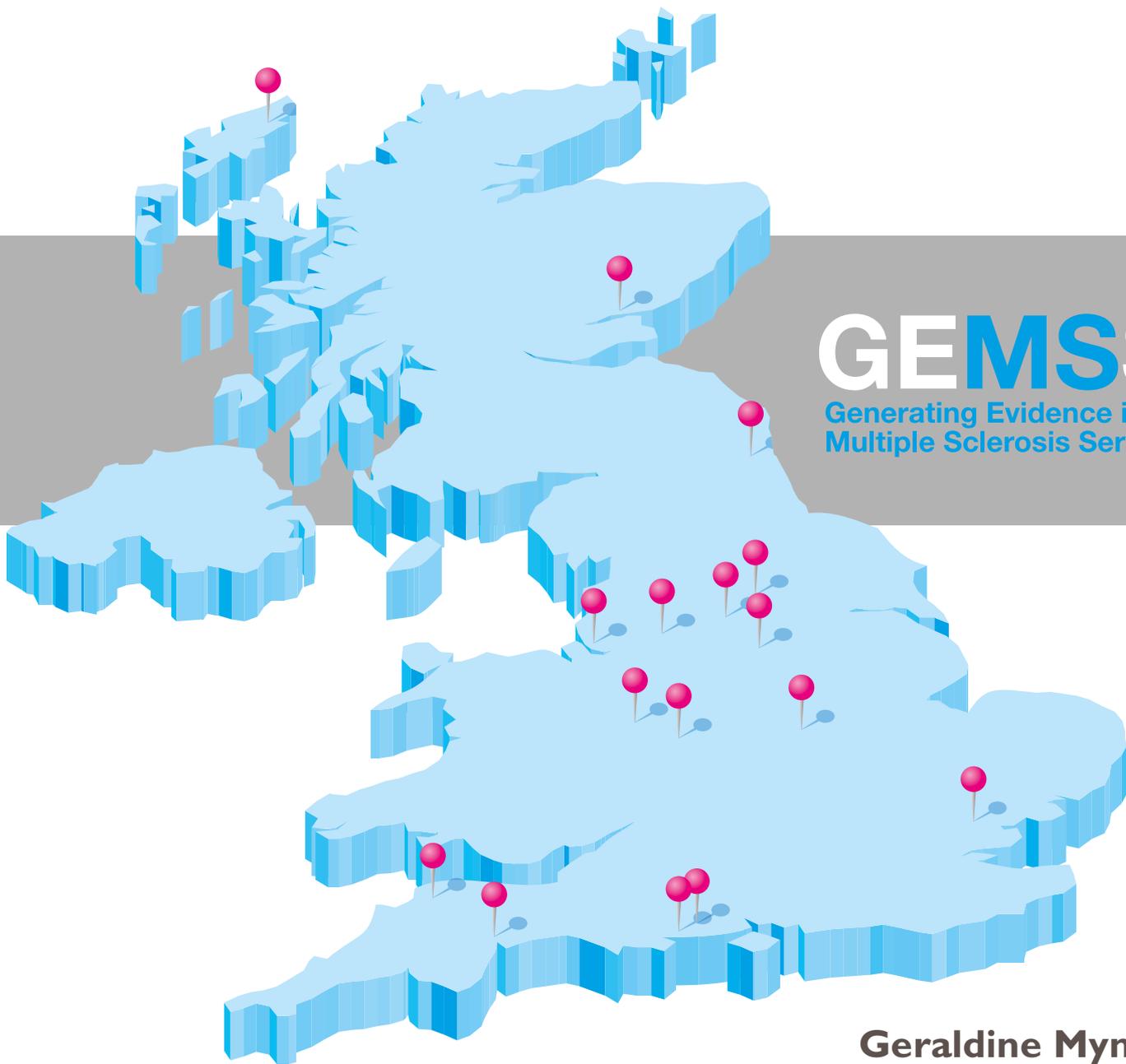


Evidence for MS Specialist Services:

Findings from the **GEMSS**
MS specialist nurse
evaluation project



GEMSS
Generating Evidence in
Multiple Sclerosis Services

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Abbreviations used in this report:

AHP	Allied Health Professional
CCG	Clinical Commissioning Group
CIS	Clinically Isolated Syndrome
DMDs	Disease Modifying Drugs
IV	Intravenous
MDT	Multidisciplinary team
MSSN	MS specialist nurse
NHS FT	NHS Foundation Trust
PPMS	Primary progressive MS
pwMS	People with MS
RRMS	Relapsing remitting MS
SMART	Specific, Measurable, Achievable, Relevant, Time-bounded
SNIAT	Specialist Neurological Intervention Audit Tool
SPMS	Secondary progressive MS
WTE	Whole Time Equivalent



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Note: On some stacked bar charts, numbers do not add up to exactly 100%. This is due to rounding.



Foreword

Each person with multiple sclerosis has a unique experience of living with the condition. There are many symptoms of MS and these affect each person differently and for each individual, their future is difficult to predict. The MS Trust believes that everyone affected by MS needs access to health professionals who understand this challenging long term condition and are skilled to treat it. MS specialists are key to ensuring that expert care is available for every individual.

The MS Trust created and supports the GEMSS programme in order to make sure that people with MS, of whatever type or stage, can continue to receive the best possible care, that the NHS can be confident that the resources invested in MS care are well spent and that MS health professionals have the tools and resources they need to continue to improve the services they provide.

GEMSS is a unique collaboration. Our goal has been to work alongside the MS teams to help them become more effective and to secure and improve their services in a challenging financial environment. The MS Trust has been at the forefront of supporting MS specialist nurses for many years and we have focused the first project in the GEMSS programme on their role. We know that there are still not enough MS nurses in the UK and that many are working under very challenging conditions. GEMSS aims to ensure that they have the evidence, the support and the skills to demonstrate their value, to make meaningful improvements to their services and, where appropriate, to grow their services to ensure that everyone with MS receives the care they need.

The findings in this report demonstrate how far MS nursing has come and sets an agenda for future improvement, based on evidence drawn directly from MS services and the people with MS using them. Critically, the report also highlights the vital importance of the wider multidisciplinary team in providing a high quality and equitable service. MS specialist nurses are one element of the support team needed by people living with MS, a team involving physiotherapists, occupational therapists, psychologists, neurologists and rehabilitation physicians along with many other community services.

We would like to thank all the MS nurses and allied health professionals, along with others in their teams that participated in the project. Their commitment, perseverance and creativity within the project was unfailing and their dedication to improving care for people with MS is truly inspirational.

We hope this report will help the continued drive to improve care for people living with MS. We look forward to continuing to work with NHS MS services and the experts providing them.

Pam Macfarlane

Chief Executive



I. Introduction

This chapter presents:

- The background to the GEMSS programme and its objectives
- A brief introduction to what MS is and how it affects people living with it
- Why collecting outcomes data for specialist nursing services is challenging
- An overview of the project approach and evaluation framework
- What is in the rest of this report

GEMSS (Generating Evidence in MS Services) is a national programme of work, funded and facilitated by the MS Trust, which aims to help health professionals working in MS to evaluate and improve their services and to demonstrate what works best to meet the needs of people with MS. This report draws on data collected through the first project within the GEMSS programme, focusing on the value of MS specialist nursing in the UK. The project, whilst having evaluation of MS specialist nursing as its primary objective, has also involved members of the wider multidisciplinary MS team needed by people with MS to help them manage this complex condition.

This report has a number of intended audiences:

For MS specialist nurses and their managers	It represents a compendium of data about what MSSN services can achieve, against which other services can benchmark themselves. It also highlights ways in which MSSN services can improve.
For service managers and commissioners	<p>It demonstrates the value of MS specialist nurses to people with MS across the disease trajectory. It also validates the value of MSSNs to the NHS and sets out a clear definition of what MSSNs can deliver.</p> <p>The report highlights the importance of the wider multidisciplinary team in supporting people living with MS throughout the disease trajectory and clarifies how MS specialist nurses fit into this broader context of multidisciplinary MS care.</p>
For policy makers	It highlights the ongoing inequity between people with MS who live in areas where MSSNs have sustainable caseloads and those who do not, and calls for all services to be resourced at a level where everyone with MS can benefit.



1.1 Why the GEMSS MS specialist nurse evaluation project?

The impetus for the project was the publication of *Defining the value of MS specialist nurses* by the MS Trust in March 2012. This report found that, whilst people with MS and other health professionals had a compelling story to tell about the positive value of MS specialist nurses, there was little published evidence to demonstrate that services were effective. Furthermore, MSSNs themselves lacked the skills, tools, time and impetus to collect data about their service activity and outcomes which could build the evidence base. *Defining the value* identified further work needed to strengthen the case for specialist services, specifically:

- To describe clearly the different service models currently operating amongst different MS nurses.
- To define clearly what is meant by 'caseload', make explicit the assumptions underpinning the idea of an acceptable caseload, and define what this is, according to service models.
- To share good practice across the MS nursing community in terms of efficient and effective working practices.
- To develop a set of 'SMART', evidence-based quality standards for MS nursing services, against which performance can be measured, together with an effective tool for measuring the experiences of people with MS.
- To improve MS nurses' skills in evaluating their services through data collection, clinical audit and measuring patient experience.
- To bring together data on the value of MS specialist nurses to make a robust case to commissioners.

GEMSS was launched to address these issues. The MS specialist nurse project is the flagship GEMSS project and aims to support MSSN services to address the evidence gap around service effectiveness, whilst building the skills and confidence of health professionals to collect and analyse data and develop insights about services. GEMSS therefore has a professional development component and a service development component, helping to create an improvement culture in the services taking part.

In addition, GEMSS aims to leave a lasting legacy for MS services more generally by developing a set of common quality standards and tools by which they can be measured. The MSSN project has benefitted greatly from the involvement of allied health professionals (AHPs) from some of the participating teams. This has strengthened the insights arising from the project and reinforced the importance of a multidisciplinary service to comprehensively meet the needs of people with MS. None of the health or social care professionals who work with people affected by MS can be effective in isolation. The GEMSS programme will continue to work with AHPs and the wider MS team and publish further reports to continue the drive to improve services.



A brief introduction to MS^a

The **range of symptoms and disabilities** caused by MS, and the **unpredictable course** of the disease, make it particularly complex and challenging to manage.

There are three main types of MS. 85% of those people diagnosed have **relapsing remitting MS (RRMS)** at onset¹. When experiencing a relapse, people with MS can become very unwell for a period of days, weeks or months. They may recover completely, but around half of relapses leave some form of residual disability². Many people with relapsing remitting MS are treated with **disease modifying drugs (DMDs)**. These are typically started soon after diagnosis to reduce the severity and frequency of relapses³, and they may reduce disability⁴. Until recently, most DMDs were administered by self-injection or IV infusion, but some newer treatments are given orally. Injectable DMDs require patients to be trained in their use, and all DMDs carry risks and have an intensive schedule of monitoring for safety and efficacy.

Many people are diagnosed with MS in their 20s and 30s when they may be studying for qualifications or building their career. MS is also more prevalent in women than men, which gives rise to additional issues around planning a family and the impact of pregnancy and childbirth. Women with MS need to consider how their choices might impact on the course of the condition as well as the risks from MS medications taken before and/or during pregnancy. People with MS need support around these issues as well as concerns about work or training, negotiating changes in family relationships and ante- and post-natal support

Relapsing remitting MS may transition into **secondary progressive MS (SPMS)**, where there is a sustained increase of disability, independent of relapses. Around 58% of people with RRMS will develop SPMS, taking a median of 19 years after diagnosis⁵.

10-15% of people with MS are diagnosed with **primary progressive MS (PPMS)**⁶, where symptoms get progressively worse over time from the outset, rather than appearing as relapses. There are currently no disease modifying drugs that work in PPMS and none have any effect on the gradual accumulation of disability in SPMS⁷. Those people who develop advanced MS may be confined to wheelchair or bed, may require feeding using percutaneous endoscopic gastrostomy (PEG), have severe cognitive difficulties and significant speech problems.

All types of MS have symptoms which can include fatigue, pain, vision problems, walking difficulties, numbness, pins and needles and burning sensations, cognitive problems, continence issues, depression, sexual difficulties, speech and swallowing difficulties, spasticity and tremors. Symptoms can come and go throughout the course of the disease, and a particular symptom may be severely disabling but then improve (although often not completely). Some symptoms (such as neuropathic pain) can be very difficult to treat, and people with MS therefore need support to live with these day to day. The specialist expertise of a whole range of professionals including physiotherapists, occupational therapists, speech and language therapists,

^a Adapted from the earlier GEMSS report, [MS Specialist Nursing in the UK 2014: The case for equitable provision.](#)

For an explanation of the term 'benign MS', see the MS Trust website: <https://www.ms-trust.org.uk/a-z/types-ms>



orthoptists, psychologists, continence specialists and rehabilitation physicians may be needed at different times to assess and treat symptoms effectively, and to prevent secondary complications from developing as a result. Around 17% of people with MS were admitted to hospital in England as an emergency at least once during 2013/14 (an average of 0.26 emergency admissions per person with MS)⁸, with the most common reasons being bladder and bowel related complications and respiratory infections. Social workers, social carers and community nurses also have a vital part to play for those pwMS living with advanced MS.

MS specialist nurses play a vital expert role in assessing problems, providing treatments and advice and coordinating care, but the quality of care for people with MS is also dependent on the availability of this wider team around the MSSN who have expertise in MS. Both the National Institute for Health and Care Excellence (NICE) and Quality Improvement Scotland recommend that everyone with MS should have an annual review with an MS specialist, and that they should have access to a full multidisciplinary team when required^{9, 10}.

1.2 The GEMSS approach

The GEMSS evaluation project was conceived, funded and facilitated by the MS Trust, working collaboratively with independent evaluation consultants Geraldine Mynors and Jane Suppiah to provide the project facilitation. An Advisory Group ([Appendix E](#)) provided expert input through regular meetings.

The project ran over two phases.

- In GEMSS I (2012/13), five teams (four MS specialist nurse teams and one multidisciplinary team) worked with the MS Trust GEMSS Facilitators to co-develop an evaluation framework for MS specialist nurse services and a series of data collection tools to gather data about them. They then used these over the course of a year, April 2012 – March 2013. Each team produced an evaluation report at the end of the year for their local managers.
- In GEMSS II (2014/15), a further eleven teams (nine MS specialist and two multidisciplinary teams) evaluated their services using the tools developed in GEMSS I, from April 2014 – March 2015. Each team produced a local evaluation report and recommendations for improving their service. Four of the five GEMSS I teams continued to collect data in 2014 – 15. Some tools were adapted and piloted to capture more insights about the contribution of the multidisciplinary team.

The teams selected to take part in GEMSS were chosen through a competitive selection process to represent a cross-section of MS services, rural and urban, large and small, community and hospital based. All teams in the UK were invited to apply. In the event, two teams selected were in Scotland, the rest in England. Beyond the need to ensure diversity, the only other criterion used to select teams was a demonstrable willingness and enthusiasm to engage with the process and support from the host organisation. An important criterion for participation was that the local NHS Trust/ Health Board was willing to enter into a Memorandum of Understanding with the MS Trust to allow for the anonymised data collected to be shared, analysed and published.



Each participating GEMSS team identified one or two 'leads' for the project^b who attended a two day residential initial training. Facilitators also visited each team at the start of the project to explain it to local stakeholders and ensure that the data collection tools were in place. Ongoing support for participating teams through the year included two further face to face workshops (at MS Trust conferences), regular conference calls, further site visits from facilitators and phone/email support as needed.

A separate report¹¹ describes in more detail the process of running the project and the impact of the project on participants and their services. [Appendix A](#) describes the evaluation tools that were developed with the project participants to collect data.

Whilst the focus of GEMSS is MS specialist nurses, one team in GEMSS I and two in GEMSS II included allied health professionals^c, and this afforded the opportunity for the data collection tools to be piloted with other professions and to develop insights about the value of therapy services for people with MS. This report focuses on the GEMSS findings for MSSNs, but [Figure 26](#) below highlights the importance of multidisciplinary team working, and the data collected by the AHPs who took part in GEMSS will be published separately^{d,12}.

1.3 The GEMSS evaluation framework and data collection tools

There are significant challenges in collecting evidence about how MSSNs achieve improvements in outcomes for people with MS. Specialist nursing is a complex intervention with multiple inputs and multiple outcomes which are difficult to measure.

- Specialist nurses work within multidisciplinary teams, with many different service models, hence attribution of outcomes to nurses specifically is challenging.
- MS specialist nurses now cover virtually all of the UK (albeit with unmanageably large caseloads in some areas) and hence it is neither possible nor ethical to establish a matched control group of people with MS (pwMS) without access to an MSSN, against which to compare outcomes.
- MS is a progressive condition in which deterioration is probable for most, and hence the challenge is to measure relative, rather than absolute improvements, something which is very difficult without a control group.
- There is a lack of reliable data, either nationally or locally, on the prevalence of MS and the use of health services by people with MS – data which could be used to relate differences in use of nursing services to differences in unscheduled care, for example.

For this reason, the GEMSS project was conceived as a pragmatic evaluation, as distinct from a research study, collecting data from multiple sources to build up a picture of services and what they achieve. At the outset, an evaluation framework for MS specialist nursing ([Figure 1](#)) was developed jointly with teams taking part in GEMSS and the GEMSS Advisory Group. This identified the activities which MSSNs undertake^e, the ways of working which define MSSN activity and the outcomes which

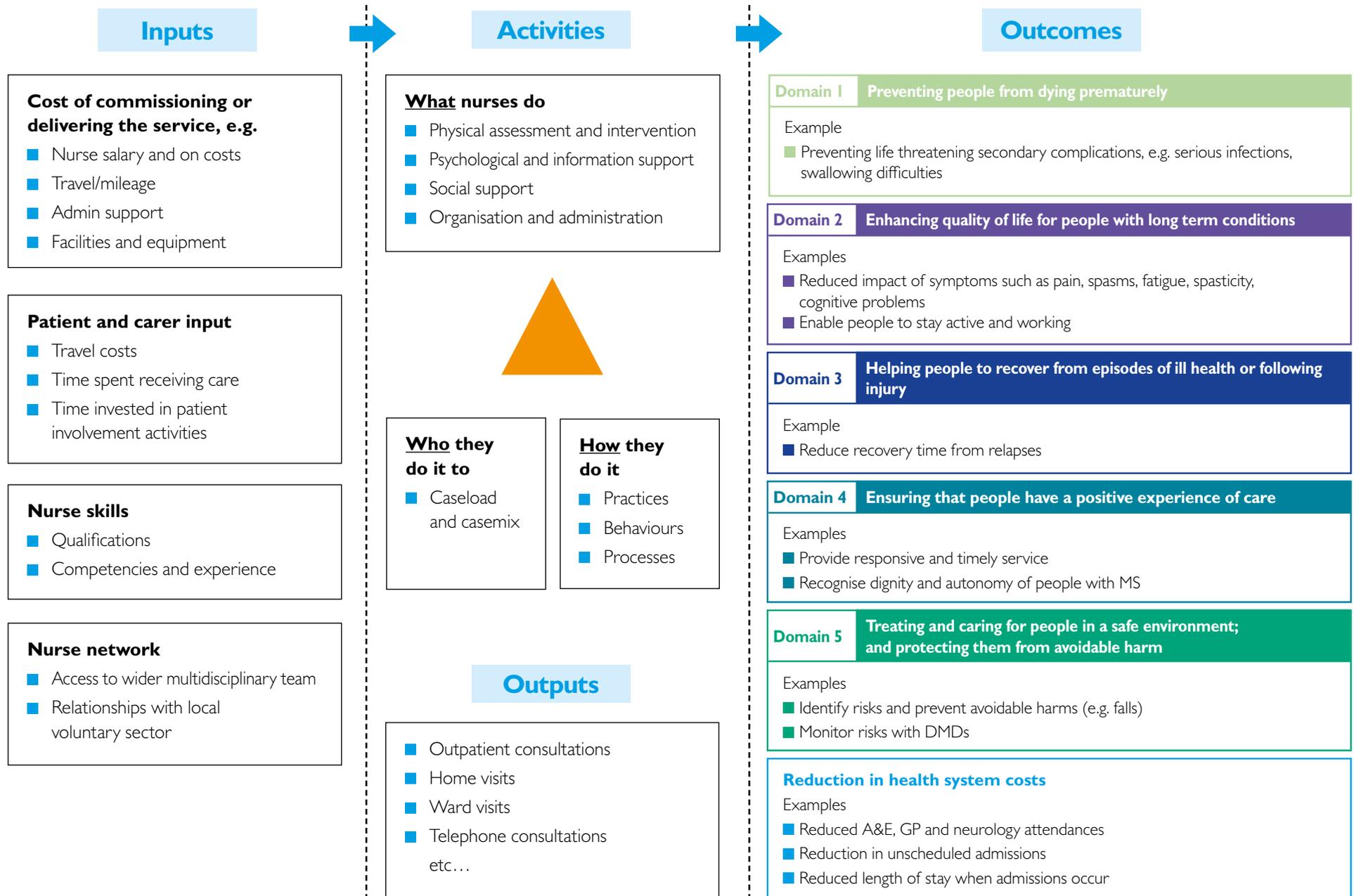
b In smaller teams the Leads comprised the whole team.

c 4 physiotherapists, 3 occupational therapists and an orthoptist. An MS social worker also took part.

d Because of the relatively small number of AHPs who took part from each profession, drawing general conclusions is challenging. However, the SNIAT data will be published in the article referenced, and a forthcoming article in the MS Trust Way Ahead periodical will report on the patient survey results for AHPs.

e MSSN activities along the disease trajectory of MS are described in detail in an earlier GEMSS report, [MS specialist nursing in the UK 2014: the Case for Equitable Provision](#).

Figure 1: Summary of the GEMSS evaluation framework





MSSNs seek to achieve for their patients, mapped to the five domains of the NHS Outcomes Framework for England and to the three Quality Ambitions for Scotland.

