording the MS subtype of patients, there is variation in how management guidelines are followed, and patients are frequently not being offered annual review and care planning.

A UK-wide audit would provide the data to empower clinical teams to change and improve their MS services, and care for all MS patients in their personal and work environments. This would create a wider understanding on the variance of current service provision and capacity limitations, as well as supporting commissioners to improve service provision to better meet the needs of all people with MS.

Professional key points

Clinical audit of services is essential.

This should be undertaken at a national level so that the results can indicate variation in services.

Action improvement plan

- Implement clinical audit of MS services to address variation in care.
- Develop SPMS KPIs with national reporting. Policy makers must act on the results to reduce variation in care.

Good practice

Develop a national MS audit that will also specifically define subtypes of MS. A pilot audit is already taking place (pilot ends 2020). MS services should ensure they participate in the full audit from roll-out in 2020.

Glossary

CCG	Clinical commissioning group
DMT	Disease-modifying therapies
EDSS	Expanded Disability Status Scale
EMA	European Medicines Agency
HES	Hospital Episode Statistics
HQIP	Healthcare Quality Improvement Partnership
ICD-10	International Classification of Diseases Version 10
ICS	Integrated care services
KPI	Key performance indicator
MS	Multiple sclerosis
NIC	Neurology Intelligence Collaborative
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NNAG	National Neuro Advisory Group
ONS	Office for National Statistics
OCPS-4	Office of Population Censuses & Surveys, classification of procedures and interventions version 4
PAS	Patient Administration Systems
PPMS	Primary progressive multiple sclerosis
QOL	Quality of life
RRMS	Relapsing remitting multiple sclerosis
SPMS	Secondary progressive multiple sclerosis
STP	Sustainability and Transformation Partnerships
SUS	Secondary Users Service
THIN	The Health Improvement Network

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Appendix

Healthcare policy and guidance

There has been a range of policy relating to neurology and MS over the last decade, including:

- **Guidelines and quality standards**
 - National Institute for Health and Care Excellence (NICE)
 - International Quality Standards
- **NHS Improvement, NHS England and Public Health England**
 - MS treatment algorithm and Blueteq
 - Getting It Right First Time and RightCare
 - Long-term conditions, population management and service models
 - Workforce crisis
- **Devolved nations policy**

Guidelines and Quality Standards

The NICE Clinical Guidelines on diagnosis and management of MS in Adults were first published in 2014⁵. They cover the diagnosis and management of MS, promoting symptom management and rehabilitation, comprehensive annual reviews of care and effective relapse treatment. SPMS is not comprehensively covered by the guidelines, although they do make reference to the need to find 'the critical and as yet unmet challenge to find effective and well-tolerated treatments for secondary progressive MS'. Sections 1.5 on 'MS symptom management and rehabilitation' and 1.6 on 'Comprehensive review' hold the most relevance for people with SPMS.

Updates to the evidence on diagnosis, symptom management and rehabilitation were made in 2018 and for spasticity in 2019.

NICE Quality standards for MS²⁹ were published in 2016, but again there is little specifically relevant to SPMS. While most people with SPMS will have previously been diagnosed with RRMS, some people will have had their early symptoms missed or misdiagnosed, and so do present for a diagnosis of SPMS. There is no mention of the complexity of diagnosis in SPMS or guidance to support this diagnosis in the NICE guidance.

Within the NICE Quality Standards for MS, sections 3 'Coordinated care', 4 'Physical activity' and 6 'Comprehensive review' are relevant for SPMS in the broader sense, but do not provide insight into preserving existing function or enabling proactive self-management without treatment options. Again, the sections on diagnosis (1 and 2) make no reference to the complex challenges of diagnosing SPMS.

While these standards are a starting point for improving quality, the MS community did not feel these were sufficiently comprehensive, and both the MS Society and MS Trust set out additional areas they felt should have been included. Building on these standards, an International consensus group have outlined consensus quality standards formulated through a five-round Delphi process³⁰. These standards cover six aspects of the care pathway: symptom onset, referral and diagnosis, treatment decisions, lifestyle, disease monitoring and managing new symptoms. The group states that:

“Time matters in MS and irreversible neural damage and cell loss occurs from disease onset. This very much applies to SPMS which should be diagnosed promptly as patients transition from RRMS to SPMS. The MS community has endorsed a management strategy of prompt diagnosis, timely intervention and regular proactive monitoring of treatment effectiveness and disease activity to improve outcomes in people with MS. These quality standards for core, achievable and aspirational care provide MS teams with a three-level framework for service evaluation, benchmarking and improvement and have the potential to produce a profound change if they are adopted for the care of people with SPMS.”