Evaluation tools were developed in collaboration with participating MSSNs to enable teams to collect data about their services to demonstrate whether, and how, their services delivered the evaluation framework activities and outcomes. In summary, the following data was collected:

Inputs	<ul style="list-style-type: none"> ■ Detailed description of each service
Activities	<ul style="list-style-type: none"> ■ Caseload register, including age, gender, type of MS, disability and disease modifying drugs (DMDs) used ■ Performance against four GEMSS Key Process Indicators on service responsiveness ■ Topics covered and interventions carried out during consultations (three week audit opted into by six teams)
Outputs	<ul style="list-style-type: none"> ■ Service activity – e.g. consultations, home visits, ward visits, patient group education sessions, phone calls ■ Activity against capacity in job plans (opted into by eight teams)

1.4 Other outputs from the project

Using the first six months of GEMSS data collected in 2014/15, together with a national survey of MS specialist nurses, the MS Trust developed and published a 'sustainable caseload' model for MSSNs¹³ and a national report identifying estimated caseloads for MSSNs serving each Clinical Commissioning Group and Health Board in the UK¹⁴.

The GEMSS patient survey has also been made available more widely to any MS team who wishes to use it via the MS Trust Patient Survey Service^f and the GEMSS capacity planning tool has been shared at MS Trust workshops and remains available. The MS Trust is currently using the GEMSS data to develop a model business case for MS specialist nurse services.

^f See the [MS Trust website](#) for details.



1.5 In the rest of this report

The remainder of this report highlights the findings of GEMSS based on the data collected during 2014/5 by 34 MS specialist nurses working across 15 services which, together, have a combined caseload of more than 15,000 people with MS.

- In [Chapter 2](#), we describe the **teams who took part** and highlight similarities and differences in service models.
- In [Chapter 3](#), we give an **overview of the caseload data** collected through GEMSS, which offers some valuable insights about the overall characteristics of pwMS in the UK, issues related to work and employment, and their contact with health professionals.
- In [Chapter 4](#), we describe the **activity of the GEMSS teams**, including the topics covered during consultations with pwMS and report on their performance in terms of responsiveness, highlighting differences in productivity between teams and reasons for this.
- In [Chapter 5](#), we describe the **outcomes of MSSN** input for people with MS and for other professionals working with them, based on the surveys carried out during GEMSS.
- In [Chapter 6](#), we discuss what the GEMSS data is able to show us about the **economic effectiveness of MSSN services** in the NHS.
- Finally, in [Chapter 7](#) we present the report's conclusions, highlight some of the **challenges** which MS specialist nursing is currently facing, **opportunities** for improving MS specialist nurse services which the GEMSS data has revealed and issues relating to the wider context for MS multidisciplinary services.



Chapter 2: The GEMSS Teams

This chapter presents:

- An overview of the GEMSS teams and their caseloads
- Differences in the models of service operating among the teams
- The varying roles of MSSNs in relation to disease modifying drugs and advanced practice activities
- Service case studies illustrating the diversity of teams within GEMSS

Key findings:

- The average caseload of the GEMSS teams is 511 people with MS per whole time MSSN, far in excess of the 358 'sustainable' caseload recommended by the MS Trust. Three teams have more than twice the sustainable caseload.
- There are broadly three models of care operating in terms of who each team focuses on: everyone with MS in their area, those on DMDs or those with progressive MS.
- MSSNs have different roles in relation to DMDs, depending on whether or not they are based within a centre where DMDs are prescribed.
- Most MSSNs are employed at band 7 and work in small teams, but some larger teams have greater diversity of roles which allows for succession planning.
- Only around a quarter of MSSNs in GEMSS are nurse prescribers, but those who are cite major benefits in terms of their ability to manage whole episodes of care.

The GEMSS teams were chosen to represent a wide range of services. The map in [Figure 2](#) shows the 16 teams who took part in GEMSS phases I and II.

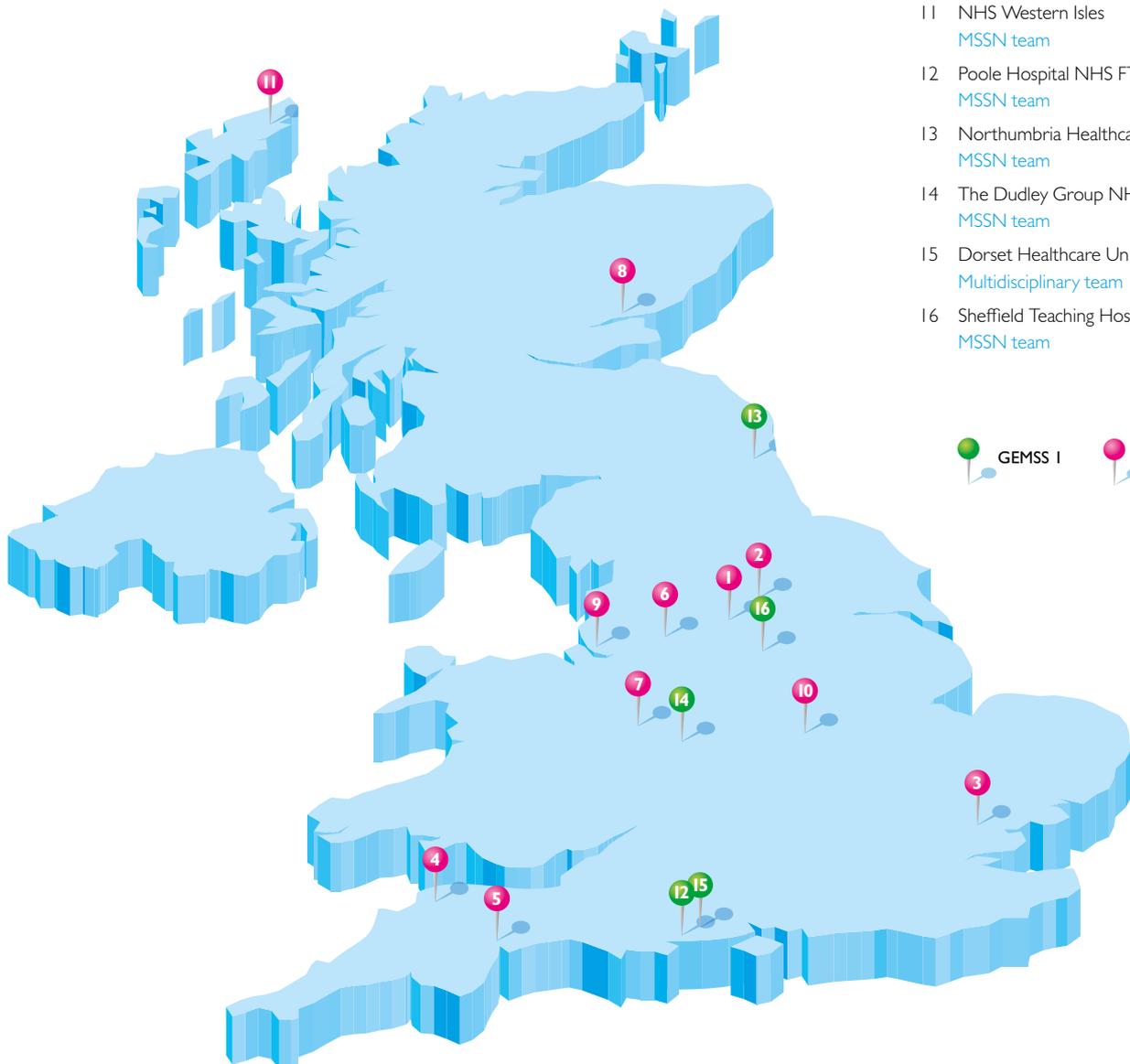
The 15 teams collecting GEMSS data in 2014/15 are summarised in [Figure 3](#)^g. The caseload descriptions are elaborated further in [2.1](#) below. At March 2015, the MSSNs in these teams had a combined caseload of over 15,000 pwMS. Based on recent prevalence estimates¹⁵ the English teams' caseloads represent around 15% of pwMS in England, and the Scottish teams' caseloads represent approximately 12% of pwMS in Scotland.

^g The Sheffield Teaching Hospitals team took part in GEMSS I but did not continue with data collection in 2014/15.



Figure 2: Map of GEMSS teams

- | | | |
|--|---|---|
| 1 Calderdale & Huddersfield NHS FT
MSSN team | 5 Royal Devon and Exeter NHS FT
MSSN team | 8 Tayside and North Fife
Regional MS Service
Multidisciplinary team |
| 2 Leeds Teaching Hospitals NHS Trust
MSSN team | 6 Salford Royal NHS FT
MSSN team | 9 The Walton Centre NHS FT
Multidisciplinary team |
| 3 Mid Essex Hospital Services NHS Trust
MSSN team | 7 The Shrewsbury and Telford Hospital
NHS Trust
MSSN team | 10 University Hospitals of Leicester
NHS Trust
MSSN team |
| 4 Northern Devon Healthcare NHS Trust
MSSN team | | 11 NHS Western Isles
MSSN team |
| | | 12 Poole Hospital NHS FT
MSSN team |
| | | 13 Northumbria Healthcare NHS Trust
MSSN team |
| | | 14 The Dudley Group NHS FT
MSSN team |
| | | 15 Dorset Healthcare University NHS FT
Multidisciplinary team |
| | | 16 Sheffield Teaching Hospitals NHS FT
MSSN team |



 GEMSS 1
  GEMSS 2



Figure 3: MS specialist nurse teams collecting data in 2014/15

Team name ^h	WTE MSSNs in team ⁱ	Caseload at March 2015	DMD prescribing? ^j	Summary of caseload covered by the service
Calderdale & Huddersfield	2	858	N	All pwMS, shared care with Leeds for people on DMDs
Dorset Neurology Service	0.9	301 ^k	N	MS caseload is part of wider neuro-rehab caseload. Focus on people with progressive MS/complex needs, others in area go to Poole
Dudley ^l	0.8	303	Y	All pwMS, no home visiting, community MS nurse covers people with complex needs
Exeter	1	745	Y	All pwMS
Leeds	2	1006	Y	All pwMS in City of Leeds, people on DMDs only for outlying areas
Leicester	1.6	1511	Y	All pwMS
Mid Essex	1.35	629	Y	All pwMS, but no home visiting
Northern Devon	1	404	Y	All pwMS
Northumbria	1.8	363	N	Focus on progressive MS, shared care with Newcastle for people on DMDs
Poole	2.4	941	Y	All pwMS in West Dorset, otherwise focus on RRMS as Dorset Neurology Service covers people with complex needs
Salford	7.3 ^m	3691	Y	All pwMS
Shrewsbury & Telford	1.8	1054	Y	All pwMS
Tayside	2.33	1280	Y	All pwMS
Walton Centre	2.35	1940 ⁿ	Y	All pwMS but no home visiting
Western Isles	0.9	92	N	All pwMS, shared care with Glasgow for people on DMDs
TOTAL	29.53	15118		

h Abbreviated team names are used from here on throughout this report for brevity.

i Average numbers working across the year 2014/15. In some cases this does not reflect the full establishment of the service where MSSNs were on long term sick leave or there were vacancies.

j This denotes whether disease modifying drugs (DMDs) are prescribed by neurologists working within the service. This is distinct from the 72 DMD Prescribing Centres designated under the Department of Health Risk-sharing Scheme.

k The MS caseload is part of a wider caseload of 729 people with neurological conditions. The MS nurse is one of five neuro-practitioners in the service.

l Only the hospital based MSSN took part in the GEMSS project. Dudley Group is an integrated hospital/community provider and the community based MSSN within the team did not take part in GEMSS.

m Includes 60% of the time of the MS nurse consultant in the team which designated for clinical activity.

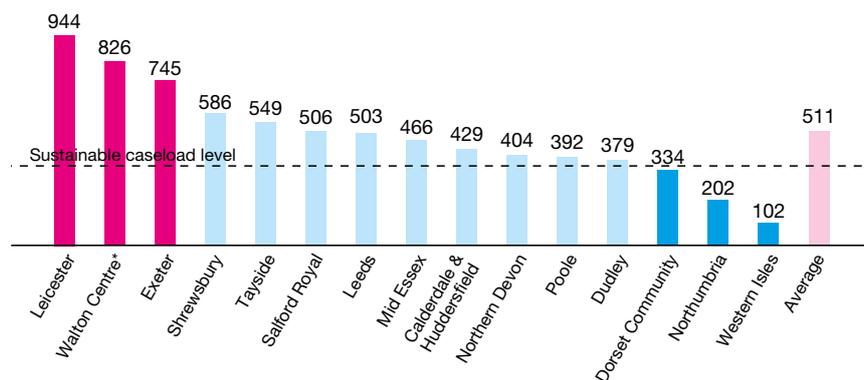
n The stated Walton Centre caseload represents only pwMS who were seen by an MS specialist nurse or AHP or called the Nurse Advice Line in 2014/15. The Walton Centre has a wider caseload of approximately 3900 pwMS under the care of a neurologist.



The teams' organisational settings range from neuroscience centres (Salford, the Walton Centre, Leeds and Tayside) to community based providers (Northumbria, Western Isles, Dorset Neurology Service), with the remainder of the teams based in other hospital settings. The teams also vary in size, with Salford being the largest MSSN team in the UK and three teams having lone-working MSSNs^o.

Figure 4 shows the caseload per whole time equivalent (WTE) MSSN of the GEMSS teams. Twelve of the 15 teams have more than the MS Trust recommended 'sustainable' caseload of 358 pwMS per WTE MSSN¹³ and three, shown in dark pink, (Leicester, the Walton Centre and the Royal Devon & Exeter) have more than twice the recommended caseload. The three teams with 'sustainable' caseloads, shown in dark blue, are exceptionally rural (Northumbria and Western Isles) and/or focused on people with progressive MS and complex needs (Northumbria, Dorset Neurology Service), and hence the 'sustainable' number will inevitably be lower.

Figure 4: Caseload per WTE nurse



^o This is reasonably reflective of the UK: as at July 2014, MS Trust data shows that of 145 MSSN 'teams' across the UK, 84 were single handed MSSNs, 57 had 2-4 nurses and only four teams had 5+ nurses.

* Caseload relates to pwMS in contact with the MSSNs and AHPs in the past year, which is a subset of the full Walton Centre caseload of pwMS.



2.1 Differences in service models

MS specialist nursing is a relatively new profession, but the role is constantly developing. Caseloads are growing and ageing as people with MS live for longer¹⁶, and increasingly MSSNs are required to manage complex care for people with advanced MS. The pace of change within DMDs has been fast, placing demands on MSSNs to enhance their practice and revise pathways. MS prevalence means that MS nursing operates on relatively small scale within most Trusts and Health Boards, with many one- and two-nurse teams. The commissioning of MS services in England is characterised by complexity and variation (discussed in [Chapter 6](#)). All 34 MSSNs taking part in GEMSS undertake broadly the same range of roles in relation to pwMS on their caseload, throughout the disease trajectory, from new diagnosis through to progressive disease and complex care, as described in MS Specialist nursing: The Case for Equitable Provision¹⁴.

However, there are a number of important differences in the models of care operating among the GEMSS teams, as highlighted in [Figure 3](#) above.

2.1.1 Caseload across the disease trajectory

There are three broad service models, differentiated by whether the service covers everyone with MS or focuses on those with RRMS or progressive MS and more complex needs.

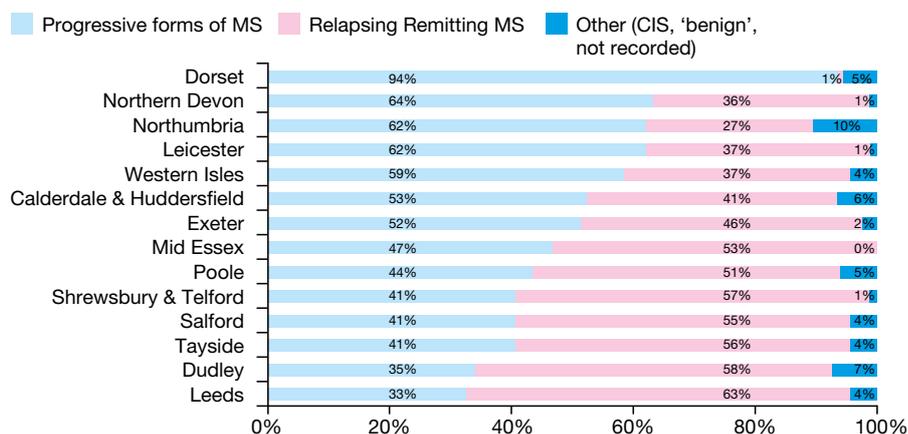
Services covering everyone with MS	The majority of services aim to cover everyone with MS in their locality across the disease trajectory from diagnosis to advanced disability and end of life care.
Focus on people with relapsing remitting MS and those taking DMDs	Some hospital based services (e.g. Dudley) have community based MSSNs or disability/rehabilitation teams on part of their 'patch' focusing on people with progressive MS and therefore focus more on those with relapsing remitting MS and DMDs. Some services (e.g. Poole, Leeds and Sheffield ^p) are 'hybrids': they manage everyone with MS for part of their 'patch' and just those with RRMS or needing DMDs for other areas.
Focus on people with progressive MS and complex needs/advanced disability	Community based multidisciplinary rehabilitation or specialist nurse teams may focus on people with progressive MS and more complex needs, often as part of a wider neurology caseload. Dorset Neurology service and the community MSSN service within the Dudley Group MS service (not part of GEMSS) are examples.

These models are reflected in the varying breakdown of types of MS within MSSN team caseloads, shown in [Figure 5](#) opposite.

^p The Sheffield team was part of GEMSS I but did not collect data in GEMSS II.



Figure 5: Type of MS within GEMSS team caseloads



2.1.2 Different roles in relation to Disease Modifying Drugs

MSSNs play a key role in supporting treatment with **disease modifying drugs** (DMDs). These may be prescribed for relapsing remitting MS, typically beginning soon after diagnosis, to reduce the frequency and severity of relapses. Until recently, most DMDs were administered by self-injection at home or IV infusion in hospital but some of the newer DMDs are taken orally. Injectable DMDs require pwMS to be trained in their use. DMDs are currently evolving rapidly, with three new drugs approved by NICE during 2014^q. All DMDs have the potential for side effects and carry small, but potentially serious risks.

MSSNs play a number of roles in relation to DMDs, including:

- Identifying pwMS who may benefit from DMD treatment and alerting neurology colleagues to this
- Supporting pwMS through the decision making process about whether to start on a DMD and which one to choose, from the options available based on their history and knowledge of the eligibility criteria
- Liaising with pharmacists and home delivery companies
- Arranging blood monitoring and other monitoring for safety and efficacy and following up on results
- Supporting pwMS to identify and manage side effects, such as injection site reactions and gastric problems
- Supporting pwMS to switch/escalate or discontinue therapy depending on progress.

In addition, some of the nurses undertake additional clinical activities such as:

- Carrying out injection training for self-injected DMDs (this is done by pharmaceutical company employed nurses in some centres)
- Carrying out pre-infusion checks on pwMS coming for IV DMDs, or actually administering these IV infusions.

q NICE technology appraisals TA 303 (teriflunomide/Aubagio®), TA 312 (alemtuzumab/Lemtrada®), TA 320 (dimethylfumarate/Tecfidera®) available from www.nice.org.uk



In relation to DMDs, MSSN services fall broadly into three categories:

MSSNs based in prescribing centres	Almost all of the GEMSS MSSNs work within a prescribing centre and carry out the full range of roles in relation to DMDs.
MSSNs not within a prescribing centre but managing people with all types of MS	Three GEMSS teams (Northumbria, Calderdale & Huddersfield and Western Isles) share care for people on DMDs with their nearest neurology centre (Newcastle, Leeds and Glasgow respectively). The centre will manage assessment for DMDs and the decision making process, but pwMS on DMDs are then jointly managed by the prescribing centre MSSNs (who usually undertake monitoring) and local MSSNs (who typically manage MS symptoms and relapses). Ensuring that this takes place safely and with minimal duplication, and that pwMS understand how to relate to both teams of nurses, can present additional challenges.
Caseload excludes those on DMDs	Community based multidisciplinary rehabilitation or specialist nurse teams focusing on people with complex needs will not have people taking DMDs in the caseload.

2.1.3 Setting of employment and patient contact

Where teams differ is whether or not they are able to see pwMS outside a clinic setting in their own homes or nursing homes. This difference is largely independent of employer type (community or acute provider). Two of our GEMSS teams (Walton Centre and Mid Essex) are entirely hospital based, relying on non-MS specialist community nurses to see people with advanced progressive MS who cannot make it to a clinic. All other GEMSS teams offer home visits, but vary in their capacity to reach into nursing homes.

In terms of clinic activity, all of the GEMSS teams offer clinics in a variety of acute and outreach clinic settings including peripheral hospitals, community clinics and (in some cases) GP surgeries, enabling them to offer care closer to home than would be the case if they remained in one centre.

Telephone work, and increasingly email contact, form a large proportion of the activity of the teams. All hospital based teams visit pwMS on wards if they are admitted to the hospital in which the team is based. They are able to advise ward staff and assist with discharge planning.

These issues are discussed further in section [4.5](#) on MSSN productivity below.

2.1.4 Skillmix and job banding within teams

27 of the 35 GEMSS nurses are employed as Band 7 Nurse Specialists, with two team leaders (Poole and Salford) at band 8, and the remainder at band 6.



Two of the larger teams (Salford and Leeds) also employ a support nurse at band 5 or 6 to work within the team and carry out roles such as DMD monitoring, administering IV DMDs (this work may otherwise be carried out by ward or infusion suite nurses) and other less advanced roles such as triaging incoming calls and ordering information leaflets. These are not MS specialist nurses and their head count has not been included in calculating caseload per whole time MS nurse.

Some teams have administrative support available to them for activities such as typing letters and reports, filing results, responding to non clinical telephone calls, scheduling appointments and organising self-management courses. The availability of administrative support for these routine activities is one of the underpinning assumptions in the MS Trust sustainable caseload model¹³. The value of this administrative support is highlighted in section 4.6 below. However, four teams have no administrative support at all, and a further two only have support for typing letters from neurologists' secretaries.

2.1.5 Extended roles and autonomy

The Royal College of Nursing Specialist Nursing and Advanced Practice project^r has identified a number of features which characterise advanced practice in relation to specialist nurses. These include:

- High levels of clinical experience in their field
- Qualifications and advanced skills
- Self-development and reflexive practice
- Autonomous clinical practice, including receiving and making referrals, being responsible for whole episodes of care, undertaking assessments and examinations, prescribing
- Leadership and management roles, including developing other staff
- Participation in research and educational activities/teaching.

The GEMSS MSSNs feature these characteristics to varying degrees. All of them run nurse-led clinics and receive and make referrals. All respond to pwMS contacting them about acute deteriorating symptoms and suspected relapses and are able to diagnose an MS relapse independently. Some larger services (notably the Walton Centre and Salford) operate multidisciplinary relapse clinics including neurology colleagues and in other cases the MSSN may arrange an urgent review with a neurologist to carry out a relapse assessment, depending on local protocols.