National Service Framework for long-term neurological conditions

Although 15 years old, the National Service Framework for long-term neurological conditions²² is still one of the most comprehensive sets of guidelines for optimal management of long-term neurological conditions such as MS. Almost all of the 11 quality requirements (QRs) have relevance to SPMS and although out of date, the QR statements below and the evidence-based markers attached to each can still provide a useful picture of aspirational care.

- **QR1:** A person-centred service
- **QR3:** Emergency and acute management
- **QR5:** Community rehabilitation and support
- **QR6:** Vocational rehabilitation
- **QR7:** Providing equipment and accommodation
- **QR8:** Providing personal care and support
- **QR9:** Palliative care
- **QR10:** Supporting family and carer
- **QR11:** Caring for people with neurological conditions in hospital or other health & social care settings

NHS Improvement, NHS England and Public Health England

MS treatment algorithm

The purpose of NHS England's 2018 treatment algorithm for multiple sclerosis disease-modifying therapies¹⁰ is to provide a framework to aid decision-making for MS specialists and patients, to help reduce excessive variation in practice and ensure safe and effective prescribing. The algorithm is constrained by the regulatory status, NICE approvals and commissioning status of the DMTs licensed for MS in England. It is reviewed by NHS England's Neuroscience Clinical Reference Group to reflect any new NICE Technology Appraisal Guidance or approvals within three months of guidance publication. One of the key points in relation to SPMS is that patients will have DMTs discontinued when they meet the following criteria:

- Development of inability to walk (EDSS 7.0), persistent for more than 6 months due to MS
- Confirmed SPMS with an observable increase in disability for more than a 12-month period, in the absence of relapse activity. SPMS would usually only be diagnosed in patients with an EDSS of 6.0 or greater (except for the rare phenotype of 'relapsing-progressive multiple sclerosis' detailed in section 13).

This is very relevant as it outlines at what point a patient's DMT will be discontinued, which may result in a reluctance to provide a diagnosis of SPMS.

In order to reduce variation in prescribing and provide an auditable model for monitoring prescribing, MS drugs are subject to a system called Blueteq³¹.

Blueteq was established for the High Cost Drugs Management Process in NHS England's Commissioning Intentions³². DMTs are high cost drugs for MS and are subject to a pass-through for payment (to NHS England Specialised Commissioning) of the actual price charged to providers. Although Blueteq is in place, the Get it Right First Time (GIRFT) report³³ and the MS Academy Raising the Bar work programme³⁴ have highlighted the marked variations in prescribing that exist – although one could say that Blueteq is still in its infancy and improvements may yet be coming.

RightCare and GIRFT

Several initiatives are raising the profile of MS in neurology policy. The NHS RightCare Progressive Neurological Conditions Toolkit (2019)² is seeking to raise standards of care across several long-term neurological conditions, including MS, and calls for formalised multi-disciplinary teams across specialist teams to deliver holistic and joined-up care for those with MS. One of its four System Improvement Priorities is 'Comprehensive access to holistic support' (particularly for advanced MS patients). This states that every MS centre should have a designated lead for advanced MS and that everyone with advanced MS should:

- Have access and referral to local and community-based, and other specialist services including: fatigue management, emotional support, peer support, neuro rehab, vocational rehab, palliative care and neuropsychology services
- Be offered an annual review with a member of the MS MDT.

NICE guidance (2014) also reinforces these recommendations, advocating a multidisciplinary approach (1.3) and suggesting that every individual has a management plan which includes who to contact if their symptoms 'change significantly' (1.2.6).⁵

The Elective Care Transformation Programme³⁵ (2019) neurology handbook³⁶ further details the need for 'alternative models of care', as outlined in the NHS Long Term Plan (2019)³⁷, 'targeting interventions for those people who are most vulnerable and at risk' and specifically outlining community multidisciplinary clinics as a means of transforming outpatient care. This handbook is one of several from NHS England and NHS Improvement seeking to transform elective care, including respiratory, urology, ophthalmology and general practice, all of which are relevant to a person with SPMS; the main problems for people with advanced SPMS relate to respiratory and urology issues (discussed in more detail below; see Figure 11).

The Getting it Right First Time (GIRFT) programme for neurology³³ has highlighted the significant variation that exists in neurology services. The full report for this is not expected until September 2020, but detail about how different areas are managing MS also raises the possibility that if the outcomes of patients treated in different regions were identified this might allow clinicians to understand which treatment strategies are most effective, in particular for SPMS.

Long-term conditions and new service models

Healthcare is under increasing pressure in today's society, with more than 15 million people – 30% of the UK population – living with one or more long-term conditions³⁸, and one in six living with a neurological condition³⁹. The 'House of Care' model is the vision for the management of long-term conditions for the future. Shown in Figure 12, this model requires an integrated and holistic approach, with shared responsibilities across patients and professionals which "should be proactive, holistic, preventive and patient-centred"⁴⁰. The complex and individual nature of SPMS means many people will be experiencing comorbidities which need managing in an integrative way, rather than alongside their MS, and include general health issues, such as high cholesterol, high blood pressure, arthritis and chronic lung disease^{41,42} as well as those commonly associated with MS.