In terms of managing whole episodes of care, out of 35 MSSNs in GEMSS, eight are nurse prescribers. Being a nurse prescriber results in a step-change in autonomy in that nurses are (depending on their competencies and local policies) able to:

- Prescribe high dose steroids for relapses, with associated omeprazole, where otherwise they would need to arrange a prescription via a neurologist or GP.

^r Project publication in development.



- Prescribe a range of symptomatic treatments, typically for neuropathic pain (e.g. gabapentin, amitriptyline, nortriptyline, pregabalin, clonazepam, carbamazepine, duloxetine), spasticity (e.g. baclofen, gabapentin, tizanidine), bowel and bladder treatments.
- Renew prescriptions for DMDs which would otherwise require sign off from a neurologist.

Those nurses who are prescribers cite numerous benefits to their practice, including smoother pathways and reduced delays for pwMS to obtain treatment, the ability to discuss side effects and regimens at the time of prescribing (thereby increasing adherence), and improved patient safety compared to prescribing 'by proxy' via GPs. However, being a nurse prescriber carries both responsibilities and requirements in terms of training and access to real time advice and mentoring from an experienced prescriber to ensure their practice is safe and effective¹⁷, something which some practitioners working outside hospital settings may find challenging to achieve.

The following case studies illustrate the very diverse nature of the GEMSS teams:



Case study: Northumbria Healthcare NHS Trust – a small community based team

Team: 1.8 WTE band 7 MSSNs.

Caseload across the disease trajectory: Everyone with MS, caseload is 62% people with progressive MS.

Co-located with neurologists/DMD prescribing: No.

Role in relation to DMDs: Shared care for people on DMDs with neuroscience centre in Newcastle.

Settings for patient contact: Community clinics (six locations) and home visits (54% of consultations).

Jane Metcalfe and Miriam Forster are community based MSSNs covering rural Northumberland. The team offers a community based service to people newly diagnosed with MS right through to those requiring end of life care. The service complements the acute neurology and MSSN service delivered by the Royal Victoria Infirmary (where DMDs are prescribed) and the rehabilitation services for people with complex care needs offered at Walkergate Park Hospital, both in Newcastle.

The caseload of the service has grown rapidly from 250 in August 2012 to 363 in March 2015. Planned reviews take place at three, six or twelve monthly intervals, or at a frequency depending on patient need and the MSSNs conduct a short phone assessment before home visits leading up to this to identify the level of input required. This enables the team to direct home visit capacity to those in most need. A recent audit undertaken by the team¹⁸ showed that the service covers around half of the MS population in Northumberland, with most of the rest attending a neuroscience centre.

67% of the caseload have disability recorded as 'moderate' or 'severe' (see definition in section 3.5). The average age of people on the caseload is 58, above the GEMSS team average of 54. Most of the MSSNs' time is spent coordinating care for pwMS with complex needs, liaising with other members of the multidisciplinary team and working closely with the Community Matrons. It is not unusual for the team to drive 3000 miles in a month.

The team places particular emphasis on up-skilling other members of the community team and runs information sessions on MS for social care staff, community matrons, GPs, nursing home staff and therapists. They are involved in running Getting to Grips self management courses facilitated by the Northumberland MS Society branches and often attend MS Society branch events and run symptom management sessions.



Case study: Salford Royal Infirmary – a large neuroscience centre team

Team: 6.7 WTE band 7 MSSNs plus one band 8 nurse consultant, supported by a band 6 support nurse, working within a wider team of neurologists.

Caseload across the disease trajectory: Everyone with MS, caseload is 41% people with progressive MS.

Co-located with neurologists/DMD prescribing: Yes.

Role in relation to DMDs: Manage everyone with DMDs in Greater Manchester; Nurse Consultant can renew DMD prescriptions.

Settings for patient contact: Clinics at Salford hub and 13 outreach locations, home visits (12% of consultations).

Salford Royal NHS Foundation Trust is a specialist neuroscience centre covering the whole of Greater Manchester and parts of Derbyshire and Cheshire; an area with 12 Clinical Commissioning Groups and approximately 3 million population. The MSSN team is the largest in the UK, with six band 7 MSSNs, a support nurse and a Nurse Consultant serving a caseload of almost 3,700. The service operates with a hub and spoke model. Both neurologists and MSSNs deliver outreach clinics and ward consultations across 13 district hospital 'spokes' and the regional 'hub' in Salford. The majority of consultations take place in the 80 nurse led clinics per month but 12% take place as home visits for pwMS meeting set criteria. Each MSSN is assigned to a sub-region and within community settings they contribute to the coordination and management of care of pwMS alongside community based teams (where these exist).

The Trust has integrated management and patient information systems across 12 of the 13 hospital sites covered by the MSSN service. For example, telephone activity is now recorded on the SCM (Sunrise Clinic Management) system which enables MSSNs to instantly review all previous patient contact by phone.

Over 1100 people on the caseload are taking a DMD. The initiation of pwMS on new therapies and stringent monitoring now required on certain DMDs is coordinated by one senior MSSN on the team. During 2014/15, 822 people (22% of the caseload) contacted the service with suspected relapses and 18% of patient survey respondents said that the MSSN service had diagnosed and/or started treatment for an MS relapse during the year. The service aims to contact people with acute deteriorating symptoms for assessment within two working days and they achieved this 98% of the time. Dedicated relapse and DMD clinics run bi-monthly and pwMS can receive direct rapid referral into the neurology service from these. The service has also developed a band 6 MS support nurse role which assists with succession planning.

Within the team, the role of MS Consultant Nurse Karen Vernon is around 60% clinical practice, with the remainder of the time spent offering expert advice for other members of the team regarding complex pwMS or situations. All staff members undergo annual appraisals by the MS Consultant Nurse, with mid-term meetings and monthly one to one sessions if indicated. The Consultant is also a wider managerial role within the neurology directorate.



Case study: Dorset Community Neurology Service – a multidisciplinary community rehabilitation team

Team: 0.9 WTE band 7 MSSN working within a wider team of neuro-practitioners including a neuro-physiotherapist, neuro-occupational therapist, a neurology nurse specialist (all at band 7) and a support worker, alongside a rehabilitation medicine consultant.

Caseload across the disease trajectory: Focus on complex needs. 94% of pwMS on the caseload have progressive MS and 48% have severe disabilities, requiring help with all daily activities. The 301 people with MS on the caseload are part of a wider caseload of 729 people with neurological conditions.

Co-located with neurologists/DMD prescribing: No

Role in relation to DMDs: None.

Settings for patient contact: Clinics at outreach settings, home visits (75% of consultations with pwMS).

The Community Neurology Service is a multidisciplinary community based service of nurse and therapist neuro-practitioners and support workers delivering care to people with a long-term neurological condition including those in the advanced stages of progressive disease. The service sits within Community Services, Dorset HealthCare University NHS Foundation Trust. The service was initially established in 1991 and has developed from a telephone support service for people with a long-term physical condition to a holistic specialist service supporting people with conditions ranging from multiple sclerosis (around 42% of our caseload) and Huntington's disease, to people with head, spinal cord injuries, neuromuscular conditions and cerebral palsy. The service operates across South and East Dorset, Bournemouth and Poole.

The service is structured around monitoring and managing the complexity of a patient's condition by providing a single access point to specialist therapists and nurses with neurological expertise – neuro-practitioners. All the nurses and therapists within the team have the knowledge and expertise to deliver holistic neurological assessment and case management but also practice in their primary professional capacity based on a system of internal team referral.



Chapter 3: MS specialist nurse caseload and casemix

This chapter presents:

- An analysis of the combined caseload of the GEMSS teams in terms of age, gender, type of MS, disability and DMD treatment rates
- An analysis of the DMDs prescribed within the prescribing centres taking part in GEMSS
- An analysis of the effects of MS on pwMSs' ability to continue to work
- The range of health professionals pwMS had consulted during the past year.

Key findings:

- The average age of pwMS on the GEMSS combined caseload is 54. A growing proportion (20%) are over 65.
- 72% of the combined caseload is female, but only 56% of those with PPMS are female.
- GEMSS team caseloads are growing at a faster rate than the 2.4% per year estimated increase in MS prevalence. This may be due to people who have been out of contact with services being re-referred in as new treatments become available.
- 51% of the combined caseload have relapsing remitting MS, 35% have secondary progressive MS and 11% have primary progressive MS. The true proportion of people with progressive MS in the population may be higher than this as there is evidence to suggest some of these people are not in contact with MSSN services.
- 38% of pwMS on the combined caseload rely on a stick, frame or wheelchair, and a further 16% have severe disability and are immobile.
- 27% of the combined caseload is taking a DMD. This equates to 52% of those with RRMS. This is lower than the European average.
- The rates of prescribing within caseloads, and the types of DMD used, vary widely, and the reasons for this need to be more fully understood.
- Around half of working age people with MS who were diagnosed more than 10 years ago report that they have stopped work early on ill health grounds.
- MS specialist nurses are the professionals that the most people with MS (78%) have seen about their MS in the past year. 51% of pwMS reported that they had seen a neurologist in the past year about their MS. However, 10% said they had seen neither, and hence had not had the specialist annual review recommended by NICE/Quality Improvement Scotland.
- People with progressive forms of MS had less contact with MSSNs and neurologists in the past year than those with RRMS, but were more likely to have seen a therapist, social worker or community nurse.

Information on the size and characteristics of the population of people with MS across the UK is inexact and incomplete. There is currently no comprehensive MS register⁵ and estimates of the number of people with MS in the UK vary widely¹⁵. The data from GEMSS therefore presents an opportunity to understand more about the pwMS served by MS services.

⁵ The [MS Register in Scotland](#) gives a measure of incidence but not prevalence.



3.1 How the caseload data has been collected and analysed

As part of GEMSS, each MSSN team established a comprehensive database of all the pwMS on their caseload. The minimum fields that they were asked to populate were gender, date of birth, type of MS the last time it was recorded in notes, DMDs taken and disability (in three broad categories related to Expanded Disability Status Scale^t score). Many teams chose to collect further information such as time with MS, date of last review or planned review frequency.

We cannot be sure that the people on MS teams' caseloads represent everyone with MS in their local area, for two reasons:

- People in England can be seen at any provider they choose, therefore may not necessarily be seen by their nearest MSSN. Service boundaries are fluid and overlapping.
- There are some pwMS who are not under the care of any MS service. The number of such people is currently unknown, but a recent audit suggested that around 9% of people with MS in Northumberland are currently not in contact with any MS service¹⁸. Those who are not in contact with a specialist service are more likely to have been diagnosed many years ago and may be minimally affected by their MS or, conversely, so severely affected that they reside in nursing homes or under the care of community disability teams.

Nevertheless, the GEMSS dataset gives a substantial population for analysis.

Methodology note – caseload data

For some teams, putting together the caseload register was a relatively straightforward task using existing databases (such as the iMed system, already in place for a number of teams). For others, the task was a challenge, and the starting point was a data request from hospital information systems for unique identifiers for everyone seen in an MS coded clinic over the past three years in order to create a basic register which could be augmented with the required information. All teams had reliable records from the outset about pwMS in their caseload on DMDs because of the monitoring requirements around them. In general, the data represents a snapshot of caseloads at the end of 2014/15, but in some cases (e.g. Leicester) the data was collected at an earlier point and not systematically updated through the year. The Walton Centre is excluded from the caseload analysis because pwMS on the MSSN caseloads are only a sub-group of the wider caseload of the service. The Poole and Tayside services are also excluded from the analysis of disability as they had incomplete data.

^t The Expanded Disability Status Scale (EDSS) is a method of quantifying disability in multiple sclerosis and monitoring changes in the level of disability over time. It is widely used in clinical trials and in the assessment of people with MS and ranges from 1 (no disability) to 10 (death from MS). For a more detailed explanation see the [MS Trust website](#).

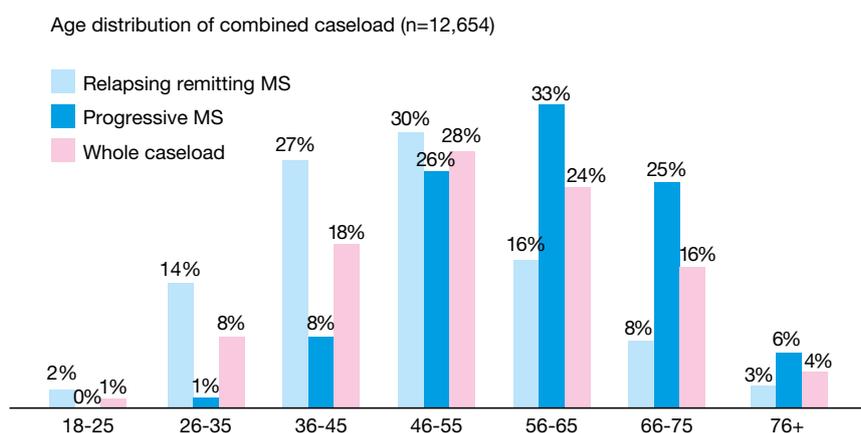


3.2 Gender and age of pwMS

72% of the combined caseload is female, reflecting the well established gender differential between men and women in MS¹. Of the people with a diagnosis of primary progressive MS within the combined caseload, 54% were female and 46% were male, reflecting the fact that this form of MS affects relatively more men than other forms¹⁹.

The average age of pwMS on the combined caseload is 54 (team average ages ranged from 49-61). Figure 6 shows the distribution of ages. Whilst MS is a disease generally diagnosed in young adults¹, a growing proportion of the caseload are older people¹⁶: 20% of the combined caseload are over the age of 65^u.

Figure 6: Caseload age distribution



Notably, the average age of people with a diagnosis of relapsing remitting MS was 48, whereas the average age of those with a diagnosis of secondary progressive MS was 60, the same as the average age of those with a diagnosis of primary progressive MS.

3.3 Growth in MSSN caseloads

Recent estimates suggest that the number of people with MS in the UK is growing at around 2.4% per year¹⁶, as people live longer with MS. The number of new cases of MS across the UK each year is estimated to be around 5000¹⁵, or 21 per WTE MSSN based on the 2014 workforce¹⁴. However, our GEMSS teams in general reported that their caseloads grew by substantially more than 2.4% during 2014/15. Possible explanations for this include:

- **Data collection:** MSSNs are generally good at recording newly referred patients accurately and promptly, but may have less effective systems for identifying and removing people who have moved away or died from the caseload database.

^u Children under 18 are not shown. There are six within the combined caseload, but this is not representative as most of the small number of children diagnosed with MS are treated in specialist children's centres which did not form part of GEMSS.



■ **Increases in new referrals:** The number of people newly referred into the GEMSS teams' services seems to be higher than would be expected, at an average of 37 per WTE MS nurse per year. This may indicate some people with MS being re-referred back into specialist services having been out of contact with them for some time, perhaps due to the availability of new treatments and trial therapies.

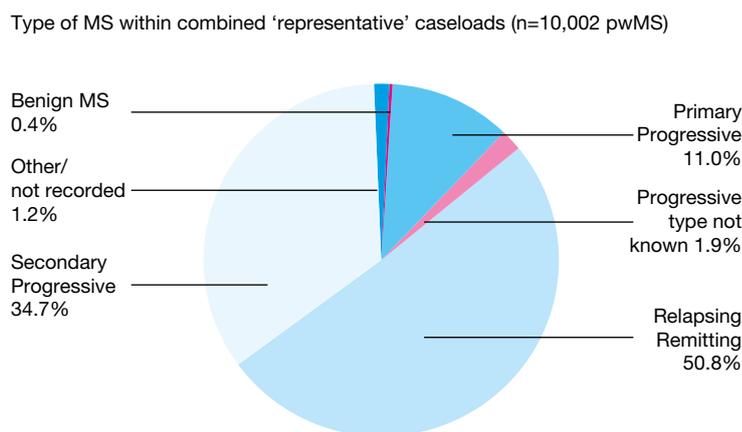
Overall, the reasons for the growth in MS caseloads is not clear and this underlines the need for more accurate local prevalence data across the UK to enable service planning.

3.4 Type of MS

Figure 7 shows the overall breakdown of the combined caseload by type of MS. Those recorded as having Clinically Isolated Syndrome or 'possible MS' are excluded^v. In order to ensure that the caseload analysis is as representative as possible of pwMS in the wider population, the analysis is restricted to services serving everyone with MS in their area (see [Figure 3](#) above).

Whilst studies have shown that around 85% of pwMS are initially diagnosed with relapsing remitting MS¹, progression to secondary progressive MS means that only around 50% of the GEMSS team's combined caseload have RRMS, with just over a third having secondary progressive disease. For the reasons described in section [3.1](#) above, people with progressive disease in the population may be slightly under-represented in MS service caseloads.

Figure 7: Type of MS of combined caseload



^v Around 2% of patients on the GEMSS teams' caseloads were recorded as having CIS or possible MS but these were excluded from the analysis as most MSSNs do not see patients until they have a confirmed diagnosis of MS.



3.5 Level of disability

The breakdown of disability in the combined caseload is given in figure 8^w. More than half the people on the overall caseload have significant levels of mobility impairment, needing at least a stick, walking frame or chair to move about. A substantial proportion, 16%, have severe impairment and would thus find it difficult, if not impossible, to come to a hospital setting for treatment or review.

Figure 8: Disability of pwMS on the combined caseload

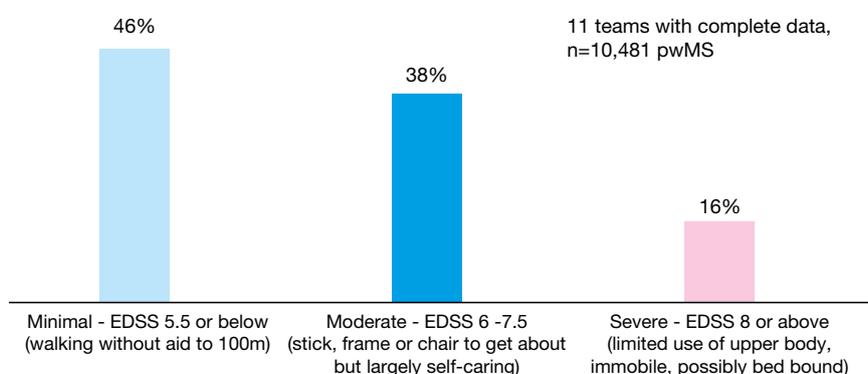
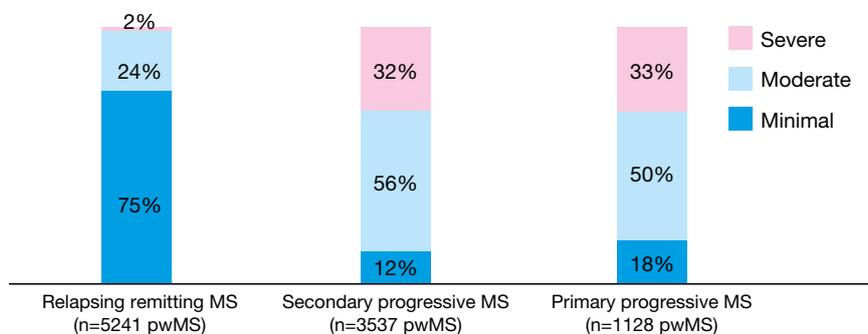


Figure 9 shows the breakdown of disability for those with a clearly recorded MS type^x. As expected, people with relapsing remitting forms of MS have the least disability, and those with progressive forms of MS have the most.

Figure 9: Disability by type of MS



^w Based on 11 teams for whom disability data was complete on over 97% of their caseload. Poole and Tayside excluded.

^x Those with stated diagnoses such as 'progressive not known' and 'possible MS' excluded.



3.6 Treatment with Disease Modifying Drugs

There are currently eleven DMDs approved in the UK for some of the relapsing forms of MS. These drugs are only prescribed by neurologists, and NHS funding for them is guided by technology appraisals from NICE (in England) and the Scottish Medicines Consortium (in Scotland) and, for the self-injectable DMDs which were originally not approved by NICE, the parameters of the Department of Health Risk-sharing Scheme under which they have been made available. The overall funding criteria for DMDs in England are summarised in the NHS England Clinical Commissioning Policy²⁰.

DMDs reduce the frequency and severity of relapses rather than always stopping them entirely. Some clinical trials and long term studies have suggested that, through the reduction in relapses, some of the drugs slow the build-up of disability, but this is not yet fully established. The prescribing guideline of the Association of British Neurologists²¹ summarises the current position.

3.6.1 Treatment rates for pwMS

Overall, for the eleven MSSN teams where we have data on pwMS taking DMDs linked to type of MS:

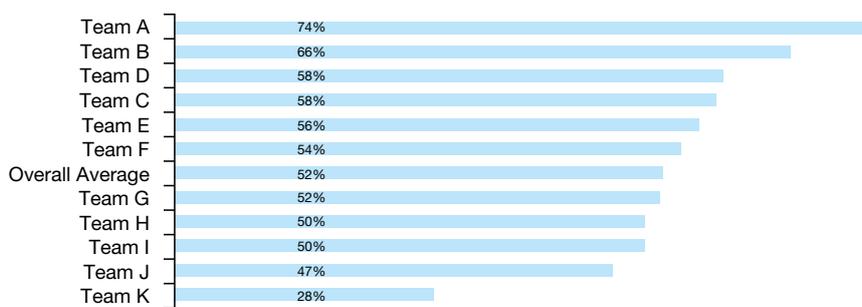
- 27% of pwMS on the combined caseload (n=10,775) are taking DMDs. This is higher than the 21% estimated for the UK in a recent report on DMD use across Europe²², but still below the European average^y
- 52% of those with relapsing remitting MS are taking DMDs
- 7% of those recorded as having secondary progressive and 1.4% of those with primary progressive MS are taking DMDs
- 3% of those recorded as having CIS are also taking DMDs.

Treatment rates vary significantly by team as shown in [Figure 10](#) which is based only on people recorded as having relapsing remitting MS, thereby excluding type of MS within casemix as a reason for variation between teams. Teams have been anonymised because the reasons for variation in prescribing practices have not been fully explored with the neurologists involved in these services. However, we can say that the differences in prescribing rates are not explained by obvious features of the services, such as whether they are neuroscience centres or community based services. The variation may reflect neurologists' prescribing practices, and potentially other features of casemix not explored through GEMSS. This will be explored further through the forthcoming MS trust project, [MS Forward View](#).