Figure 12
House of care model

Sources: King's Fund (2013)
Delivering better services for people with long-term conditions: Building the house of care.

Population management and planning

Population management of MS is the means by which everyone within a locality who has MS has access to specialist services. Not everyone will need to use services at the same time, but it is a means of ensuring that those who have most need will be seen as well as those who may be receiving treatment. Currently, services in the main see patients who are actively receiving therapy. Patients with progressive and secondary progressive forms of the disease not on DMTs have largely been excluded – often due to service capacity issues. However, we know that increasing disability results in increasing problems, so assessment of need and preventative care are vital considerations to ensure that those who would benefit most from specialist services do so.

If necessary, this could mean reducing the number of people seen by that service directly or by introducing new models of care management; this might include IT solutions, such as virtual clinics. Workforce issues also mean we need to think of IT solutions to expand the capacity of services, as well as new roles, including MS service coordinators and neuro-pharmacists who can support DMT administration.



Figure 13
MS population and specialist services

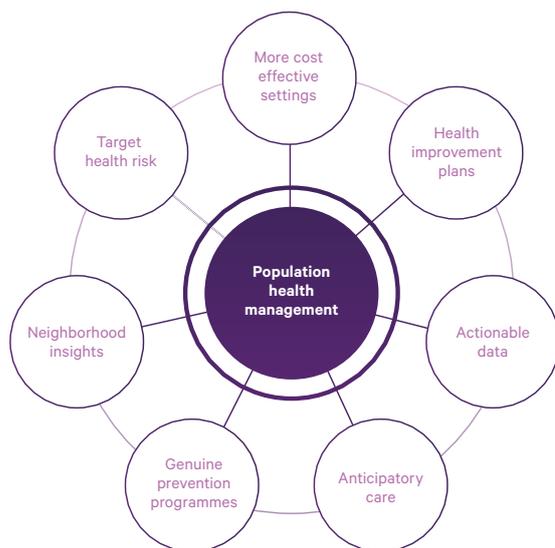


Figure 14
Population
health
management

Population healthcare

NHS RightCare's Commissioning for Value⁴³ work shows marked variation in the way services are delivered. This highlights the need to focus on the value that populations receive from the money invested in care, with a greater emphasis on preventative care.

Quality focuses on the patients who are treated, but value focuses on all the people in need. Value must take into account that there may be either overuse and underuse of services, neither of which is a good thing. Overuse can lead to waste or even patient harm, while underuse leads to failures in prevention and unfairness of access to services. These problems are not addressed by focusing just on the quality of care.

Workforce crisis

Workforce is a major issue in MS care and there is a need to ensure there are sufficient numbers of specialist MS neurologists, nurses and allied health professionals in the workforce. There is also a need for succession planning for our current specialist MS workforce.

The Association of British Neurologists workforce survey⁴⁴ has identified an emerging workforce crisis due to the combination of an increase in newly appointed part-time consultants, and the increased number of early retirements. There are already long-standing vacancies in some areas of the country. The report suggests that there are not enough new neurologists being trained to stem emerging workforce problems.

They also found significant regional variation, with by far the greatest concentration of consultant neurologists being situated in London/the south east, with over a third (35%) of the national total. This is followed by Scotland with 11% of the total, and Merseyside and the Northwest, with 9%. This coupled with similar issues in the nursing workforce is challenging for MS services.

The Neurological Alliance patient experience survey⁴⁵ showed that for far too many people with neurological conditions, there is a long wait for a confirmed and accurate diagnosis. In some cases, this is followed by a wait of several months for treatment to start. This is almost certainly related to the workforce challenges seen around the country.

Delays in diagnosis of MS are often brought about by lack of knowledge among non-specialist staff managing people with MS. In particular, it is important that patients who transition to SPMS still have access to MS specialists. The pressure of demands on MS teams, however, often means that this patient group have been ignored. The MS Trust have established an advanced MS champion role¹ specifically to manage patients with complex needs, and the MS Academy is developing new specialists in MS care²⁶.

Social care and societal impact

The All-Party Parliamentary Group of MS produced a report in 2016 called 'Employment that Works: Supporting People with MS in the Workplace'¹⁸. The report found that people with MS lose an average of 19.4 working years, and that those with SPMS are least likely to be in employment; 28% of people with SPMS are employed, compared to 69% of people with RRMS and 43% of people with primary progressive MS¹⁸.

The UK has among the worst employment rates for people at an EDSS score of 6.0¹⁷, a score which is attributed to those with SPMS by the NHS England Treatment Algorithm for MS DMTs¹⁰. These data, alongside the report findings, suggest that employment is an area requiring renewed focus for those with SPMS, as the lack of it could be having an impact both on their sense of involvement and worth in society, linked to positive mental wellbeing, and on the wider economic picture of health.