^y The same report found 2013 DMD treatment rates as high as 69% of all pwMS in Germany, for example.



Figure 10: DMD treatment rate by team for RRMS

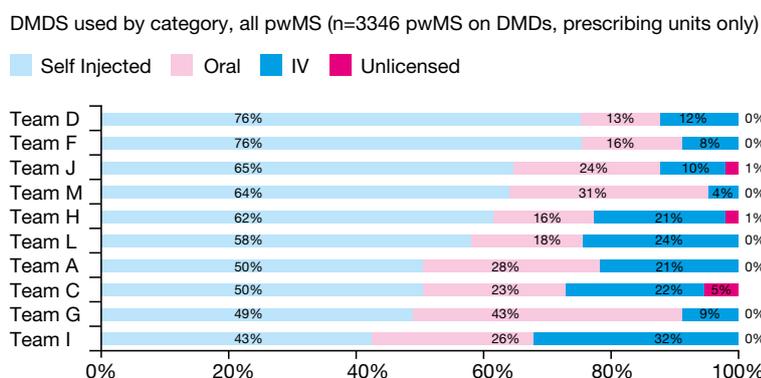


3.6.2 Type of DMD treatment prescribed

Just as treatment rates vary, so do the forms of DMD treatment used. Figure 11 shows a snapshot at the end of March 2015 for the ten GEMSS teams^z within DMD prescribing centres used by broad category. The 27% of the combined caseload who are taking DMDs are made up of 18% of pwMS who take self-injected DMDs, 6% who take oral DMDs and 5% who use IV DMDs.

However, for many teams, the balance of DMDs used is changing rapidly, as the newer, DMDs become more established and widely used. Whilst this was not systematically recorded during GEMSS, one team which did look at this issue, Leicester, noted that of the 380 people taking a DMD at the end of the year (25% of the caseload), 62 had started and 107 switched over the course of the year, meaning that MSSNs supported the initiation of a new DMD to 169 pwMS (11% of the caseload).

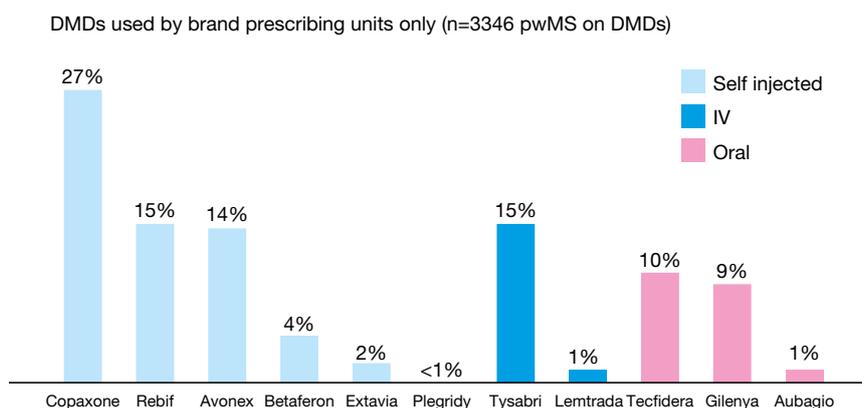
Figure 11: DMDs used by category



^z Other than the Walton Centre



Figure 12: DMDs used by product^{aa}

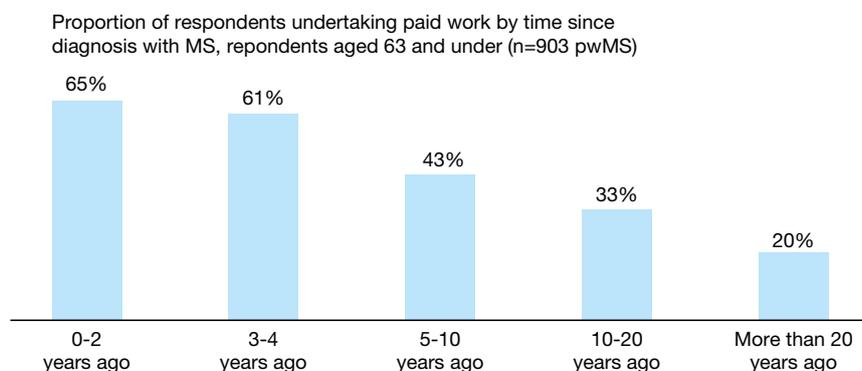


3.7 People with MS and work

The GEMSS project has looked at the working status of pwMS within MSSN caseloads, as understanding this is helpful for shaping services around people's working lives and understanding the support people need to remain in work or make the transition to reducing or stopping work. The source of this data is the GEMSS patient survey, answered by 1,254 people with MS across thirteen of the fourteen GEMSS teams.

Looking only at working age respondents (defined as those age 63 and under), 42% said that they were in paid employment, but the proportion falls with time from diagnosis with MS, as shown in figure 13.

Figure 13: Work and time since diagnosis



^{aa} Unlicensed therapies, which between them account for fewer than 1% of pwMS on treatment, are not shown.



Of the 526 working age respondents who did not say they were doing paid work, 455 provided reasons, shown in figure 14. 80% of these respondents said that they had stopped work early on ill health grounds, illustrating the impact that MS so often has on employment. Figure 15 spells this out in more detail, showing the proportion of working age respondents who had stopped work early on ill health grounds, by length of time with MS.

Figure 14: Reasons for pwMS stopping work

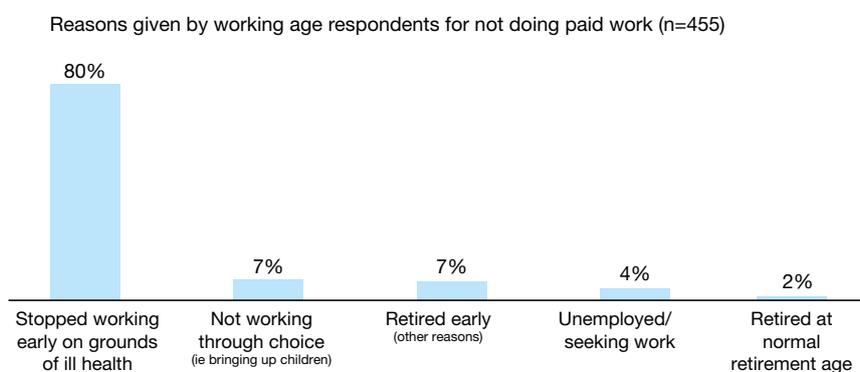
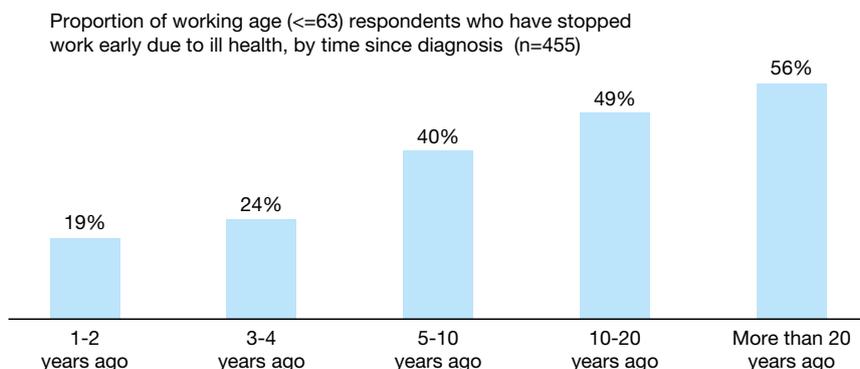


Figure 15: Stopping work early on ill health grounds



3.8 Use of other health services for MS-related needs

Finally in this chapter, we report on what the GEMSS data tells us about how pwMS are using services beyond those provided by MSSNs to help them manage their MS.

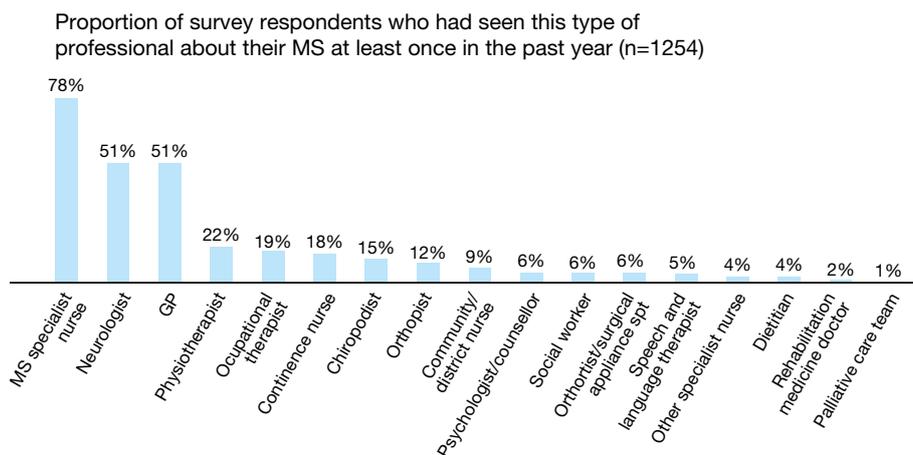
1208 respondents to the GEMSS patient survey were asked about the number of times they had seen a health professional about their MS during the past 12 months^{bb} and 1203 respondents answered. 95% of respondents said that they had seen a

^{bb} This question was not included in the Northumbria survey.



health professional about their MS in the past year (there was no significant difference between types of MS), and between them, they reported 11,445 face to face consultations with health professionals, an average of 9.5 per respondent. Figure 16 shows the proportion of respondents who had seen each type of professional at least once during the past year. MSSNs were the health professional that the most people had seen concerning their MS. Overall, 78% of respondents had seen an MS nurse, and 82% had seen either an MS nurse or a neurologist during the year. However, 18% of respondents had not been seen either in the past year and hence by definition have not had the comprehensive annual review by an MS specialist, as recommended by NICE⁹. It should be noted that respondents to the survey by definition represent those on an MS specialist nurse caseload, and therefore do not include those people with MS in each area who may be entirely out of contact with services.

Figure 16: Proportion of respondents seeing different professionals in the past year



The average number of contacts which respondents reported they had had about their MS in the past year is shown in figure 17. This shows that MS specialist nurses, along with GPs, were by far the most often consulted professionals about MS, but that for those who saw them, therapists and district nurses were also important. The data shows that 10% of pwMS had seen neither an MSSN nor a neurologist in the past year about their MS, and by definition therefore had not had the specialist annual review recommended by NICE⁹.



Figure 17: Number of consultations with different professionals about MS in the past year

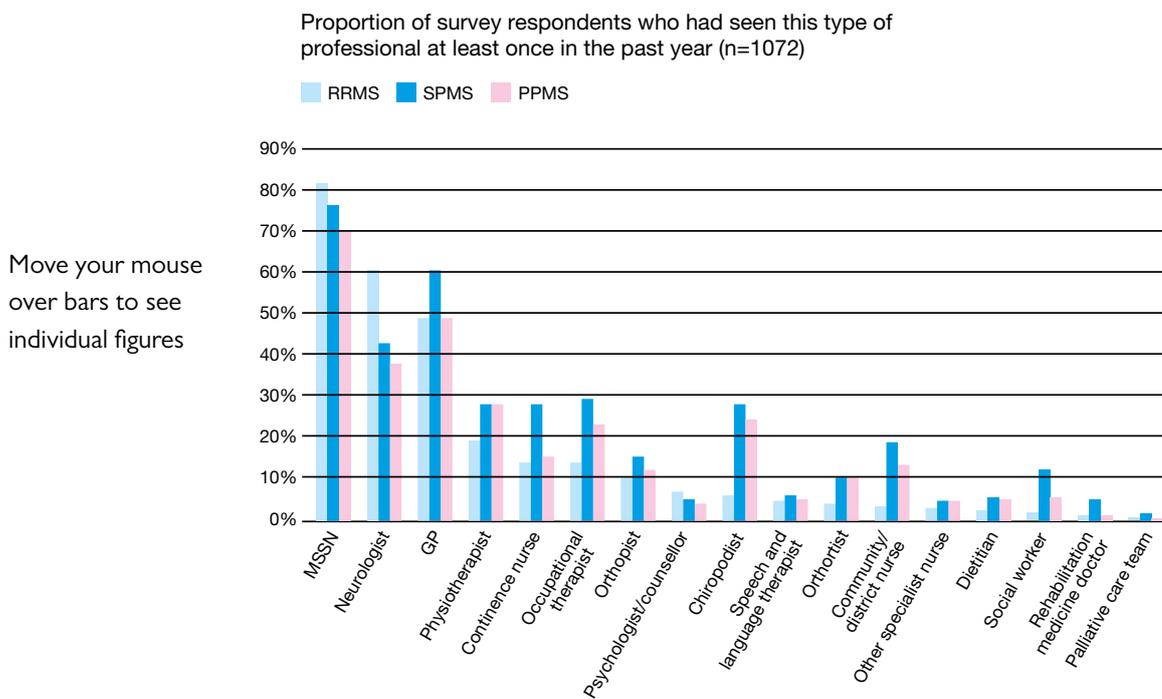
	Mean consultations (all respondents)	Mean consultations (only respondents who saw this type of professional at least once)
MS specialist nurse ^{cc}	1.71	2.3
Neurologist	0.74	1.5
GP	2.00	4.1
Physiotherapist	1.22	5.8
Occupational therapist	0.59	3.2
Continence nurse	0.44	2.5
Chiropodist	0.62	4.3
Orthoptist	0.2	1.7
Community / district nurse	1.04	12.0
Psychologist / counsellor	0.2	3.5
Social worker	0.11	1.9
Orthotist / surgical appliance spt.	0.11	1.8
Speech and language therapist	0.13	2.7
Other specialist nurse	0.07	1.9
Dietitian	0.07	1.8
Rehabilitation medicine doctor	0.05	2.5
Palliative care team	0.03	3.6

Figure 18 shows differences between professions consulted by type of MS. This clearly shows that people with relapsing remitting MS are more likely to have seen an MS specialist nurse or neurologist in the past year about their MS than those with progressive MS. Those with progressive MS were significantly more likely to have seen a therapist, district nurse or social worker and nearly a third had seen a chiropodist. What this data cannot tell us is how much unmet need there is for additional support from these other professionals.

cc. The number of consultations that survey respondents reported they had had with an MSSN in the past year, at 1.7, is higher than the 'true' average across the GEMSS teams based on activity data and caseload, which is 1.4. See [Appendix C](#) for a discussion.



Figure 18: Proportion of pwMS seeing different professionals by MS type





Chapter 4: MS specialist nurse activity, responsiveness and productivity

This chapter presents:

- A summary of how much input from MSSNs pwMS are receiving, by type of MS
- The range and number of topics covered by MSSNs during consultations with pwMS
- Case studies showing the importance of multidisciplinary team working for MSSNs
- The role of MSSNs in assisting people to self-manage their MS
- Views of pwMS about the timeliness and amount of input received from MSSNs
- The Key Process Indicators which were used by the GEMSS teams to track the responsiveness of their services
- MSSN productivity in terms of outpatient consultations, home visits, phone calls and other activity achieved per WTE MSSN
- Levers and supportive infrastructure which can improve the productivity of all MSSNs to the level of the best.

Key findings:

- On average, pwMS on GEMSS team caseloads had 1.4 face to face contacts with an MSSN in the past year and 1.5 telephone discussions with an MSSN. This is significantly less than the 2.4 face to face consultations (on average) estimated to be necessary in the MS Trust 'sustainable caseload model'.
- PwMS who are on DMDs get more contact from MSSNs than those who are not, suggesting that those with progressive forms of MS may be getting even less contact with their MSSN than the averages above would suggest.
- MSSNs cover a wide range of topics in consultations, ranging from physical mobility and balance to vocation, sight and hearing and end of life issues, an average of 8.1 (out of a possible 19) per consultation. 84% of consultations cover understanding of the condition and 65% cover bladder and bowel issues, the most common reason for unscheduled admissions in MS. The comprehensive range of issues covered by MSSNs with pwMS in their care is key to coordinating effective onward referral and coordination of care by the wider MDT
- Within home visits, MSSNs are able to cover more topics than in clinic appointments. Consultations with people with progressive forms of MS also cover more issues than those with people with RRMS, illustrating the complex range of issues which need to be addressed in this vulnerable group.
- MSSNs play a key role in helping pwMS to understand the condition and manage their own wellbeing, but there is significant unmet demand from pwMS for formal group education programmes. 68% of pwMS who responded to the GEMSS survey said that they had not been invited to a course about managing MS symptoms but would like to be.
- 80% of pwMS said that the amount of contact they had with their MSSN in the past year was about right, but 20% would have wanted more. 9% said they didn't know when they were seeing their MSSN next and would like to know.



- On responsiveness, 78% of people were able to speak to an MSSN the same or next working day last time they phoned them, but 11% said it was generally not easy enough to get hold of their MSSN. Given the value placed by pwMS on their MSSN as a consistent first point of contact for concerns and anxieties, having a responsive service is essential to maintain this role and avoid increased calls to GPs, who cannot provide a specialist response.
- Activity per WTE nurse varies greatly between teams. Levers to maximise the productivity of MSSNs include ensuring that an MSSN is focused on specialist clinical tasks, having a process for triaging telephone calls, using capacity to the full through smart scheduling, using home visits sensibly and keeping written communications succinct and structured.
- Having sufficient administrative support is an essential enabler to maximising MSSN productivity and effectiveness, as demonstrated by some of the most productive teams.

Participating GEMSS teams recorded their activity over the course of the year, identifying numbers of clinic consultations, home visits, inbound and outbound telephone calls (to/from pwMS and carers and others), new patient assessments and pwMS contacting the service about acute deteriorating symptoms and suspected relapses. The GEMSS patient survey also asked respondents to say how much contact they had had over the past year with their MSSN, and what they thought about the level and timeliness of the input they had received.

4.1 How much input are pwMS getting from MSSNs and where?

The amount of input received per pwMS on the caseload of our GEMSS teams is summarised in figure 19.

Figure 19: Input per person with MS on the caseload

	User reported (from patient survey)	MSSN reported (average per pwMS on caseload)	MSSN reported Range across teams ^{dd}
Face to face consultations per year (clinic or home visit)	78% of respondents reported having had at least one face to face consultation in the past year	1.4	0.7 to 2.4
Telephone calls to the MSSN service during the year ^{ee}	42% of respondents reported having at least one discussion with their MS nurse on the phone in the past 12 months.	1.5	0.7 to 3.0

^{dd} Excluding the Western Isles, a very atypical service with unusually high input per pwMS.

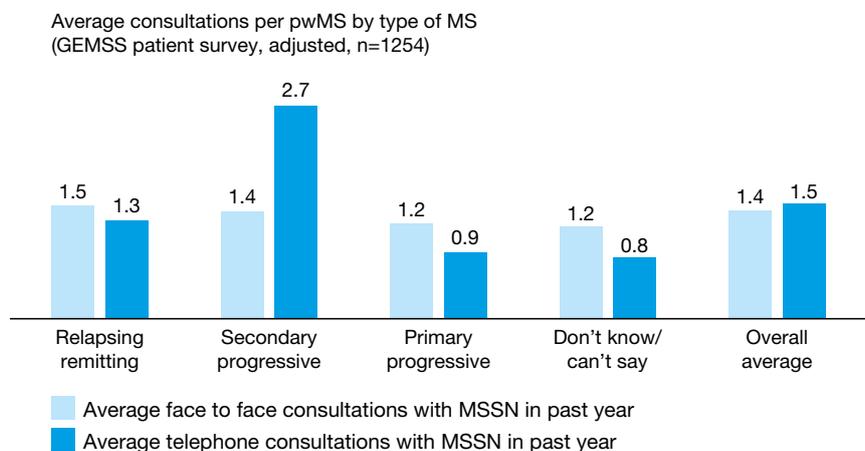
^{ee} A call to the service which then resulted in a call back from the MSSN was counted as one incoming call, regardless of how many attempts the MSSN had to make before reaching the pwMS.



However, behind these averages lies significant variation between individuals. The patient survey suggests that around 22% of people on the caseload didn't see an MSSN at all over the course of the year. Around a third of pwMS saw an MSSN once during the year, most saw the nurse between two and four times, whilst 5% of pwMS had more than five consultations over the year.

Figures 20 and 21 show the differences in the amount of input that pwMS reported they had received in the past year by type of MS and whether they were taking DMDs^{ff}. Notably, those with secondary progressive MS (SPMS) and those taking self-injected DMDs were the people who telephoned their MS nurse the most. This may reflect, for those with SPMS, increasing symptoms and psychosocial challenges and a more established and longstanding relationship with the MSSN service. High numbers of calls from those taking self-injected DMDs may reflect difficulties with self-injection (e.g. injection site reactions) and the supply of DMDs at home. Those using IV DMDs had more face to face consultations with an MSSN than others, reflecting the fact that some MSSNs are involved in administering IV DMDs, and most who work within prescribing units aim to see all pwMS coming in for IV DMDs even if they are not directly involved in the administration of the drugs.

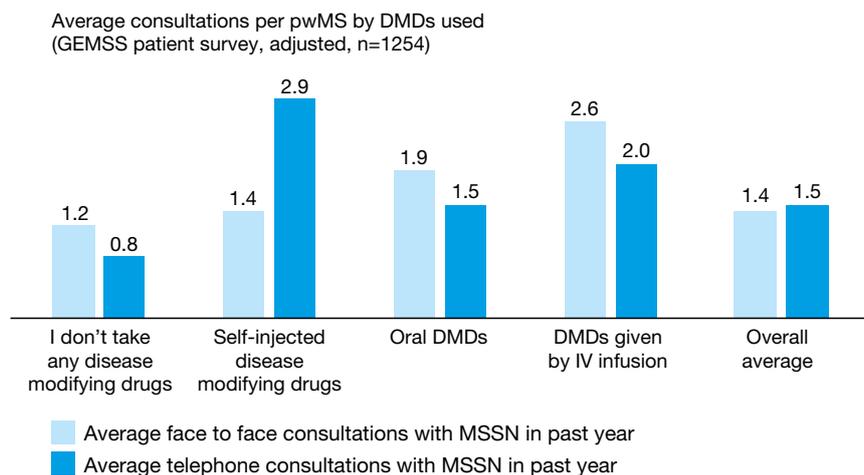
Figure 20: Input per pwMS by type of MS



^{ff} Patient survey has been adjusted to reflect 'true' service utilisation – see [Appendix C](#) for discussion.