‘All our health’ (Public Health England)

Published in 2015 and updated in 2019, this framework of evidence⁴⁶ to guide healthcare professionals in preventing illness, protecting health and promoting wellbeing has some relevant areas for SPMS, specifically around social prescribing⁴⁷, which is depicted in Figure 15.

At the core of social prescribing is connecting people into their local community in a way that is meaningful to them and that they will find enriching to others, and relies on link workers who ‘support people in personalised care... and connects people to community groups and agencies for practical and emotional support’, and ‘collaborate with local partners to help community groups be accessible and sustainable and support people starting new groups’⁴⁷.

Other themes in ‘All our health’ that are relevant to people with SPMS include:

- Falls (2019)
- Pressure ulcers (2015)
- Respiratory care (2015)
- Workplace health (2019)
- Wellbeing and mental health (2019).

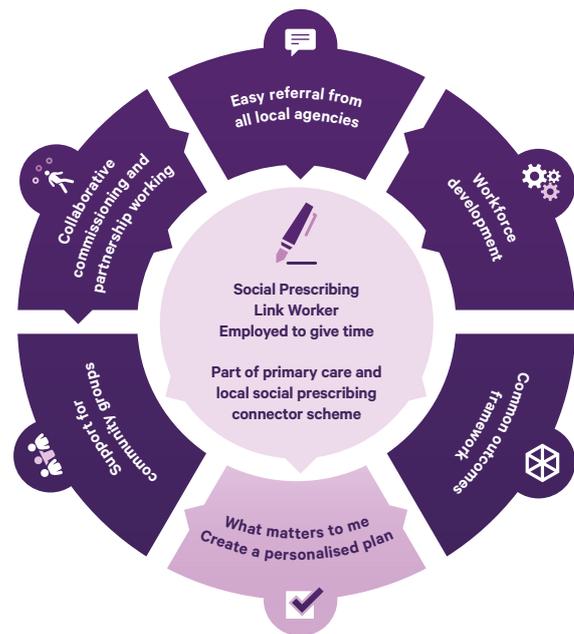


Figure 15
Social prescribing

Sources:
Public health England (2019) Social prescribing, applying all our health.

Raising the bar for MS and the ‘no patient left behind’ principle

The MS Academy is supporting clinical leaders in ‘raising the bar’ for MS, tackling service variance nationally²⁷. Within the work, social determinants of health are being assessed and the social impact of MS considered. Loneliness and isolation have been highlighted as common challenges for people whose MS renders them emotionally or physically unable to leave the house or engage in social activities easily. With loneliness and depression both lifestyle risks for dementia, the link between these emotional states and the health of the brain deserves consideration.

Service planning and outcome indicators: CCG Outcome Indicators Set

There is little available in the Commissioning Framework²² or CCG Outcome Indicators Set⁴⁸ pertaining directly to neurology. However, section 2.1 of the CCG Outcome Indicators Set looks at health-related quality of life for people with long-term conditions while section 2.2. considers the proportion of people who are feeling supported to manage their condition.

The majority of MS care is planned around people with RRMS. However, services need to have specific strategies in place for SPMS because these patients are likely to be costing the most. Those with SPMS are a group whose needs in this are largely unmet and who, once unresponsive to DMTs, are often left ill-equipped to self-manage their condition without immunotherapy, and without the confidence that they can still have a good quality of life.

Devolved nations specific policy

ICS development was mandated by the NHS Long Term Plan in 2019³⁷ and should enable better long-term planning and coordinated care in England for complex conditions, such as MS, with joined-up multi-year budgets, data sharing, cross-sector planning and risk sharing, along with personal care planning/personal budgets for these patients.

Health Boards in Scotland, Wales and Northern Ireland already provide a joined-up system with the opportunity for integrated care across health and social care.

Scotland

General standards for neurological care and support⁴⁹ were published by Health Improvement Scotland in 2019 after the original standards for neurological health services were found not to have been universally adopted. This has led to unwarranted variation in care for people with a neurological condition. Standards 1 to 3 refer to the organisational level of care, ways of working and leadership, and standard 4 refers to diagnosis. Standards 5 to 7 are relevant for those with SPMS and, while broad statements, all refer to person-centred, individually-directed services and support.

- **Standard 5:** Assessment of needs – People living with neurological conditions are offered a holistic needs assessment with opportunities for review as an individual's needs change.
- **Standard 6:** Treatment and management – Treatment and ongoing support for people living with a neurological condition is high quality and person-centred.
- **Standard 7:** Person-centred care – People living with neurological conditions experience high-quality, well-coordinated and person-centred services.