Figure 2 I: Input per pwMS by DMDs used



How much input per person with MS is optimal?— note on the MS Trust 'sustainable caseload' model

Defining what a typical pwMS 'needs' is very difficult, but in September 2014 the MS Trust convened a consensus group to make an estimate. The group modelled a 'sustainable' caseload¹³, using a weighted average, based on what we know about the make-up of a typical caseload through GEMSS, and assuming the following:

- Everyone should have, at minimum, one face to face review with an MSSN during the year, in line with NICE/Quality Improvement Scotland guidelines^{9, 10}.
- People newly diagnosed with MS will need 3 consultations during their first year, to help them to come to terms with the diagnosis, understand the condition and make any decisions needed about treatment with DMDs.
- Those diagnosed more than a year ago will, on average, need 1.5 consultations during the year if not on DMDs, and 2.5 if they are on DMDs. This average will reflect additional consultations for pwMS making the transition from one functional level to another, for example from being able to walk to relying on a wheelchair, from being continent to needing interventions to support continence.

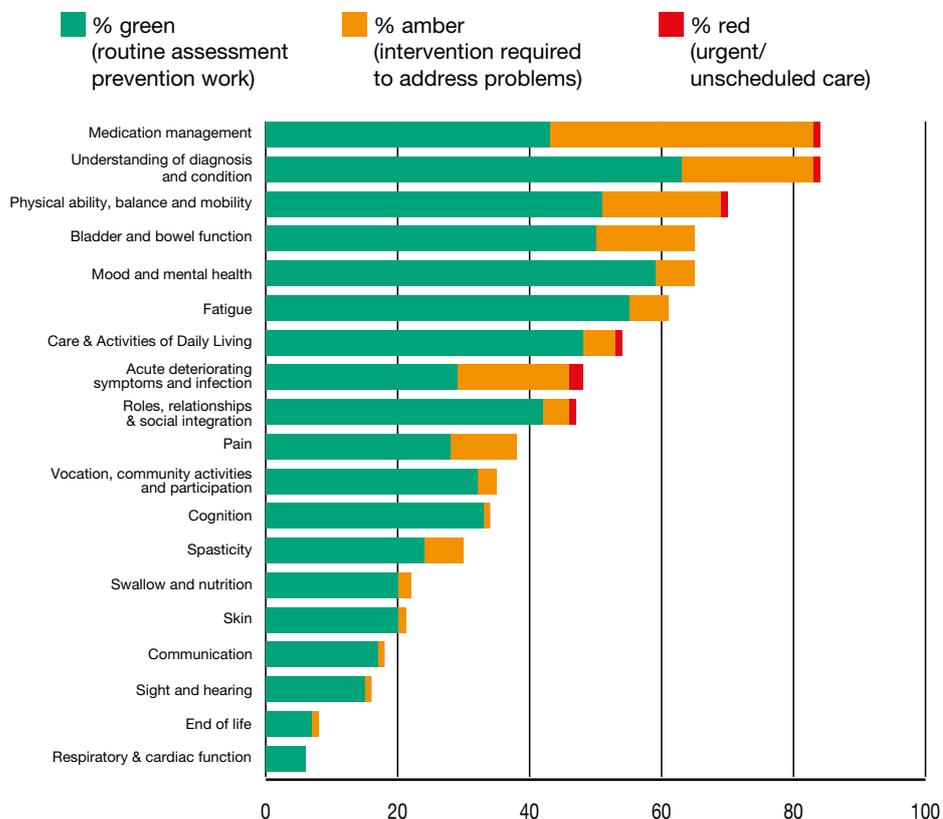
Based on these assumptions, the MS Trust sustainable caseload of 358 pwMS per WTE MSSN is based on pwMS on average seeing their MSSN 2.4 times per year, rather than the 1.4 achieved by our GEMSS teams.



4.2 Topics covered in consultations with MSSNs

Six of the GEMSS teams, plus an additional neuro-disability team based in East Staffordshire, used the Dorset Specialist Neurological Intervention Audit tool to audit a sample of their consultations and establish what topics were being covered in consultations and at what level of urgency (from routine preventative and monitoring work, to urgent and unscheduled care). [Appendix D](#) gives more details. 451 MSSN consultations were recorded over a three week period⁸⁸. Figure 22 shows the range of topics, from a possible nineteen, covered in consultations between MSSNs and people with MS. A number of things are clear from this chart. First is the wide range of topics covered in consultations – an average of 8.1 per consultation. 84% of consultations covered the topics of 'medication management' and 'understanding of diagnosis and condition', and 65% covered 'bladder and bowel function', the most common cause of unscheduled admissions in MS⁹. Secondly, the majority of topics covered, 80%, were at the level of routine assessment and prevention work, whereas only 19% of topics covered needed to address problems and only 1% were at the level of dealing with crises requiring urgent unscheduled care. This highlights the role of MSSNs in intervening early to prevent problems down the line.

Figure 22: Topics covered in MSSN consultations



Move your mouse over bars to see individual figures

gg AHP consultations were also recorded, and the data will be published elsewhere¹².



Figure 23 shows the average number of topics covered by consultation type. This highlights that in the context of a home visit, it is possible to offer a more in depth consultation than in a clinic setting. This may reflect the additional needs of people who are allocated home visits, or reflect that more time is usually available.

Figure 23: Number of topics covered by consultation type

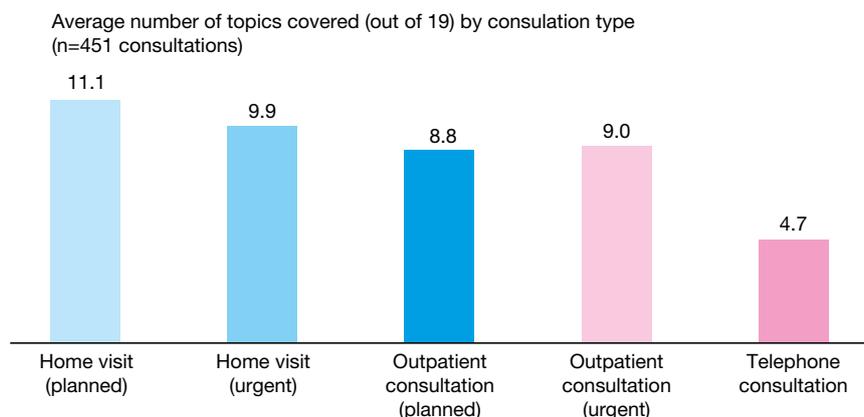
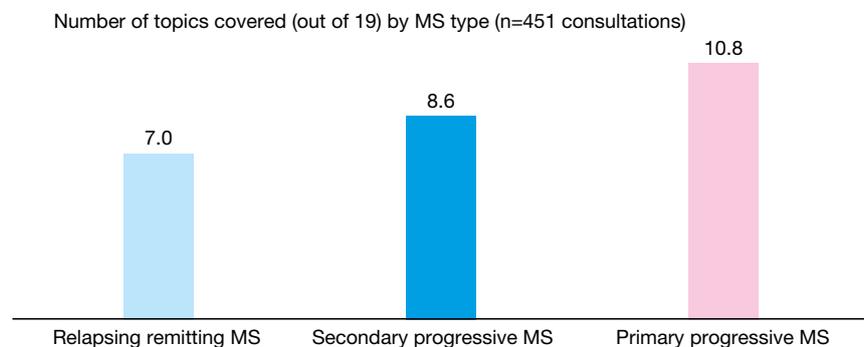


Figure 24 shows the number of topics covered by the type of MS^{hh} and figure 25 shows what these topics were. This clearly indicates the increasing levels of complexity of managing people with progressive forms of MS, and the increasing importance amongst these people of needs around cognition, spasticity, skin, swallowing and nutrition and communication, all of which will require multidisciplinary support from other specialists besides just MSSNs.

Figure 24: Number of topics covered by type of MS



hh Clinically isolated syndrome has been excluded due to small sample size.



Figure 25: Topics covered by type of MS

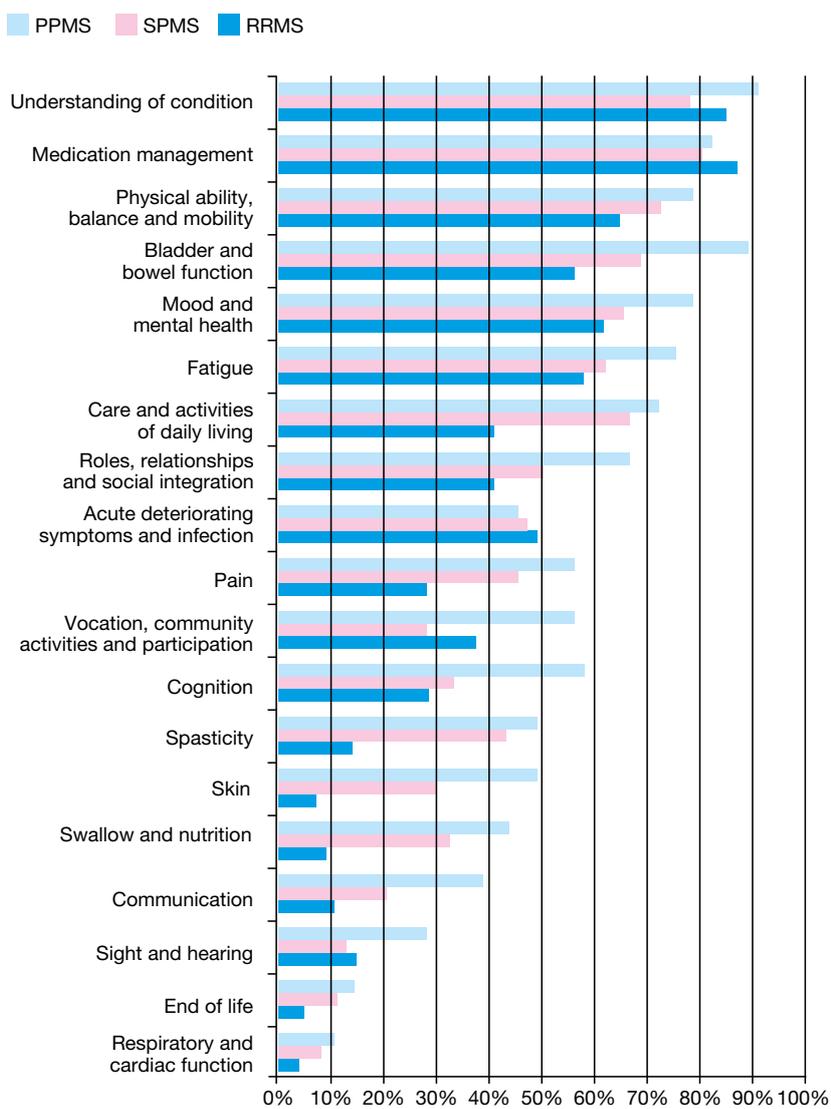




Figure 26: MDT working: examples of good practice

MSSNs' work within the wider multidisciplinary team

GEMSS has highlighted the vital importance of expertise from a wide range of specialists to help pwMS to manage the complex range of issues which MS can bring. This works best when there is close working between MSSNs and other members of the MDT to ensure that roles are clear and that the needs of pwMS are met without undue duplication.

Many of the GEMSS teams had excellent examples of this close, joined up working, even across organisational boundaries. For example:

The Walton Centre MS team is made up of five MS-specialist neurologists, three MSSNs, two MS-specialist physiotherapists (1 WTE), two MS-specialist occupational therapists (1 WTE) and an MS-specialist orthoptist (0.2 WTE), all working closely together in a single department with a shared office and regular team/service development meetings. This allows for shared clinical working, including a weekly multidisciplinary relapse clinic at which pwMS with suspected relapses can be jointly assessed and advised, self-management groups run jointly by MSSNs and AHPs and the development of joint treatment plans for pwMS involving medical, nursing and therapy input to address problems.

The Calderdale and Huddersfield MSSN service runs two joint sessions per month with the physiotherapist and occupational therapist (alternately) from the local community rehabilitation team. This enables the MSSN to identify pwMS who would benefit from rehabilitation and then see them jointly with the most appropriate therapist, either in clinic or at home, and create a joint plan of action for the management of difficult symptoms. As the MSSN is also a nurse prescriber, the team is able to manage whole episodes of care.

The Dundee MS service consists of a consultant neurologist, three MSSNs and an MS specialist physiotherapist, all working within Ninewells Hospital in Dundee, and an MS specialist social worker based in Dundee City Council. The purpose of the service is to provide pwMS with a dedicated team that promotes and supports an inter-professional approach, and this is achieved by joint meetings and close communication between the team. Occupational therapy provision has been identified as a gap in the team.

The Dorset Neurology service (described in greater detail on [page 26](#) above) is an integrated multidisciplinary team that uses a 'neuro-practitioner' approach to streamline roles and avoid duplication between team members.

However, whilst GEMSS provides examples of good practice, there are challenges. In many areas, MSSNs reported notable gaps in services, for example an absence of local provision in certain professions or very long waiting lists (sometimes due to vacancies remaining unfilled)ⁱⁱ or an absence of neuro-specialist provision. In other instances, the challenges of working across multiple organisational boundaries across large geographic areas make joint working hard to achieve.

ii Further evidence for these gaps is highlighted by a recent [MS Trust Survey of specialist AHPs](#), published Sept 2015.



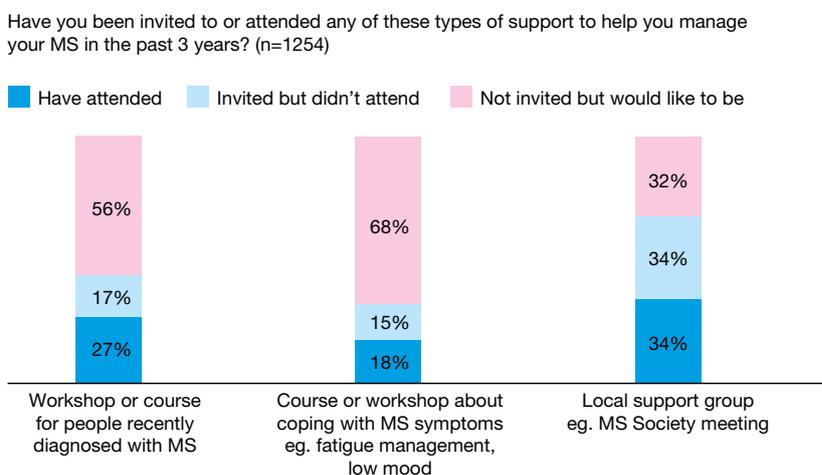
4.3 The MSSNs' role in self-management education for pwMS

A key role for MSSNs is educating pwMS about the condition and helping them manage their own wellbeing, deal confidently with things that might not need an MSSN input and recognise issues (such as relapses) that mean it's important for them to seek specialist help. As well as undertaking this work within consultations (as shown in [Figure 22](#) above), most of the GEMSS teams are involved in delivering self-management programmes to people with MS, either organised by themselves, therapy colleagues or by local third sector partners such as MS Society branches or MS Therapy Centres. Programmes include 'Getting to Grips' courses (following the format laid out by the MS Society for those with a new or recent diagnosis), Fatigue Management courses, Symptom Management courses, exercise and MS classes and, in one case, an MS Mindfulness course. Most teams are also involved to some extent in up skilling other health professionals looking after people with MS, including GPs, community nurses and staff working in nursing homes.

However, whilst these activities are very valuable, the activity data collected during GEMSS shows that the number of pwMS reached by teams with these activities is very small compared to their overall caseload. Although 13 out of 16 GEMSS teams had carried out some kind of group education over the year, the total number of pwMS reached numbers fewer than 400 out of an overall caseload of over 15,000. For many, this reflects a lack of time within job plans dedicated to this work, so that it has to be done in evenings and at weekends, together with a lack of administrative support to take on the workload involved in making courses run.

The GEMSS survey asked respondents whether they had accessed support to help them to self manage their MS, either in the form of self management courses or through local peer support groups such as MS Society branch meetings. The results, shown in figure 27, show significant unmet demand for self management support, with half to two-thirds of respondents saying that they have not been invited to a newly diagnosed course or symptom management course, but that they would like to be.

Figure 27: Respondents' use of self management support



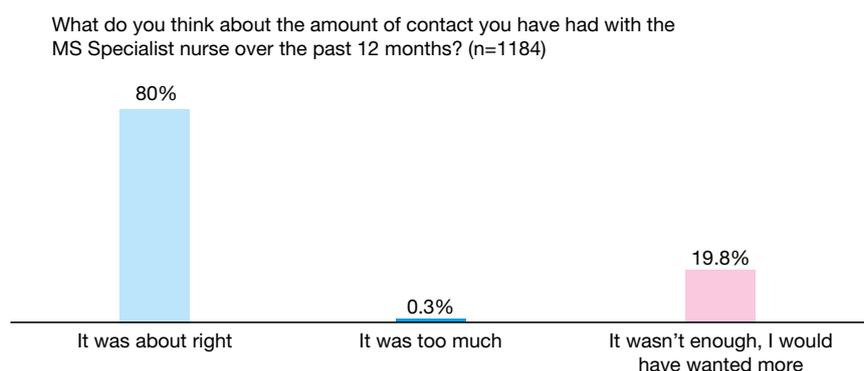


Looking just at respondents diagnosed in the past four years (n=175), encouragingly the proportion who have attended a newly diagnosed course is higher, at 46%, but 38% still said that they had not been invited to a course but would like to be in future.

4.4 Views of pwMS about the timeliness and amount of input received

The GEMSS patient survey asked pwMS what they thought about the amount of contact they had had with their MSSN over the past year, and the results are shown in figure 28. Whilst most people felt that they had had enough contact, around a fifth said they would have wanted more contact, and this was a frequent source of comment in the open questions of the survey. Virtually no respondents thought they had too much contact with their MSSN.

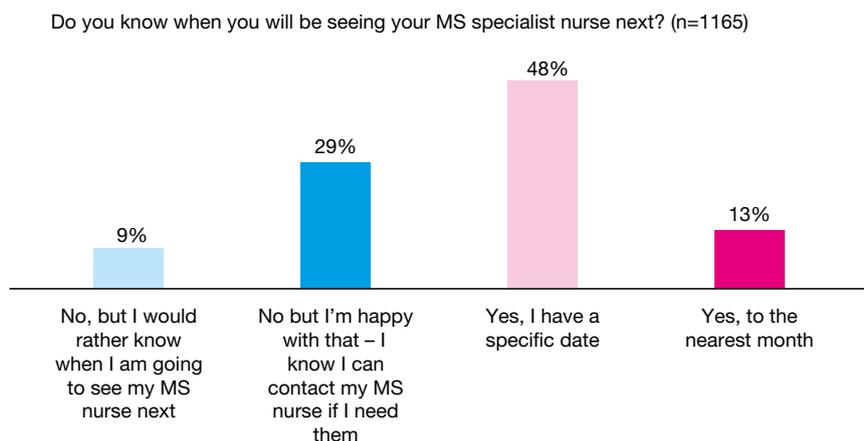
Figure 28: Respondents' views of the amount of contact they had with their MSSN



The survey also asked respondents to say whether they knew when they would be seeing their MSSN next, and the results are shown in figure 29. Whilst nearly two thirds of respondents knew to the nearest date or month when they would be seeing their MSSN next, 38% of respondents said that they didn't know, and 9% were unhappy with this situation. This result highlights the importance of regular reviews to people with MS and the need to ensure that people are reviewed proactively, at least once a year.



Figure 29: Respondents' views on when they would be seeing their MSSN next



In an unpredictable condition like MS, the ability for people to phone their MS nurse when they experience an acute deterioration in their symptoms, possible relapse or simply have a question requiring specialist help, is invaluable, and in these situations a rapid response is needed.

Responsiveness when pwMS contacted services was generally good, but with some exceptions – particularly for single-handed practitioners if they were on leave. Overall, three quarters of respondents said that it was easy enough 'most' or 'some' of the time to make contact with an MSSN, but 11% said it was not easy enough (figure 30). The number of respondents giving this response varied widely between teams, from 0% to 20%. Figure 31 shows that 78% of respondents were able to speak to an MSSN the same or the next working day on the last occasion that they phoned the service, but 22% were not.

Figure 30: Respondents' views on ease of contacting their MSSN

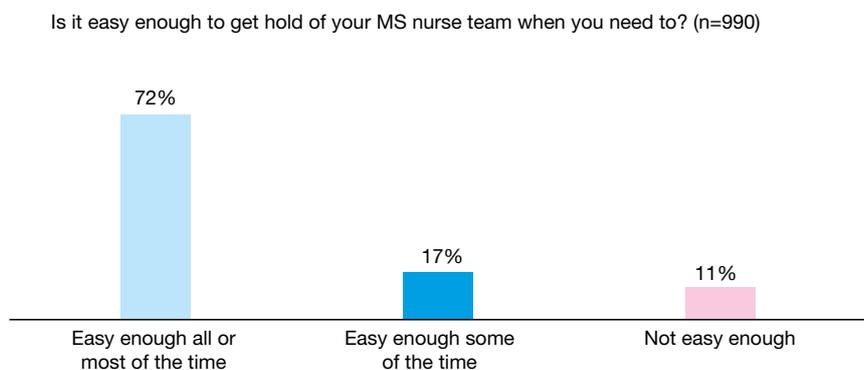




Figure 31: Respondents' reports of speed of telephone response from an MSSN

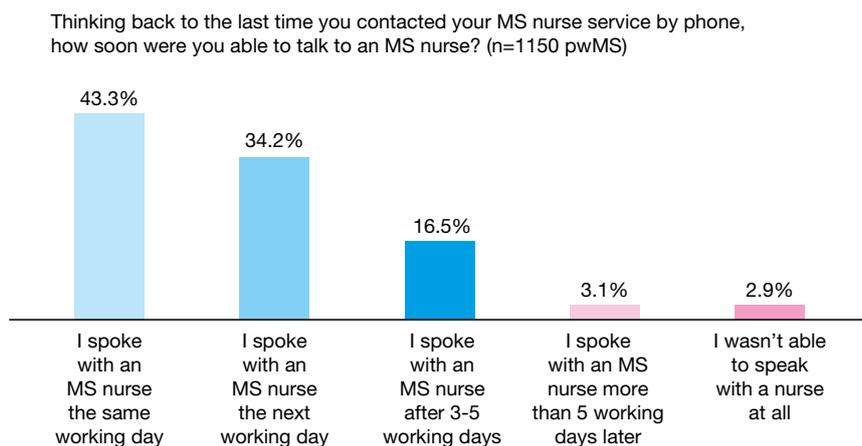


Figure 32: The GEMSS Key Process Indicators

The GEMSS Key Process Indicators

Within GEMSS, each team monitored their performance against four Key Process Indicators, three measured monthly and one annually. These were agreed at the start of the programme to be important in measuring aspects of work which contribute to improving outcomes for pwMS. Although the basic measures were the same for all teams, each team set their own target to aim for in terms of working days. They were encouraged to choose a target which was **sensitive**, i.e. both **realistic** (there would be little point in setting it as a level so much higher than current performance that achievement each month would be 0%) but also **stretching** (performance of 100% every month doesn't tell you much either). Because the teams set themselves different standards against which to monitor their services on KPIs 1-3, it is not possible to aggregate the results for all the GEMSS teams. (On KPI 4, we have an understanding of overall performance through the GEMSS patient survey, as reported in [Figure 16](#) above.) In general, however, we can say that using these measures was a helpful way for the teams themselves to track their services and highlight areas for improvement. Some teams observed large dips in performance when individual team members were absent for any reason, and whilst in small or single handed teams this may be unavoidable, in larger teams it highlights the importance of managing leave and having cross cover arrangements.