Northern Ireland

Public Health Agency in Northern Ireland together with the NI Neurological Conditions Network led a consultation in 2011 which made 12 recommendations covering four areas⁵⁰:

- Accurate information and diagnosis
- Control and choice
- Day-to-day living and independence
- Employment, social life.

Wales

The Welsh Government published a neurological conditions delivery plan in 2017⁵¹ with eight different delivery themes; however, none of these specifically relates to SPMS.

Summary

In summary, the literature review finds that there is very little policy or guidance that is specifically related to SPMS. Historically, the most relevant item is the National Service Framework for Long Term Conditions²², which addressed many of the Quality Requirements relevant to SPMS; however, this document is now obsolete. The NHS RightCare Progressive Neurological Conditions Toolkit² and other emerging policy could support this patient group, but at the moment none specifically refers to SPMS. Guidance that explicitly address the needs of people with SPMS should be developed and a concerted effort is required to lobby Government and policy makers to ensure this focus in emerging policy.

For people with SPMS, increasing impairment and disability impacts quality of life because without targeted monitoring and support when problems arise this will have serious consequences, not only for the person but for the NHS.

Data tables

MS prevalence estimates^{13, 14, 15}

The values represented assume that 85% of the MS population will have RRMS and 2 in 3 of these will go on to develop SPMS⁵. 15% of the remaining MS population will have PPMS. Figures in these tables reflect a total population breakdown not actual numbers.

Nation	Code	Organisation name	Population	Total with MS	RRMS	PPMS	SPMS
England	N/A	England	55,977,178	105,540	89,709	15,831	59,836
Scotland	N/A	Scotland	5,438,100	15,750	13,388	2,363	8,929
Wales	N/A	Wales	3,138,631	5,590	4,752	839	3,169
N. Ireland	N/A	Northern Ireland	1,881,641	4,830	4,106	725	2,738
England	02N	NHS Airedale, Wharfedale and Craven CCG	160,106	307	261	46	174
England	09C	NHS Ashford CCG	129,281	248	211	37	141
England	07L	NHS Barking and Dagenham CCG	211,998	407	346	61	231
England	07M	NHS Barnet CCG	392,140	753	640	113	427
England	02P	NHS Barnsley CCG	245,199	471	400	71	267
England	99E	NHS Basildon and Brentwood CCG	262,412	504	428	76	286
England	02Q	NHS Bassetlaw CCG	116,839	224	191	34	127
England	11E	NHS Bath and North East Somerset CCG	192,106	369	314	55	209
England	06F	NHS Bedfordshire CCG	455,229	874	743	131	496
England	15A	NHS Berkshire West CCG	489,709	940	799	141	533
England	07N	NHS Bexley CCG	247,258	475	404	71	269
England	15E	NHS Birmingham and Solihull CCG	1,179,020	2,264	1,924	340	1,283
England	00Q	NHS Blackburn with Darwen CCG	148,942	286	243	43	162
England	00R	NHS Blackpool CCG	139,305	267	227	40	152
England	00T	NHS Bolton CCG	285,372	548	466	82	311
England	02W	NHS Bradford City CCG	85,957	165	140	25	94
England	02R	NHS Bradford Districts CCG	341,873	656	558	98	372
England	07P	NHS Brent CCG	330,795	635	540	95	360
England	09D	NHS Brighton and Hove CCG	290,395	558	474	84	316
England	15C	NHS Bristol, North Somerset and South Gloucestershire CCG	959,968	1,843	1,567	276	1,045
England	07Q	NHS Bromley CCG	331,096	636	540	95	360
England	10H	NHS Buckinghamshire CCG	542,512	1,042	885	156	591
England	00V	NHS Bury CCG	190,108	365	310	55	207
England	02T	NHS Calderdale CCG	210,082	403	343	61	229
England	06H	NHS Cambridgeshire and Peterborough CCG	889,112	1,707	1,451	256	968