Key Process Indicators for MSSN services

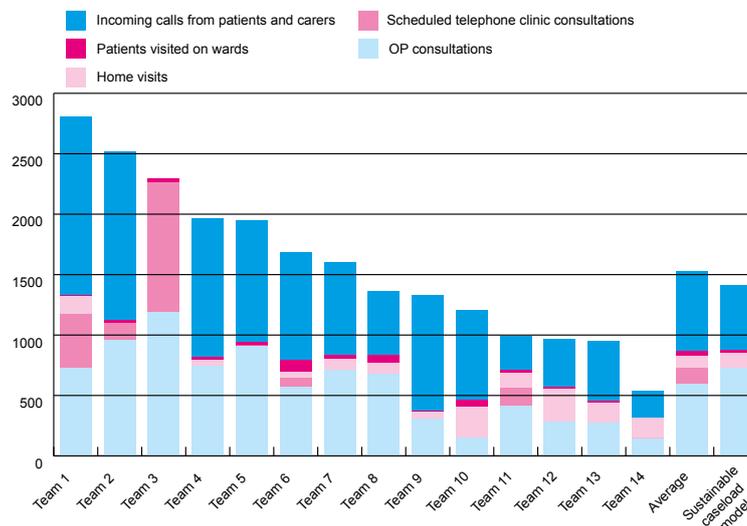
1. % of newly referred patients seen by the service for a holistic assessment by the MSSN within x working days of receipt of the referral (most teams chose to measure against 10, 15 or 20 working days)
2. % of incoming phone calls from patients responded to within x working days (most teams chose to measure against 2 or 3 working days)
3. % patients with acute deteriorating symptoms (including suspected relapses) contacted for assessment and appropriate management within x working day(s) of alerting the service (most teams chose to measure against 1 or 2 working days)
4. Proportion of pwMS on the caseload who have had a face to face review with an MSSN in the past year (measured once each year)

4.5 MSSN productivity

Figure 33 summarises the level of 'output' of MSSN teams taking part in GEMSS^{jj} and demonstrates wide variability per WTE nurse. The chart also shows the assumptions about output made in the MS Trust 'sustainable caseload' model for a whole time nurse with a caseload of 358 pwMS^{kk}.

Figure 33: Activity per WTE MSSN 2014/15 by team

Move your mouse over bars to see individual figures



The proportion of face to face consultations delivered in pwMS's homes varies widely - from 0% for the two teams operating entirely from clinics up to 81% for the Dorset Neurology Service - with an average of 12% across all the teams. The extent of this variation can only partially be explained by differences in casemix or rurality of services

jj Dorset Neurology Service excluded as MS activity takes place alongside activity in other neurological conditions.

kk This was informed by the first six months' of GEMSS data, looking at the most productive of the teams who were working with a number of conditions in place, such as administrative support. The totals given assume a 42 week working year, allowing 10 weeks for leave and statutory and non-statutory training.



All teams carry out a significant proportion of their work over the telephone, with four teams carrying out formal, scheduled telephone clinics in addition to dealing with incoming calls. An analysis of nurses' activity undertaken during phase I of GEMSS using the 'Cassandra' tool²³ showed that 42% of nursing interventions were carried out over the phone, and as **Chapter 3** describes, telephone work constitutes a large proportion of activity. An increasing number of teams are also now responding to email and even text message contact from pwMS, although their ability to do so is constrained by the pace of change within NHS organisations towards policies enabling this form of communication to be appropriately recorded and governed.

Finally, five teams are offering, in addition to ad hoc telephone support, formalised telephone clinics in which they pre-arrange a time to call a pwMS and have a more structured consultation. In some cases (Leicester and the Walton Centre, for example), these clinics are being used to deliver episodes of care as an alternative to an emergency appointment when a pwMS is experiencing a relapse or acute deteriorating symptoms. In another (Mid Essex), phone clinics are used for a small proportion of planned reviews where this saves time for the pwMS. In another (Western Isles) telemedicine is used for selected pwMS living in outlying and inaccessible island areas. A further advantage of telephone clinics is that they allow more complex issues to be given the time they need for a fuller discussion than would be possible during a call between other commitments, and for these episodes of care to be properly recorded in patient notes at the time and (in England) charged for with a tariff to commissioners. The Walton Centre service is described in **Figure 35**. Overall, telephone clinic consultations represent around 13% of all consultations, but their use would seem to be a helpful, growing trend.

What goes into an MS specialist nurse job plan?

The fixed clinical commitments of outpatient clinics, home visit sessions and scheduled telephone clinics (for some teams) typically take up 5-6 half day sessions per week for most of the MSSNs taking part in GEMSS, and the MS Trust 'sustainable caseload' model assumes that five sessions, or half the working week, are taken up with these activities. However, there are many other activities which need to take place in the remaining half of the week, but are scheduled more flexibly. These include:

- Responding to incoming calls from pwMS and their carers, and from other health professionals. This typically accounts for around a day a week of MSSN time (for a full time MSSN)
- Clinical administration, such as checking blood results, writing reports on patients and liaising with professional colleagues
- Visiting pwMS admitted to wards, helping to assess patients in A&E, visiting pwMS admitted as daycases for infusions for pre-infusion checks
- Delivering self-management education to pwMS and education sessions to other health professionals and staff
- Attending meetings including team/staff meetings, audit and MDT meetings.

To accommodate these activities means that job plans need to be carefully planned, something which the MS Trust capacity planning tool can help with^{II}. Additional roles, such as wider team management, research or lecturing commitments, will require dedicated time to be allocated to them.

II [See the MS Trust website for details of how to access this tool.](#)



4.6 Maximising the productivity of MS specialist nurses

As **Figure 33** above clearly demonstrates, MSSN teams are highly variable in their level of productivity. Some of this can be explained by factors beyond the control of the service, for example:

- Home visits in a very rural area will inevitably take much longer than in an urban area.
- Teams serving a high proportion of people with progressive MS and high levels of disability will, rightly, offer more home visits than one with a less dependent caseload, and consultations will need to be longer.
- A service which is not permitted to carry out home visits will have higher productivity, but at the expense of being able to see pwMS who are unable to get to a clinic.

However, through GEMSS, we have identified a number of factors which lead to high productivity and which can, and should, be maximised in order to ensure that the high levels of skills and expertise offered by MSSNs can be used to best effect. In order to achieve the performance of the most productive of the GEMSS teams, the following needs to be in place.

4.6.1 Focusing MSSN time on specialist nursing tasks

Non-clinical administration accounts for a significant amount of time for many of the GEMSS MSSNs (averaging 8% of their workload according to an audit undertaken during GEMSS phase I²³), and this is a source of frustration and reduced productivity. Of our fourteen GEMSS teams only ten have any kind of administrative support, and for three this is limited to audio-typing of clinic letters (something which, over time, may be replaced with voice recognition in any case). A skilled administrator who understands the MS service can be an invaluable support to the MSSN team and take away many of the non-specialist activities needed to ensure that the service runs smoothly, as shown in **Figure 33**. Responding to telephone calls from patients is an important part of the MSSN role, but without a 'filter' to triage incoming calls can become unmanageable.

Other tasks which are sometimes undertaken by MSSNs but could be better done by someone else include administering IV DMDs (which can be done by a support nurse or infusion suite nurse) and injection training.

|| [See the MS Trust website for details of how to access this tool.](#)



Figure 34: Case study: Role of an MSSN team administrator/coordinator

What can a good administrator do for the MSSN team?

Mid Essex is one of the most productive GEMSS teams in terms of the number of patient contacts achieved in the year, and also achieved high levels of satisfaction from patients responding to the GEMSS patient survey, particularly on responsiveness. With 1.35 WTE MSSNs for a caseload of 625 people with MS, they were able to see each person on their caseload on average 2.1 times during the year – well above the GEMSS average of 1.4. One of the explanations for this is their use of administrative support to free up their specialist time. The team has an administrator (0.6 WTE at band 4) who is supported by an assistant (0.2 WTE at band 3) to support them. Their tasks include:

- Typing up and sending out edited letters, MDT referrals and reports.
- When the MSSNs are out of the office, taking incoming messages from the answering machine and filtering out and dealing with non-clinical ones. Brief notes are made for the MSSNs to enable them to prioritise which calls need their most urgent attention.
- Telephoning all patients coming to nurse-led clinics beforehand to ensure attendance to make sure that all slots are used, or that if there are going to be unavoidable gaps that the MSSNs can use their time for something else.
- Playing a key role in DMD management, checking funding is in place for patients prescribed DMDs, generating DMD prescriptions ready for signing by the neurologist, completing registration forms and liaising with home care companies for people on DMDs.
- Organising ophthalmic monitoring for pwMS newly prescribed Gilenya.
- Faxing letters to GPs (on the nurses' instruction) to recommend the use of oral steroids in the case of confirmed relapses, or for urgent medication changes
- Printing and filing test results.
- Booking review appointments proactively for pwMS who have not been seen for some time, according to local protocols and planned review frequency.
- Ordering patient information booklets and other resources.
- Maintaining the smooth running of the office and stocks of stationery.

Helen Willis, MSSN, commented 'Our administrator really saves us a lot of time because she now knows the service and the specialty – you only have to mention that something needs doing and she knows exactly what to do'.



Figure 35: Case study: establishing a nurse advice line

Introducing a Nurse Advice Line at the Walton Centre

The Walton Centre has a very large caseload, with an establishment of 2.6 WTE MSSNs^{mm} for over 3900 pwMS under the care of the neurologists at the Centre. Nurses are frequently out of the office at 'spoke' clinics, and so getting hold of one on the telephone was previously very difficult for pwMS.

During 2014, the team worked with the IT department to develop and trial a new **Nurse Advice Line** (NAL), open 9am – 4.30pm Monday to Friday. Rather than going to an answering machine, all calls to the service are now answered by a trained call handler who takes the details of the caller and filters out and deals with any administrative enquiries. If the caller wishes to speak to an MS Nurse then they are booked into a designated telephone clinic and given a two hour window on a date that suits them to receive a call back. The NAL system allows nurses to look ahead, see who is booked in (with the reason for the call) and triage and bring forward urgent calls if possible. They aim for all calls to be responded to within two working days. Messages from pwMS can also be sent via email.

Nurses calling back have access to case notes and all calls are fully documented. The system allows for data to be recorded on the ID of each caller, date of call, reason for call, outcome and date completed and response times are monitored monthly as part of a report on Key Process indicators.

The MSSNs staffing the telephone clinics now have 44 slots a week. An audit carried out during April – September 2014 showed that, of 1057 calls to the Line:

- Only 70% of callers needed to speak to an MS nurse, illustrating the value of the call handler in filtering out administrative issues.
- 34% of those who needed a call back received one the same or next working day.
- 92% of those calling with suspected relapses received a call back within 2 working days.

PwMS responding to the GEMSS patient survey said:

“[The service has] improved due to manned service on phone.”

“Introduction of the new telephone service has made it easier to get hold of the MS nurses and it is a much friendlier and helpful way of contacting them than previously via a very impersonal answering machine.”

The service still has work to do to improve and re-audit response times, but the evidence shows that the service has improved the ability of pwMS to get expert advice from an MSSN when needed. The Walton Centre MSSN team is among the most productive teams who took part in GEMSS, and the NAL is undoubtedly one reason for this.

^{mm} Establishment during 2014/15, this has since increased.



4.6.2 Smart scheduling and using capacity to the full

High levels of productivity require a high level of utilisation of outpatient and home visit slots. Within GEMSS, we found individual teams, despite being very stretched and busy, often not using all of their available slots, with as many as 39% of these going unused in one service. High outpatient DNA rates – standing at more than 10% in five of 14 GEMSS teams – are one issue, and highlight the need for reminder systems for people with MS, many of whom have cognitive issues, particularly if appointments are booked far in advance. In some cases, reminder systems used generated cancellations and re-scheduling requests from patients but slots vacated were not systematically refilled before the clinic taking place. Home visit capacity was sometimes under-utilised because visits were not grouped to minimise travel time.

A further source of productivity loss is the use of 'one size fits all' appointment lengths. The number of appointments booked per half day clinic varies between four and nine: in reality, different pwMS are bound to need different lengths of appointment, for example a new patient will need at least an hour, whereas a routine DMD review might only need 30 minutes. Some teams made good use of double appointments to accommodate these different needs.

An administrator can play a key role in maximising utilisation of slots. MSSNs should regularly review their clinic structure and ensure that they leave enough, but not too many urgent appointment slots for relapses and other urgent needs. Telephone triage can be used innovatively to determine whether pwMS need planned reviews before booking them in (although an annual face-to-face review for all people with MS, as recommended by NICE⁹ remains a minimum). Having basic data collection systems in place, so that activity against plan can be measured, is an important pre-requisite to enable services to be planned effectively.

4.6.3 Using home visits sensibly

Home visits are very useful and valuable for some pwMS, but because they are so time consuming they should not be offered just based on patient preference or because all clinic slots are full. Based on the GEMSS teams' experience, we suggest that around 15% of face to face contacts with pwMS should be carried out as home visits, within services that look after everyone within MS. Achieving this requires a clear policy within the service which is communicated to pwMS. It is also important that there is sufficient clinic space (including urgent slots held open until the week) to ensure that home visits are not substituted for clinic sessions due to constraints on outpatient facilities. Outreach clinics and 'pop up' clinics held near to centres of population can be a useful substitute for home visits by allowing pwMS to see an MSSN near home and in a more accessible venue than a large hospital, but still making best use of nurse time.

4.6.4 Structured communications

Qualitative comments made by GPs in the GEMSS health professional survey suggested that some MSSNs' written communications could be improved. Some MSSNs write very long, narrative clinical letters after seeing a patient; others don't consistently write to GPs after every consultation. Ensuring that each consultation is followed by a succinct, structured communication with key findings and actions is a simple step which can improve communication and productivity for some teams. Information systems which generate letters linked to electronic patient records can help and are increasingly common.



Chapter 5: The outcomes of MSSN services

This chapter presents:

- An overview of the patient reported benefits of MSSN input from the GEMSS survey of pwMS
- Evidence, both quantitative and qualitative, of the value of MSSNs in achieving each of the five outcomes of the NHS outcomes framework for England
- Evidence from the GEMSS health professional survey of the impact of MSSNs on their professional colleagues.

Key findings:

- 77% of pwMS reported at least one benefit of MSSN input in the past year, and on average respondents identified 4.5 benefits.
- 73% of pwMS thought that having an MSSN had improved the overall coordination of their care.
- During the year, MSSNs responded to contacts from around 21% of pwMS on their caseload who were concerned about suspected relapses or acute deteriorating symptoms. 24% of people with RRMS responding to the GEMSS survey said that their MSSN had diagnosed and/or started treatment for an MS relapse during the year.
- MSSNs perform well against national measures of patient experience. 71% of pwMS said they would be 'extremely likely' to recommend the service to friends or family in a similar situation. 95% said they were definitely treated with dignity and respect by their MSSN and 90% that they definitely had trust and confidence in their MSSN.
- Features of MSSN services particularly valued by pwMS were consistent availability and accessibility, a positive and empathetic attitude, specialist expertise and knowledge and accessibility of location.
- MSSNs reduce the workload of other health professionals (particularly neurologists and GPs) and can play a valuable role in improving the MS-related skills and knowledge of other professionals including GPs, nursing home staff, non-neuro-specialist therapists and social workers.

The primary source of the evidence is quantitative and qualitative patient reported data from the GEMSS patient survey, answered by 1,254 people with MS, supplemented with case studies from the GEMSS teams, and a health professional stakeholder survey sent to people working with each team. These are described in more detail in [Appendix B](#) and [Appendix C](#).

The NHS Outcomes Framework for England provides the framework in the GEMSS evaluation framework for describing and measuring outcomes, and the GEMSS teams within England used these to organise the evidence presented in their local reports^{oo}.

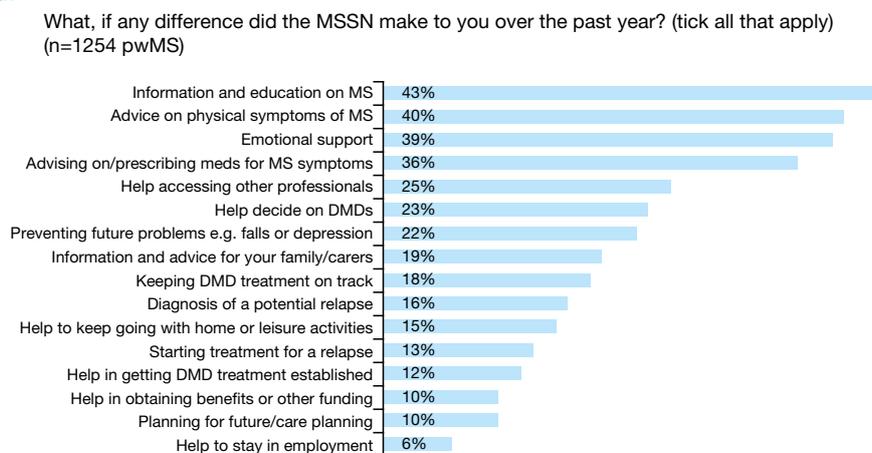
^{oo} The two Scottish teams used the NHS Scotland Quality Ambitions of 'a person centred service', 'a safe service' and 'an effective service' to organise their evidence.



5.1 Overview of patient-reported benefits of MSSN input

Figure 36 shows the proportion of respondents to the GEMSS patient survey who said that the MSSN service had benefitted them in different ways.

Figure 36: Ways respondents benefited from MSSN services in the past year



77% of respondents said that the MSSN service had made at least one positive difference to them. The average number of benefits that pwMS who said that the service had made a positive difference to them ticked was 4.5.

A specific question asked people whether they thought having an MSSN had improved the overall coordination of their care. The results are shown in [Figure 37](#). Nearly three quarters of respondents said that the MSSN had definitely improved coordination, reflecting the fact that many MSSNs bridge the boundaries between acute and community care. This was further highlighted in many of the examples given by respondents of MSSNs coordinating care, referring to other professionals or brokering services or equipment from other services on their behalf using their assessment skills and specialist network.

“ The MS nurses have sought very quickly for me to obtain help from other health professionals for physiotherapy and urology/colorectal problems.”

34 year old woman, diagnosed with RRMS < 1 year ago

“ [The MSSN service] has enabled my mother to stay at her family home and also helped to manage all health concerns. [Her] MS nurse has supported her to be assessed by other relevant professionals”.

Survey completed by daughter of 63 year old woman with SPMS, diagnosed more than 20 years ago



“ The occupational therapist has supplied me with grab rails and a shower step which have both helped make my life a little easier. The physiotherapist gave me some exercises which may help my mobility. The MS nurse initiated all of these appointments.”

69 year old man with PPMS, diagnosed more than 20 years ago

“ We have a patient with MS who comes to the day hospice. As a trusted member of the caring team, the MS nurse attended a meeting about care planning, and supported and advocated for the patient and his family.”

Palliative care doctor working with Calderdale & Huddersfield team

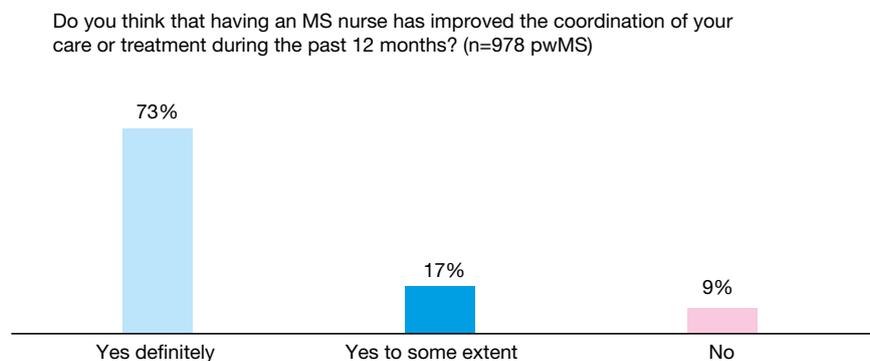
“ One of the nurses arranged a visit and flagged up an unexpected deterioration in one of our patients. They turned out to have developed a spinal cord tumour needing urgent surgery.”

Neurologist working with Leeds team

“ Just prior to Christmas, a patient contacted the MS Nurse in tears due to becoming urinary incontinent. By liaising with the Medical Continence Nurse Specialists we were able to arrange an appointment on the same day, assessed, diagnosed and commenced treatment. The patient has been reviewed by our services and her bladder symptoms have now improved immensely and she was able to have a good Christmas. It has also opened the door to discuss other issues regarding her bladder and sexual relationships.”

Continence Nurse Specialist working with the Leicester team

Figure 37: MSSNs and coordination of care





Respondents were asked to give examples of specific ways in which their MS nurse service had helped over the past year, and 539 did so. The following sections contain selected quotes from the patient and health professional surveys which highlight the types of support which had made the most difference to pwMS under each of the outcomes framework domains.

5.2 Domain 1 - Preventing people from dying prematurely

Dealing promptly and effectively with MS symptoms and crisis can avert more serious problems which can be life threatening. The GEMSS project was not designed to collect data that would directly show the impact of MSSN's work on the mortality of people with MS, but the work carried out to help people with MS to manage symptoms and prevent complications may ultimately avert premature deaths. The SNIAT data presented in [Figure 22](#) above showed that 6% of MSSN consultations identified problems requiring intervention in bladder and bowel function and 1.5% identified problems in swallow and nutrition, both areas where complications can result in serious harm.

5.3 Domain 2 - Enhancing quality of life for people with long term conditions

MSSN services have the potential to enhance quality of life for pwMS through the physical, psychological and social dimensions of care. These are discussed in the following sections, followed by a section on how MSSNs can help pwMS to self-manage.

5.3.1 Help with the physical symptoms of MS

Respondents gave numerous examples of how MSSNs had helped with the wide range of physical symptoms associated with MS such as spasticity, falls, fatigue, bladder and bowel symptoms and pain, or given advice which assisted with avoiding worsening of problems. Many highlighted the fact that the MSSN has specialist knowledge and practical know-how which GPs (who typically each have only 2-3 people with MS on their register) often lack. This includes an understanding of how different impairments may impact on one other, for example, alleviating constipation can reduce spasticity and urinary tract infections.

“ Advice on bowel problems and advice on pain killers and emotional problems.”

72 year old male with SPMS, diagnosed 10-20 years ago

“ I know the MS nurses are there if I have any problems however big or small, they have helped with pain medication and physio over the last year which has helped me reach a normal level of mobility and has helped my low mood immensely.”

32 year old female with RRMS, diagnosed 1-2 years ago



“ When going through health problem[s] due to massive spasms a phone call and discussion with regards to medication enabling me to manage lesser spasms.”

65 year old man with SPMS, diagnosed more than 20 years ago

“ My nurse has offered advice re fatigue and work and explained that if sensory symptoms come and go this can be pretty normal for somebody with MS.”

45 year old woman with RRMS diagnosed 3-4 years ago

“ My MS nurse has provided information/explanation and advice on some of the stronger symptoms of MS. Making sense of the disease and providing practical solutions. I am lucky to have a lovely GP. But he admits that he has very little knowledge of MS and will often refer to the MS nurse e.g. with regard to bladder problems.”

49 year old woman with SPMS, diagnosed 1-2 years ago

“ Although over the past 12 months my MS has been mild - she always advises me on patterns to my exacerbations. This has helped me to not overload myself with stress therefore avoiding relapses.”

Female with RRMS diagnosed 5-10 years ago, age withheld

“ I value their ability to tease apart new neurological symptoms not related to the MS that had been assumed by other health care professionals to be ‘part of MS’ - this has led to the correct non-MS diagnosis on numerous occasions to the benefit of the patients involved.”

Neurologist working with the Salford team

“ Provided emotional support and information on relapsing MS symptoms and what to expect. This reduced patients’ anxiety levels and reduced anxiety around mealtimes and swallowing.”

Speech and Language Therapist working with the Salford team

“ There are many examples where I have identified a patient I have been working with and they are having new difficulties and with discussion with the MS Nurse they have been followed up and given advice and help in their symptom management. Many examples of the MS Nurse organising medications or changes to medication through the GP and referring patients on to other services through discussion with myself. The MS nurses will often promptly identify someone needing physio and refer urgently if required.”

Physiotherapist working with the Tayside team



MSSNs often manage symptoms through the use of symptomatic therapies. Some are prescribers themselves; others make recommendations to neurology or GP colleagues.

“ I suffer from neuralgia on the left side of my face in the trigeminal nerve on my cheek. Initially amitriptyline tablets were able to deal with the pain, but when they were no longer able to the MS Nurse prescribed pregabalin 50 mg tablets for it. It has flared up 3 times during the last 12 months and the MS nurse has advised to increase & then decrease the dosage to deal with this. Her advice has been helpful in allowing my GP to amend my prescription accordingly.”

66 year old female with SPMS diagnosed 10-20 years ago

“ Prescribing pills for my trembling leg during the night which was disturbing my partner. So we are very grateful for this diagnosis because Lyrica has made a massive difference.”

44 year old woman with RRMS diagnosed 10-20 years ago

“ [The] nurse suggested increase dosage of baclofen in the evening to ease pressure pain in leg. Increase in dosage worked to relieve pain.”

66 year old man with PPMS diagnosed 3-4 years ago

5.3.2 Improvements in pwMS' understanding of the condition and psychological wellbeing

Many respondents mentioned that the MSSN had provided valuable information and education about MS, particularly at the time around diagnosis when pwMS may feel overwhelmed by the amount of information about the condition and treatment options to be taken in.

“ Upon my diagnosis, the MS nurse team armed me with lots of information about my condition and ways of managing it, along with good advice for my family. The team let me know I wasn't alone and they were only a phone-call away.”

34 year old woman, diagnosed with RRMS < 1 year ago

“ [She] helped myself and my family when I was first diagnosed 15 months ago. She has been a huge support and explained MS to me and the options for treatment. She is always available if I have any concerns or queries, answering questions that my GP, pharmacist and nurses at my local practice are unable to answer because they do not know enough about or specialise in MS.”

20 year old male with RRMS diagnosed 1-2 years ago



Some examples given were about the information given by MSSN to the wider family.

“ The MS Nurse has chatted to my wife and me about problems and answered questions fully and given helpful advice for both myself and, mainly, my wife.”

53 year old man, diagnosed with SPMS 3-4 years ago

“ [She] has made a difference to us as her carers - gives advice/guidance, signposts where necessary.”

Carers of 42 year old woman with PPMS, diagnosed 10-20 years ago

Many people with MS suffer with depression and anxiety, both as symptom of MS itself and also as a consequence of the many life challenges which they face. People with higher levels of disability often worry about end of life issues, such as whether they may need to go into a nursing home, or what will happen if they are no longer able to swallow or communicate. Stress is also known to be a factor in triggering MS relapses²⁴. Hence it is vital that people with MS have tools to help them manage their stress, and access to psychological support.

“ I can't thank D enough on the support they have given me over the last few months. With my Mum passing away I have been very scared of a relapse with the stress I have been under. The support and reassurance has helped me no end. I got a relaxation CD for sufferers that has helped me with my breathing to stay calm in times of stress.”

41 year old female with RRMS, diagnosed 3-4 years ago

“ I have suffered very low moods and low self esteem in the last few months and my MS nurse has been very support and helped me to be positive. She is one of the few people who understands the frustration of MS without having to go into long explanations.”

61 year old woman with SPMS, diagnosed 10-20 years ago

“ Our MSSN team is keeping regular tabs (every 2 weeks) via phone, clinic and domiciliary visits on patient with aggressive MS and mood disorder, something I would not have been able to do.”

Neurologist working with the Salford team

“ A newly diagnosed patient was struggling to cope with new diagnosis and its implications, while physically quite well, was depressed. The person was greatly helped by emotional support and education by the nurse which helped get back to normality quickly.”

Consultant Neurologist working with Western Isles MSSN



5.3.3 Making an informed decision about treatment with DMDs

Making a decision about treatment with disease modifying drugs can be a daunting prospect given the range of treatments now available with different eligibility criteria, efficacy, risks, possible side effects and modes of administration. MSSNs play a key role in helping pwMS through this process. 31% of people with RRMS responding to the GEMSS survey said that their MSSN had helped with this in the past year. When looking only at respondents diagnosed in the past year, the proportion who said their MSSN had helped them make an informed decision about DMDs was 47%.

“ I was unsure about the doctor’s advice and she helped me to make a decision about my DMD by discussing the doctor’s recommendations through with me as I was initially unsure about it and once I had had a chance to think about it properly the MS nurse helped me to make my own informed decision about a course of treatment.”

50 year old male with RRMS, diagnosed 5-10 years ago

“ I had a useful discussion at routine interferon monitoring appointment about new oral medication option and planning to have a family.”

32 year old female with RRMS, diagnosed 1-2 years ago

“ [She] helped me make my mind up about treatment and went through all the information. This treatment has made a difference to my quality of life.”

48 year old female with RRMS, diagnosed 1-2 years ago

“ The MSSNs helped me to decide appropriate treatment as I could talk through my circumstances with them and they provided factual information on the treatments which I could then relate to how this would affect my lifestyle.”

23 year old female with RRMS diagnosed 5-10 years ago



5.3.4 Social dimensions of care

Respondents gave many examples of where their MSSN had helped them to remain in work or to make the difficult transition to no longer working.

“ [Having] my MS nurse sit and listen when I was at my lowest was invaluable. I had reached a point where I thought I couldn’t cope with work pressures and she helped me talk through my options. She provided advice and information booklets on how to tell my children, which I found very difficult, and how my work place should make reasonable adjustments for me. She helped me with advice about benefits... I know she is always at the end of the phone should I need her and think the service that these nurses do is our lifeline.”

55 year old woman with PPMS, diagnosed 3-4 years ago

“ I had just started a new job when I relapsed. T helped write letters to Access to Work which aided transport being funded for me while I got back to being more independent. My experience with Access to Work was poor - but T did everything she could to help me gain the funding and therefore (along with my supportive employers) enable me to remain in work.”

38 year old female with RRMS, diagnosed 10-20 years ago

“ As I am applying for early retirement under grounds of ill health, the MS nurse has been supportive helping me maintain employment for as long as possible.”

54 year old female with PPMS, diagnosed 10-20 years ago

“ One of my patients has been struggling with a work related issue secondary to physical symptoms. The MS nurse input was invaluable in helping the employer understand the problems and help both the patient and employer have confidence that he could stay in work.”

GP



Other comments described occasions where the MSSN had helped them to navigate systems so that they could continue to live as full a life as possible with MS. Driving license renewal was often mentioned as something which MSSNs had helped with.

“ Without MS nurse’s input I would not have thought to enquire about my critical illness cover which I received in full. [She] Has co-ordinated a lot of the relevant people I needed to see. Information has been vital.”

52 year old female with SPMS, diagnosed 1-2 years ago

“ Advice on driving - insurance, DVLA and no tax on car.”

59 year old female with PPMS, diagnosed 5-10 years ago

“ The MS nurse assisted me with a statement for my ESA appeal (which was successful).”

50 year old male with RRMS diagnosed 5-10 years ago

Some comments mentioned the role that the MSSN had played in planning for the future, when disabilities meant that a transition to supported or nursing home accommodation became necessary.

“ She has supported me in making the difficult transition to long-term nursing care and helped inform the whole process.”

47 year old female with PPMS diagnosed 10-20 years ago

“ [She helped me] to get a place at K... Hospice on a 12 week block.”

54 year old female with SPMS, diagnosed more than 20 years ago

5.3.5 Support for self-management

A number of examples mentioned the role played by the MSSN in supporting respondents to manage their own condition. Although section 4.3 above describes significant unmet need for self-management support, where courses were offered they were praised. In other cases, respondents highlighted encouragement for self-management provided by MSSNs on a one to one basis.

“ The MS course was a great help to me and my husband - we both gained a greater understanding of MS and its affects on both of us.”

63 year old female with RRMS, diagnosed 1-2 years ago



“ The course which was run in Perth in October made a huge difference to me and my MS. I don’t feel it takes over my thought[s] as it did before the course. And having a nurse at the end of a phone helps.”

40 year old female with RRMS, diagnosed less than a year ago

“ She has discussed with me various issues such as diet and exercise/fitness to try to maintain my health and strength.”

59 year old female with RRMS diagnosed 10-20 years ago

“ The newly diagnosed education group was extremely useful for a particular patient. She found it informative and very practical.”

Physiotherapist

5.4 Domain 3 – helping people to recover from episodes of ill health or following injury

During the year, the GEMSS MSSNs recorded that they responded to nearly 4000 pwMS (equating to 21% of the caseload, or 157 contacts per whole time MSSN) who contacted the service with acute deteriorating symptoms and suspected relapses, and dealt with many more issues identified during review appointments. From the patient survey, 24% of respondents with relapsing remitting MS and 12% of respondents with secondary progressive MS said that the MSSN service had diagnosed and/or started treatment for an MS relapse during the year. Many respondents mentioned the benefit of having the MSSN service available at the end of the phone in this situation, and a number talked about the fact that GPs often don't feel confident to assess and prescribe for potential relapses without guidance from the MSSN.

“ My MS Nurse provided support and information when I had my latest relapse. She helped me by explaining that steroids were probably not the best treatment for my sensory MS symptoms, and by explaining this to my mum too (who attended my appointment with me). She also helped by referring me for further assessment for cognitive difficulties that I have been experiencing.”

34 year old female with RRMS diagnosed 1-2 years ago

“ My MS nurse makes the world of difference to my care... By having telephone support I can ... avoid hospital treatment. MS requires quick decisions of managing relapses and the MS nurse is best placed to do them.”

35 year old woman with RRMS diagnosed 5-10 years ago



“ I had a relapse earlier in the year and my GP was unwilling to prescribe steroids without advice. I phoned the team and received advice and obtained the steroids.”

51 year old female with SPMS diagnosed 5-10 years ago

“ When a patient had sudden exacerbation of symptoms the specialist nurse diagnosed a relapse and put wheels in motion for timely treatment for this. I feel this prompt response made the effects of the relapse less and more manageable than if there was a delay in responding.”

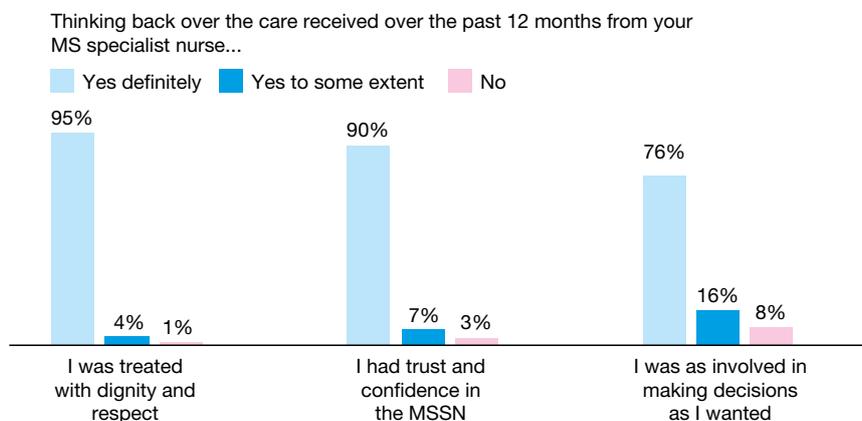
Physiotherapist working with Tayside team

5.5 Domain 4 – ensuring that people have a positive experience of care

The GEMSS patient survey asked respondents to provide feedback on key indicators of patient experience. On the ‘friends and family test’, widely used in England, 71% of respondents said that they would be ‘extremely likely’ to recommend the MSSN service to a friend or relative who needed similar care and treatment, and the Net Promoter Score averaged +66^{pp}.

The GEMSS patient survey adopted several standard questions also contained within the NHS National Outpatient Survey²⁵. The results are shown in figure 38. The results compare very favourably to national levels of satisfaction with outpatient consultations across all specialties (largely provided by doctors): on the three measures shown, the proportion of respondents (from a sample of more than 70,000) answering ‘yes definitely’ in the National Outpatient Survey was 89%, 83% and 72% respectively.

Figure 38: Reported measures of satisfaction with the MSSN service in the past 12 months



pp The Net Promoter Score can range from -100 to +100. An explanation of how it is calculated is given on the [NHS England website](#).



5.5.1 Consistent availability and accessibility of support

306 comments and examples of support mentioned the fact that the MSSN is 'there when you need them' at the end of the phone. Given the unpredictability of MS and the fact that symptoms can flare up at any time, and the fact that GPs' knowledge of MS is often limited, the availability of same day specialist advice is invaluable.

"Whenever I have had any problems I am able to ring the nurses. They always ring back and give advice/support. If I need an appointment to see them or my consultant they organise this. If I need other treatments such as IV steroids they sort this out. It makes such a difference knowing that this support is at the end of a phone."

54 year old male with PPMS, diagnosed more than 20 years ago

"My MS nurse is always there for me just a phone call away. My GP doesn't understand or know anything about MS. She advised me on my medication and spoke to my GP herself."

32 year old female with RRMS, diagnosed 1-2 years ago

"Knowing that G and J are at the end of the phone gives me great peace of mind. I sometimes have to leave a voice-mail but that doesn't bother me as I know they'll return my call. They're a real life line and have helped me to stay positive about my MS. It's great to have someone to talk to that understands! I'd be truly lost without them."

34 year old female with RRMS diagnosed 5-10 years ago

"Being able to call or see a member of the medical profession who's willing to listen and help, rather than being told to "see your consultant"."

42 year old female with RRMS diagnosed 3-4 years ago

5.5.2 Attitude and approach of the MSSN

209 comments made reference to the caring, sympathetic, supportive attitude of their MS specialist nurse as something they particularly valued. Several respondents talked about the fact that MSSNs have seen things before and are therefore able to cope with talking about difficult subjects in a way that family and friends can't. Above all, MSSNs having the time to spend discussing complex issues without rushing, at significant points in the journey, was appreciated.



“ On my third relapse - she came for a couple of hours and we discussed all my symptoms, Neurologist, future treatment, family all the combining/culmination of events and what I did etc. Moved me forward or perhaps added to my positivity of moving forward as I was already managing my relapses 3 back to back!”

50 year old female with RRMS, diagnosed 5-10 years ago

“ Emotional support from both the nurses I see is exceptional. They keep me on the straight and narrow reassuring me that I am self managing my condition well. This is due to the support they give me and knowing that they are only on the other end of the phone. If new things crop up they are able to help me describe it with the years of knowledge of other MS users and it is very reassuring. They always have time to chat about the condition and know when I am well or having a rough time. If help is needed to access other services they are always there to help.”

46 year old female with RRMS, diagnosed 5-10 years ago

“ The MS nurse is the only person I speak openly and honestly about my MS. The support and knowledge is invaluable.”

45 year old female with SPMS, diagnosed 5-10 years ago

“ My ability to cope with MS would be significantly reduced without A in my life... She inspires me to continue and cope with the MS to the best of my ability. She is my team captain and never want to lose her.”

47 year old female with RRMS diagnosed 3-4 years ago

“ I appreciate their approach within consultations - both nurses have a good sense of humour but still have a calming, empathetic approach. I feel they have the right balance. I wouldn't cope with people who were all 'doom and gloom'.”

34 year old female with RRMS diagnosed 1-2 years ago



5.5.3 Specialist expertise and knowledge

55 comments talked about the specialist expertise that MSSNs have, based on the fact that they are dealing with the complexities of MS day in, day out. Many respondents talked about how much more knowledge MSSNs had than GPs, and some mentioned that their MSSN seemed to be knowledgeable than their (non MS-specialist) neurologist.

“ They have the knowledge/information to answer my queries accurately - or know how to find the information quickly.”

53 year old male with RRMS diagnosed 10-20 years ago

“ It is good to know that there are MS specialist nurses who know about the condition and act as a bridge to MS care, they know about MS more than most doctors and save consultant visits as can give advice and support when needed and contact doctors and specialist neurologists for you.”

35 female with RRMS diagnosed 5-10 years ago

“ They are very well informed whereas visiting the doctors was a waste of time as they have very little understanding of MS.”

46 year old female with RRMS diagnosed 10-20 years ago

“ Had “a 3 way” between myself, MS nurse and neurologist who keeps assessing incorrectly - MS nurse can put him right!!”

50 year old female with RRMS, diagnosed 5-10 years ago

“ The most useful and supportive thing is because I live in an isolated situation, is the chance to speak to someone with knowledge and understanding of MS.”

Female with SPMS diagnosed more than 20 years ago, age withheld

5.5.4 Services available in most appropriate place

A number of respondents talked particularly about the ability of MSSNs to deliver home visits, something which not all MSSNs are permitted to do.

“ [The thing the service did particularly well was] offering home visits and a feeling of not being totally left alone.”

60 year old male with PPMS diagnosed 10-20 years ago



Others described the value of telephone or email support:

“ The best thing is to be able to have a telephone consultation. To travel to [the hospital] is counter productive and exacerbates MS.”

53 year old male with SPMS, diagnosed 10-20 years ago

“ Being able to give advice on phone/email and seeing me as required.”

74 year old female with RRMS, diagnosed 5-10 years ago

5.6 Domain 5 - treating and caring for people in a safe environment; and protecting them from avoidable harm

In addition to preventing avoidable harms resulting from complications such as falls and untreated infections (discussed under [5.3](#)), MSSNs play a role in managing other risks, including incorrect use of equipment, inadequate care packages and unsafe use of medicines for MS symptoms as well as DMDs. SNIAT data presented in [Figure 22](#) showed that 21% of MSSN consultations identified problems requiring intervention in terms of medication management.

PwMS gave examples of support for all aspects of safely using DMDs, including injection training, monitoring and support for starting, stopping and switching therapy. Safety monitoring of DMDs is a particularly important role not necessarily fully appreciated by pwMS but which was often mentioned in comments from other health professional colleagues, particularly neurologists.

“ [Help with] Injection site problems!”

36 year old female with RRMS, diagnosed 10-20 years ago



“ The MSSN intervened when a patient had a very serious side effect to treatment and accessed immediate investigations and treatment at the hospital.”

Other specialist nurse working with Salford team

“ The service in Dundee is excellent and I can think of many examples. One example is that the MS specialist nurse service collates all the important information of all patients, in particular those on DMD. One patient newly started on dimethyl fumarate with new visual symptoms was brought to my attention after the patient contacted the MS nurse service. Macula oedema as a treatment complication could then be excluded, but it demonstrates an effective loop of communication between patients, specialist nurses and medical staff.”

Neurologist working with Tayside team

5.7 The impact of MSSNs on their professional colleagues

The GEMSS health professional survey asked colleagues working with MSSNs to identify ways in which they themselves had benefitted from having an MSSN in place. Two themes emerge from the responses: the impact of the MSSN on the knowledge of the wider team, and the fact that the MSSN reduces workload for others, particularly neurologists and GPs.

5.7.1 Expanding the knowledge of other healthcare professionals

Health professionals – particularly non neurology specialists like GPs, nursing home staff and social workers – described many occasions where the MSSN had helped them to understand the issues for a particular pwMS or provided training on MS.

“ [Without MS nurses] it would be more difficult get advice on how best to manage patients. There would be less communication between the acute and community service and it is likely that the quality of care would not be as good as it is because of this. My knowledge of MS is improved by working with the MS nurses and they are able to provide help and examples from experience that is just not available in a book and are able to assist with coordination and treatment of complex cases.”

Community Physiotherapist working with the Mid Essex team

“ They are a source of expertise and advice for service users and healthcare professionals in the north of Powys.”

Physiotherapist working with Shrewsbury & Telford team

“ Without the MSSNs, other healthcare staff would not be aware of all available specialist treatment e.g. intrathecal baclofen.”