Nation	Code	Organisation name	Population	Total with MS	RRMS	PPMS	SPMS
England	07R	NHS Camden CCG	262,226	503	428	76	285
England	04Y	NHS Cannock Chase CCG	136,974	263	224	39	149
England	09E	NHS Canterbury and Coastal CCG	213,598	410	349	62	233
England	99F	NHS Castle Point and Rochford CCG	177,051	340	289	51	193
England	09A	NHS Central London (Westminster) CCG	185,422	356	303	53	202
England	00X	NHS Chorley and South Ribble CCG	176,862	340	289	51	193
England	07T	NHS City and Hackney CCG	288,371	554	471	83	314
England	09G	NHS Coastal West Sussex CCG	507,449	974	828	146	552
England	03V	NHS Corby CCG	70,827	136	116	20	77
England	05A	NHS Coventry and Rugby CCG	473,979	910	774	137	516
England	09H	NHS Crawley CCG	112,448	216	184	32	122
England	07V	NHS Croydon CCG	385,346	740	629	111	419
England	00C	NHS Darlington CCG	106,566	205	174	31	116
England	09J	NHS Dartford, Gravesham and Swanley CCG	264,478	508	432	76	288
England	15N	NHS Derby and Derbyshire CCG	1,019,900	1,958	1,664	294	1,110
England	15M	NHS Devon CCG	1,194,166	2,293	1,949	344	1,300
England	02X	NHS Doncaster CCG	310,542	596	507	89	338
England	11J	NHS Dorset CCG	772,268	1,483	1,260	222	841
England	05C	NHS Dudley CCG	320,626	616	523	92	349
England	00D	NHS Durham Dales, Easington and Sedgefield CCG	275,314	529	449	79	300
England	07W	NHS Ealing CCG	341,982	657	558	98	372
England	06K	NHS East and North Hertfordshire CCG	569,078	1,093	929	164	619
England	15D	NHS East Berkshire CCG	434,463	834	709	125	473
England	01A	NHS East Lancashire CCG	380,013	730	620	109	414
England	03W	NHS East Leicestershire and Rutland CCG	335,800	645	548	97	366
England	02Y	NHS East Riding of Yorkshire CCG	317,404	609	518	91	346
England	05D	NHS East Staffordshire CCG	128,418	247	210	37	140
England	09L	NHS East Surrey CCG	186,016	357	304	54	202
England	09F	NHS Eastbourne, Hailsham and Seaford CCG	191,604	368	313	55	209
England	01C	NHS Eastern Cheshire CCG	197,296	379	322	57	215
England	07X	NHS Enfield CCG	333,869	641	545	96	363
England	10K	NHS Fareham and Gosport CCG	201,622	387	329	58	219
England	02M	NHS Fylde and Wyre CCG	192,421	369	314	55	209

Nation	Code	Organisation name	Population	Total with MS	RRMS	PPMS	SPMS
England	11M	NHS Gloucestershire CCG	633,558	1,216	1,034	182	690
England	06M	NHS Great Yarmouth and Waveney CCG	217,681	418	355	63	237
England	03A	NHS Greater Huddersfield CCG	245,977	472	401	71	268
England	01E	NHS Greater Preston CCG	202,562	389	331	58	220
England	08A	NHS Greenwich CCG	286,186	549	467	82	312
England	09N	NHS Guildford and Waverley CCG	209,413	402	342	60	228
England	01F	NHS Halton CCG	128,432	247	210	37	140
England	03D	NHS Hambleton, Richmondshire and Whitby CCG	152,950	294	250	44	166
England	08C	NHS Hammersmith and Fulham CCG	185,426	356	303	53	202
England	08D	NHS Haringey CCG	270,624	520	442	78	295
England	03E	NHS Harrogate and Rural District CCG	160,533	308	262	46	175
England	08E	NHS Harrow CCG	250,149	480	408	72	272
England	00K	NHS Hartlepool and Stockton-on-Tees CCG	290,455	558	474	84	316
England	09P	NHS Hastings and Rother CCG	188,511	362	308	54	205
England	08F	NHS Havering CCG	257,810	495	421	74	281
England	05F	NHS Herefordshire CCG	192,107	369	314	55	209
England	06N	NHS Herts Valleys CCG	595,670	1,144	972	172	648
England	01D	NHS Heywood, Middleton and Rochdale CCG	220,001	422	359	63	239
England	99K	NHS High Weald Lewes Havens CCG	174,475	335	285	50	190
England	08G	NHS Hillingdon CCG	304,824	585	497	88	332
England	09X	NHS Horsham and Mid Sussex CCG	238,955	459	390	69	260
England	07Y	NHS Hounslow CCG	270,782	520	442	78	295
England	03F	NHS Hull CCG	260,645	500	425	75	284
England	06L	NHS Ipswich and East Suffolk CCG	409,248	786	668	118	445
England	10L	NHS Isle of Wight CCG	141,538	272	231	41	154
England	08H	NHS Islington CCG	239,142	459	390	69	260
England	11N	NHS Kernow CCG	568,210	1,091	927	164	619
England	08J	NHS Kingston CCG	175,470	337	286	51	191
England	01J	NHS Knowsley CCG	149,571	287	244	43	163
England	08K	NHS Lambeth CCG	325,917	626	532	94	355
England	15F	NHS Leeds CCG	789,194	1,515	1,288	227	859
England	04C	NHS Leicester City CCG	355,218	682	580	102	387
England	08L	NHS Lewisham CCG	303,536	583	495	87	330
England	03T	NHS Lincolnshire East CCG	237,642	456	388	68	259
England	04D	NHS Lincolnshire West CCG	241,193	463	394	69	263
England	99A	NHS Liverpool CCG	494,814	950	808	143	539

Nation	Code	Organisation name	Population	Total with MS	RRMS	PPMS	SPMS
England	06P	NHS Luton CCG	214,109	411	349	62	233
England	14L	NHS Manchester CCG	547,627	1,051	894	158	596
England	04E	NHS Mansfield and Ashfield CCG	200,715	385	328	58	218
England	09W	NHS Medway CCG	277,855	533	453	80	302
England	08R	NHS Merton CCG	206,186	396	336	59	224
England	06Q	NHS Mid Essex CCG	393,065	755	641	113	428
England	04F	NHS Milton Keynes CCG	275,002	528	449	79	299
England	01K	NHS Morecambe Bay CCG	330,572	635	539	95	360
England	04G	NHS Nene CCG	659,823	1,267	1,077	190	718
England	04H	NHS Newark and Sherwood CCG	121,830	234	199	35	133
England	13T	NHS Newcastle Gateshead CCG	502,704	965	820	145	547
England	08M	NHS Newham CCG	352,005	676	574	101	383
England	01H	NHS North Cumbria CCG	318,631	612	520	92	347
England	00J	NHS North Durham CCG	251,666	483	411	72	274
England	06T	NHS North East Essex CCG	338,326	650	552	97	368
England	99M	NHS North East Hampshire and Farnham CCG	211,590	406	345	61	230
England	03H	NHS North East Lincolnshire CCG	159,821	307	261	46	174
England	10J	NHS North Hampshire CCG	223,795	430	365	64	244
England	03J	NHS North Kirklees CCG	192,750	370	315	56	210
England	03K	NHS North Lincolnshire CCG	172,005	330	281	50	187
England	06V	NHS North Norfolk CCG	173,784	334	284	50	189
England	05G	NHS North Staffordshire CCG	219,571	422	358	63	239
England	99C	NHS North Tyneside CCG	205,985	395	336	59	224
England	09Y	NHS North West Surrey CCG	348,734	670	569	100	380
England	00L	NHS Northumberland CCG	320,274	615	523	92	349
England	06W	NHS Norwich CCG	219,071	421	358	63	238
England	04K	NHS Nottingham City CCG	331,069	636	540	95	360
England	04L	NHS Nottingham North and East CCG	152,799	293	249	44	166
England	04M	NHS Nottingham West CCG	113,272	217	185	33	123
England	00Y	NHS Oldham CCG	235,623	452	385	68	256
England	10Q	NHS Oxfordshire CCG	672,414	1,291	1,097	194	732
England	10R	NHS Portsmouth CCG	215,133	413	351	62	234
England	08N	NHS Redbridge CCG	303,858	583	496	88	331
England	05J	NHS Redditch and Bromsgrove CCG	183,651	353	300	53	200
England	08P	NHS Richmond CCG	196,904	378	321	57	214
England	03L	NHS Rotherham CCG	264,671	508	432	76	288

Nation	Code	Organisation name	Population	Total with MS	RRMS	PPMS	SPMS
England	04N	NHS Rushcliffe CCG	117,671	226	192	34	128
England	01G	NHS Salford CCG	254,408	488	415	73	277
England	05L	NHS Sandwell and West Birmingham CCG	504,641	969	824	145	549
England	03M	NHS Scarborough and Ryedale CCG	113,338	218	185	33	123
England	03N	NHS Sheffield CCG	582,506	1,118	951	168	634
England	05N	NHS Shropshire CCG	320,274	615	523	92	349
England	11X	NHS Somerset CCG	559,399	1,074	913	161	609
England	01R	NHS South Cheshire CCG	183,494	352	299	53	200
England	05Q	NHS South East Staffordshire and Seisdon Peninsula CCG	226,137	434	369	65	246
England	10V	NHS South Eastern Hampshire CCG	216,379	415	353	62	236
England	10A	NHS South Kent Coast CCG	211,462	406	345	61	230
England	99D	NHS South Lincolnshire CCG	150,698	289	246	43	164
England	06Y	NHS South Norfolk CCG	235,551	452	384	68	256
England	01T	NHS South Sefton CCG	159,237	306	260	46	173
England	00M	NHS South Tees CCG	277,263	532	452	80	302
England	00N	NHS South Tyneside CCG	150,265	289	245	43	164
England	05R	NHS South Warwickshire CCG	270,064	519	441	78	294
England	04Q	NHS South West Lincolnshire CCG	126,300	242	206	36	137
England	05T	NHS South Worcestershire CCG	307,344	590	502	89	335
England	10X	NHS Southampton CCG	252,796	485	413	73	275
England	99G	NHS Southend CCG	182,463	350	298	53	199
England	01V	NHS Southport and Formby CCG	116,159	223	190	33	126
England	08Q	NHS Southwark CCG	317,256	609	518	91	345
England	01X	NHS St Helens CCG	180,049	346	294	52	196
England	05V	NHS Stafford and Surrounds CCG	155,803	299	254	45	170
England	01W	NHS Stockport CCG	291,775	560	476	84	318
England	05W	NHS Stoke on Trent CCG	264,149	507	431	76	288
England	00P	NHS Sunderland CCG	277,417	533	453	80	302
England	99H	NHS Surrey Downs CCG	292,579	562	477	84	318
England	10C	NHS Surrey Heath CCG	96,474	185	157	28	105
England	08T	NHS Sutton CCG	204,525	393	334	59	223
England	10D	NHS Swale CCG	117,559	226	192	34	128
England	12D	NHS Swindon CCG	228,258	438	373	66	248
England	01Y	NHS Tameside and Glossop CCG	258,613	497	422	74	282
England	05X	NHS Telford and Wrekin CCG	177,799	341	290	51	194
England	10E	NHS Thanet CCG	141,819	272	231	41	154

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England	07G	NHS Thurrock CCG	172,525	331	282	50	188
England	08V	NHS Tower Hamlets CCG	317,705	610	518	91	346
England	02A	NHS Trafford CCG	236,370	454	386	68	257
England	03Q	NHS Vale of York CCG	362,955	697	592	105	395
England	02D	NHS Vale Royal CCG	106,251	204	173	31	116
England	03R	NHS Wakefield CCG	345,038	662	563	99	376
England	05Y	NHS Walsall CCG	283,378	544	462	82	308
England	08W	NHS Waltham Forest CCG	276,700	531	452	80	301
England	08X	NHS Wandsworth CCG	326,474	627	533	94	355
England	02E	NHS Warrington CCG	209,547	402	342	60	228
England	05H	NHS Warwickshire North CCG	193,752	372	316	56	211
England	02F	NHS West Cheshire CCG	234,251	450	382	67	255
England	07H	NHS West Essex CCG	306,910	589	501	88	334
England	11A	NHS West Hampshire CCG	566,879	1,088	925	163	617
England	99J	NHS West Kent CCG	490,426	942	800	141	534
England	02G	NHS West Lancashire CCG	113,949	219	186	33	124
England	04V	NHS West Leicestershire CCG	402,165	772	656	116	438
England	08Y	NHS West London CCG	226,099	434	369	65	246
England	07J	NHS West Norfolk CCG	175,904	338	287	51	191
England	07K	NHS West Suffolk CCG	230,997	444	377	67	251
England	02H	NHS Wigan Borough CCG	326,088	626	532	94	355
England	99N	NHS Wiltshire CCG	498,064	956	813	143	542
England	12F	NHS Wirral CCG	323,235	621	528	93	352
England	06A	NHS Wolverhampton CCG	262,008	503	428	75	285
England	06D	NHS Wyre Forest CCG	101,062	194	165	29	110
Scotland	S08000015	Ayrshire and Arran	369,670	1,087	924	163	616
Scotland	S08000016	Borders	115,270	339	288	51	192
Scotland	S08000017	Dumfries and Galloway	148,790	437	372	66	248
Scotland	S08000029	Fife	371,910	1,093	929	164	620
Scotland	S08000019	Forth Valley	306,070	900	765	135	510
Scotland	S08000020	Grampian	584,550	1,719	1,461	258	974
Scotland	S08000021	Greater Glasgow and Clyde	1,174,980	3,454	2,936	518	1,958
Scotland	S08000022	Highland	321,800	946	804	142	536
Scotland	S08000023	Lanarkshire	659,200	1,938	1,647	291	1,099
Scotland	S08000024	Lothian	897,770	2,639	2,244	396	1,496
Scotland	S08000025	Orkney	22,190	65	55	10	37
Scotland	S08000026	Shetland	22,990	68	57	10	38
Scotland	S08000030	Tayside	416,080	1,223	1,040	183	694
Scotland	S08000028	Western Isles	26,830	79	67	12	45

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Wales	W11000023	Betsi Cadwaladr University Health Board	698,369	1,243	1,057	186	705
Wales	W11000024	Powys Teaching Health Board	132,447	236	200	35	134
Wales	W11000025	Hywel Dda University Health Board	385,615	686	583	103	389
Wales	W11000031	Swansea Bay University Health Board	389,372	693	589	104	393
Wales	W11000030	Cwm Taf Morgannwg University Health Board	445,190	792	674	119	449
Wales	W11000028	Aneurin Bevan University Health Board	591,225	1,052	895	158	597
Wales	W11000029	Cardiff and Vale University Health Board	496,413	884	751	133	501
N. Ireland	N/A	Belfast HSC Trust	357,625	951	809	143	539
N. Ireland	N/A	Northern HSC Trust	476,942	1,269	1,078	190	719
N. Ireland	N/A	South Eastern HSC Trust	361,329	961	817	144	545
N. Ireland	N/A	Southern HSC Trust	383,541	1,020	867	153	578
N. Ireland	N/A	Western HSC Trust	302,204	804	683	121	456



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