Other specialist nurse working with Shrewsbury & Telford team



“If the MS nurse had not been available as a professional I would have struggled at times to understand the impact of MS and in my opinion clients would have felt very isolated.”

Social worker working with the Western Isles MSSN

“Without the MS nurse, we would not have had such insight to how MS has affected, and is affecting, the client. We would not have had such a good understanding of their needs, how they manifest, treatment options and impact of changes in treatment/disease progression - this would have made it more difficult in fully assessing needs in these situations as effectively as they have been.”

Health Visitor working with the Western Isles MSSN

5.7.2 Reducing the workload of other professionals

Health professionals, particularly neurologists, also described how the MSSN had alleviated their workload and thereby increased their capacity.

“ [Without the MS nurses], I think my workload would have been more for a number of reasons. They are often a first point of contact rather than us as GPs and they are providing a huge amount of information to patients that we might otherwise have to be doing. I think this benefits the patients also in that they are getting specialist knowledge. I think the service is invaluable.”

GP working with Calderdale & Huddersfield team

“ The MS nurse has suggested a treatment regime for a lady who has MS and has a urinary catheter in situ, which we have been having some problems with, this has included a change in her medication, and also she offered guidance on what could be the issues with the catheter as it kept blocking, this has resulted in the lady having a better quality of life.”

Nurse in a nursing home working with the Northern Devon MSSN

“ Quite simply I could not cope without the MSSNs and my patients would have suffered greatly.”

Neurologist working with the Salford team



“ Without the MS specialist nurses, it would have been an unmanageable workload, sorting out DMDs and taking calls.”

Neurologist working with Walton Centre team

“ I would not have the time or expertise to manage my MS patients properly without the MS nurse team.”

Neurologist working with the Salford team

“ If the MS nurses weren't there, more of my time would have been diverted onto trying to deal with something I am not specifically trained to do, I am unfamiliar with and do not have the time for. The neurologists would have received more letters from GPs with queries and the whole process of care would be slowed down.”

GP working with Tayside team

“ If the MSSN wasn't there I would have been busier liaising directly with Neurology services at the distant mainland hospital where our Neurology services are based.”

GP working with Western Isles team

5.8 Why doesn't everyone experience benefit from having an MSSN?

23% of respondents to the GEMSS patient survey reported that the service had made no positive difference to them in the past year. Any discussion of the positive outcomes of MSSN support would be incomplete without a discussion of why this group did not benefit. The proportion of respondents from each team who said this varied widely, from only 8% in one team (an acute service focused particularly on DMDs) to over 37% in two other teams. The proportion of respondents from each service who said that the service had made no difference was associated with caseload size per MSSN, though not significantly so. Analysis of the qualitative comments made by people who said the service had made no difference revealed only a handful of comments saying that the service had been unhelpful, or criticizing the knowledge or attitude of the MS nurse. The vast majority fell into two categories:

First, a group of respondents expressed the view that they really hadn't needed any help in the past year. Examples of the comments made include:

“ I haven't had the need to see the MS nurse (I'm one of the lucky ones) but in the past I have and they have always been a great support. I also know that they are at the end of a phone if I need them.”

49 year old female with RRMS diagnosed 10 – 20 years ago



“ In the last 12 months I have not needed anything from my MS nurse. If I did I know they would help me in all areas. However, I am very lucky that I am well and don’t need assistance at this time.”

37 year old female with RRMS diagnosed 5-10 years ago

However, a second, larger group said that they had had insufficient contact from the MS nurse service. This is borne out by an analysis of the data which shows that, of the one in five respondents who said they had had insufficient contact with the MSSN service in the past year; almost half felt that the service had made no difference to them, compared to only 14% of those who felt that they had had enough contact.

Many (though not all) were older people who had been diagnosed with MS many years ago (the average age of those who said the service made no difference was 55 compared to 51 for those for whom the service had made a difference). In several cases, they said that they had contact information for the service, but hadn’t felt able to reach out for support and wanted the service proactively to make contact with them. The comments made by many of these respondents reinforce the need for sufficient MSSNs to ensure that caseloads are sustainable and everyone with MS is offered a comprehensive annual review as a bare minimum.

“ [The] MS specialist nurse has never been in contact, and it seems that probably I don’t exist.”

71 year old male diagnosed 3-4 years ago, type of MS unknown

“ The MS nurses try but are desperately thin on the ground.”

44 year old male with RRMS diagnosed 5-10 years ago

“ It has made a difference in that the person is there to contact if needed. However they are understandably very busy. Sometimes it would help to know that there is a definite opportunity to meet and discuss. There is not really any opportunity to do this.”

53 year old female with RRMS, diagnosed 1-2 years ago

“ It would be nice to have an opportunity to see and speak to a nurse. I only see my neurologist once a year for about 15 minutes. If I did access to a nurse then I could get in touch and get answers to questions I might have over the year.”

63 year old female with RRMS diagnosed over 20 years ago

“ It appears that due to my age (over 70) and the fact that I have had MS for 29 years I have not been helped in any of the above as newly diagnosed patients with MS appear to received most of the help.”

Female aged 74 with SPMS, diagnosed more than 20 years ago



5.9 Views from pwMS on improvements needed to MSSN services

Respondents to the GEMSS patient survey were asked how the service could improve. Only 218 respondents (17%) made suggestions, and many others answered by saying 'No nothing' or similar. Over half of the suggestions made were for more contact with the MSSN service and pleas for an increase in the number of nurses. Many of the comments described frustration with the difficulty in getting hold of the MS nurse and some suggested that administrative support for MSSNs would help with this, as discussed in section [4.6](#) above.

“ They are terribly busy doing clinics, ward work and trying to give advice/organize things for MS sufferers over the phone. I feel bad ringing them (not that they have been off with me) in fact they have been invaluable to me this year because of the relapse and DMD monitoring. They need a smaller catchment area to have to cover and more time for phone advice/urgent clinic appointments as needed. The O.P waiting time is a year! It’s scary if e.g. you think you have had a relapse and are waiting to hear back news. They know a lot more about MS than GPs/A+E or emergency doctors.”

49 year old female with RRMS diagnosed 10-20 years ago

“ There is little or no contact. Job too large and spread out for one person. She doesn’t seem to have any secretarial help.”

71 year old female with PPMS diagnosed 5-10 years ago

“ They could have been more accessible to me. Hard to reach on the phone or by email and take a long time to return calls or emails. Too few MS nurses for too many clients.”

48 year old male with SPMS, diagnosed 5-10 years ago

“ I would like to have touched base with her just by phone for a brief ‘how are you doing?’ consultation. I feel I have dropped off the radar. Having said that, I phoned her once wanting advice and she did return my call the next day and helped me which was great. Other than that I’ve heard nothing and that was a good year ago.”

48 year old woman with RRMS diagnosed 5-10 years ago

Linked to the issue of capacity, a further 41 suggestions were about calls being returned more swiftly.



"[I would like them to] contact me next day or same day when I phone the service."

45 year old male diagnosed 5-10 years ago, unknown MS type

"It is sometimes difficult to get through to speak to a nurse because they have clinic commitments etc. and this can make you feel quite isolated at times when you really need their support and there is nowhere else to go."

31 year old female with RRMS diagnosed 3-4 years ago

"I think that the response on phone could be a lot quicker, it does say they will get back to you within the next 2 days but it can be nearly a week!! Not very good I'm afraid."

67 year old woman with SPMS, diagnosed more than 20 years ago

Some suggestions were about making the service available more locally or in different locations, including home visits.

" I wish the MS nurse could come out to the house and visit. There should be more MS nurses."

39 year old female with RRMS diagnosed 5-10 years ago

" We need more clinics in rural areas."

53 year old female with RRMS diagnosed 10-20 years ago

Only a handful of comments (14, representing 1% of respondents) criticised the MSSN's knowledge, attitude or practice, with a diverse range of individual issues, the two below being examples).

" [It would be good if she] treated my MS as its own not based it on what was happening/ happened to others."

22 year old male with RRMS diagnosed 5-10 years ago

" As my mum has had repeated problems with urine infections the consultant told me it would have been helpful if she had been referred to urology for a scan sooner."

Daughter/son of 67 year old female with RRMS diagnosed 5-10 years ago



Respondents to the health professional survey were also asked about how services could improve. Again, most responses were that more MSSN capacity was needed. Other, specific local issues were raised and dealt with in individual team reports. Aside from capacity, the main common theme was the need for more outreach from MSSNs and more information about the MSSN service available.

“ It would be good if she could provide training/education for community nurses dealing with MS patients, realise this is a huge ask on top of existing caseload but in an ideal world this is what I think would be beneficial.”

GP working with the Western Isles team

“ Let practices know about the existence of an MS nurse and how best to contact them and refer patients. I didn’t realise there was an MS nurse.”

GP working with Calderdale & Huddersfield team

“ It would be good to have an outline of what the service offers - possibly a handout?”

GP working with the Mid Essex team



Chapter 6: The economic effectiveness of MSSN services

This chapter presents:

- What we mean by 'economic effectiveness' and the fact that this has different meanings for different decision makers and from different perspectives.
- A very brief discussion of the complexity in the way in which MSSN services are commissioned in England.
- Evidence that MSSNs reduce ambulatory care costs elsewhere in the NHS.
- Patient reported emergency admissions for pwMS responding to the GEMSS survey.
- A discussion of how MSSNs can reduce admissions.

Key findings:

- Using conservative assumptions, the GEMSS data suggests that each WTE MSSN participating in GEMSS has saved £77.4k in ambulatory care costs (GP appointments, neurology appointments and A&E visits) during the year.
- Whilst reductions in emergency admissions are difficult to measure, we can be confident that MSSNs reduce admissions and that the savings generated are likely to far exceed the costs of employing them.
- 6% of pwMS reported that their MSSN had helped them to stay in employment in the past year, and the wider societal benefits of keeping people in work are significant.

6.1 What do we mean by 'economic effectiveness'?

When people talk about making an 'economic case' or 'business case' for specialist nurses, they may mean a variety of different things. Health economic evaluation involves weighing up the costs and the consequences of healthcare interventions, but:

- **Consequences can be measured in different ways:** for example for MSSNs in terms of unscheduled hospital admissions avoided, working days gained, relapses shortened, urinary tract infections avoided, relative improvements in quality of life for pwMS.
- **Perspective is critical:** the costs and the consequences will be very different when viewed from the perspective of a healthcare provider organisation, a commissioner, a whole health system (the perspective taken by NICE and the Scottish Intercollegiate Guidelines Network) or an individual person with MS and their carers. The different perspectives which might be taken by providers, commissioners and GPs were discussed in *Defining the value of MS specialist nurses*²⁶ and this analysis remains relevant today. The way in which NHS funding flows inevitably has a bearing on how the economics of MS specialist nursing look from different perspectives.

Figure 39 summarises types of economic evaluation commonly used in healthcare programmes with examples of what would be measured for MS specialist nurse services²⁷.



Figure 39: Types of economic evaluation of healthcare programmes

Type of analysis	Costs measured	Consequences measured	Who would take this perspective
Simple 'business case' i.e. income vs. costs	Cost of employing MSSN (together with overheads, admin support etc)	Income generated for the provider through additional work commissioned, any reductions in cost or gains in income from being able to reduce other costs (e.g. shorter length of stay for emergency admission) or redeploy other staff (e.g. neurologists)	Provider organisation (England) ^{qq}
Cost consequence analysis	Cost of commissioning MSSN service from provider organisation (England) or cost of employing MSSN (Scotland, Wales, Northern Ireland)	Reduction in costs of other healthcare which are avoided (e.g. A&E attendances, GP visits, admissions to hospital)	Commissioner (England) or Health Board (Scotland, Wales, Northern Ireland)
Cost effectiveness analysis	Cost of commissioning MSSN service from provider organisation (England) or cost of employing MSSN (Scotland, Wales, Northern Ireland)	Improvement in measurable outcomes e.g. reduction in urinary tract infections, shortened recovery from relapses, relative improvement on score on an MS Quality of Life questionnaire	Commissioner (England) or Health Board (Scotland, Wales, Northern Ireland)
Cost utility analysis	Cost of employing MSSN (together with overheads, admin support etc)	Gain in Quality Adjusted Life Years (QALYs). These are a combination of increased life expectancy and improved quality of life, measured using a preference-based cardinal scale (i.e. in a way that can be compared across all conditions)	Health Technology Assessment agency (e.g. NICE) taking a whole system perspective
Cost benefit analysis	Cost of employing MSSN (together with overheads, admin support etc)	Outcomes of services (including gains in QALYs but potentially also wider societal benefits such as reduced welfare costs and improved income for pwMS through remaining in employment) all converted into a monetary (£) value for direct comparison with costs.	Government level analysis looking at how best to allocate overall public spending.

qq Provider Trusts will also be interested in the impact of the service in quality and outcomes, not simply income vs. expenditure, but this will be a primary factor in the decision.



GEMSS was not set up as a formal economic evaluation of MS specialist nursing and has not measured consequences in a way that would allow for a cost effectiveness, cost utility or cost benefit analysis. To do this would require us to:

- Track outcomes for individual pwMS over time
- Establish a control group, without MSSN input, whose outcomes would also be tracked over time and compared
- Measure outcomes using meaningful measures which could be converted into QALYs (for CUA) or monetary measures (for CBA).

There are many practical and ethical reasons why this was not feasible.

However, the GEMSS data can assist with developing a business case for an MS specialist nurse and with looking at the cost-consequences of employing MSSNs, and this is discussed in the following sections.

6.2 Making a business case for MS specialist nurses

The average and 'best practice' activity per MSSN presented in [Chapter 4](#) of this report will assist MSSNs and NHS provider organisations to develop a business case for additional MS specialist nurses in terms of the income generation potential. This is of particular relevance in England where a purchaser-provider split operates. However, whether this income can be realised for a particular service will depend on local commissioning arrangements. In particular:

- Some services are commissioned using a national 'Payment by Results' tariff, some using locally agreed tariffs, and others (particularly community services), are still commissioned on a block contract basis, so that income doesn't automatically vary when activity varies²⁸.
- In England, a further complication is that some services are commissioned by local CCGs, whereas those based in neuroscience centres are centrally commissioned by NHS England as part of 'specialised commissioning'. This situation is currently under review.

Because of these features of NHS commissioning, local arrangements need to be fully understood before any business case is developed and this will require discussion with the local commissioning/finance team. The MS Trust is currently developing a model business case for an MS specialist nurse service and this will be published on the MS Trust website in early 2016.

6.3 The cost consequences of MSSN services

The evidence collected in GEMSS suggests that MSSN input for people with MS saves money elsewhere in the health system by:

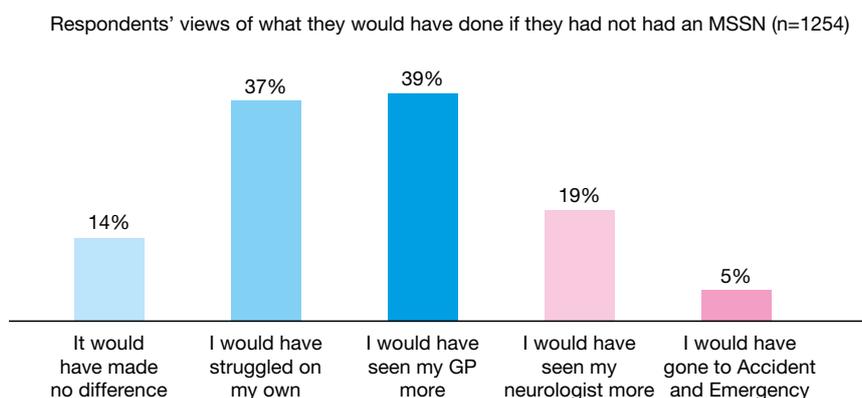
- Preventing hospital admissions and unscheduled care by undertaking early assessment and treatment of relapses, infections and other symptoms.
- Undertaking patient education on self-management and routine preventative work, to prevent symptoms becoming problematic and complications arising.
- Reducing the need for pwMS to see other, more costly professionals, such as GPs and neurologists.



6.3.1 Reduced costs of ambulatory care

Respondents to the GEMSS patient survey were asked to say what they would have done if they had not had an MS specialist nurse in the past year. The results are shown in figure 40. More than a third of respondents said that they would have struggled on their own, with the associated risk that complications of MS would potentially not be dealt with until they were at the point of crisis, requiring unscheduled care. However, nearly half the respondents said that they would have made more use of other services: GPs, neurologists and Accident and Emergency (A&E).

Figure 40: Respondents' views of consequences of no MSSN



Based on these results, we can put a cost on the ambulatory care which would have been necessary had the MSSN services not been available, using conservative assumptions. We have assumed that each person who said they would have seen their GP 'more' or gone to A&E would have done so only once during the year, and we have not made any assumption that the A&E visits would have resulted in a hospital admission.

For additional neurology appointments, only 19% of pwMS said that they would have needed to see their neurologist more if the MSSN had not been there, but we know this to be an underestimate. In order to comply with the NICE⁹ and Quality Improvement Scotland¹⁰ standards, everyone with MS would need to see a neurologist once a year in the absence of an MS specialist nurse, for a comprehensive, specialist annual review. We can also assume (conservatively) that people taking oral or self injected DMDs would need two neurologist appointments in a year, and those on IV DMDs would need four. Comparing this to current neurologist contact measured by the GEMSS patient survey (an average of 0.74 consultations with a neurologist per year per pwMS), we calculate that, without an MS nurse, each person on the caseload on average would need an additional 0.68 neurologist consultations each year.



Even on this very conservative basis, applying these results across a 'sustainable' caseload of 358 pwMS, each whole time nurse would have saved the NHS £53.6k in these ambulatory care costs, as shown in figure 41. Across the average caseload per WTE of the participating GEMSS nurses, which is 511 pwMS per WTE nurse, the saving per WTE nurse rises to £77.4k.

Figure 41: Conservative modelling of outpatient health service costs saved by MSSN services

	Additional required per year per person on caseload without the MSSN service	Number avoided (based on caseload of 358 pwMS)	Unit cost	Cost avoided	Source for cost data
Neurologist consultations	0.68	243	£174	£42,359	NHS reference costs 2012-13
A&E visits	0.05	18	£114	£2,041	NHS reference costs 2012-13
GP visits	0.39	140	£66	£9,215	PSSRU unit costs of health and social care 2013, 17.2 minute consultation
TOTAL ambulatory care costs avoided				£53,614	

6.3.2 Reduced costs of hospital admissions

Many people with MS end up in hospital each year. Based on Hospital Episode Statistics data for England analysed for a forthcoming report by NHS and the MS Trust⁸, in 2013/14 around 17% of people with MS in England were admitted to hospital as an emergency at least once, and there were 0.26 emergency admissions per person with MS. The average cost per emergency admission was £1820. The most common reasons were bladder and bowel related complications and respiratory infections, some of which could be prevented or managed at home with the right early intervention and treatment. Data published by the SWIMS study, which is tracking people in the South West of England with MS over ten



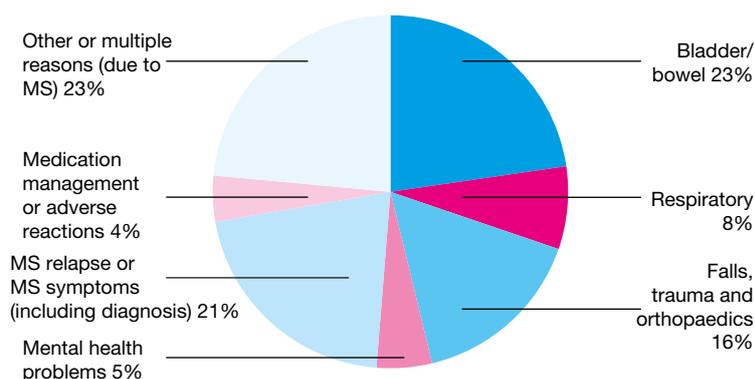
years, showed that 11% of MS relapses result in a hospital admission²⁹.

Respondents to the GEMSS patient survey were asked to say whether they had been admitted to hospital in the past year; what the reason(s) for the admission had been and whether they thought this was linked to their MS. In the analysis, the reasons for admission were coded as 'unrelated to MS', 'possibly MS related' or 'probably MS related' by the GEMSS facilitators, guided by the views of respondents (where expressed) but otherwise taking a pragmatic view. 'Possibly MS related' admissions included those for bladder and bowel issues, mobility problems, falls and mental health problems, and 'probably MS related' were admissions which respondents stated were MS related, such as for MS relapses or (in one case) a suicide attempt which the respondent attributed to their MS.

12% of respondents reported that they had been admitted to hospital at least once in the past year. Of the admissions, 90 (representing 7.1% of respondents) were for reasons probably linked to MS, and a further 29 (2.4% of respondents) for reasons possibly related to MS. Figure 42 shows the patient reported reasons for the MS related admissions grouped into broad categories. Those in the 'Other' category ranged from spasms, MS rehabilitation, pressure sores, multiple reasons from the other categories or unknown reasons where the respondent simply put 'MS'.

Figure 42: Reasons for 'probably' or 'possibly' MS related admissions

Patient reported reasons for MS related admissions in the past year (n=119)



Whilst this data is self-reported and hence subject to recall bias, and from a limited sample (1254 pwMS), these admission rates are surprisingly low when compared to the Public Health England data. One possible explanation is that those who have been admitted are less likely to have responded to the survey due to ill health (or ongoing hospitalisation), but another possible explanation is the preventative work carried out by MS specialist nurses and other members of the multidisciplinary team.

During the year, GEMSS MSSNs recorded the number of times they responded to pwMS contacting their services about an acute deterioration of their symptoms, including suspected relapses, infections, bladder and bowel symptoms and crises



relating to the home situation. These amounted to an average of 157 such contacts per WTE MS specialist nurse during the year. Even if only a relatively small share of such interventions result in a prevented admission, the savings are considerable.

Overall, on a cost-consequence basis, we can be confident that the savings to the wider NHS from having an MSSN in place comfortably exceeds the cost of employing that nurse.

6.4 Wider societal benefits of MSSN services

Beyond the costs and savings to the health service of MSSN services, they have the potential to save on wider societal costs by, for example, helping people with MS to remain in employment, or in their own homes when otherwise they would have needed to go into residential care.

To illustrate this, the GEMSS patient survey asked about employment. 5.9% of respondents said that the MS specialist nurse service had helped them stay in employment (see quotations in section 5.3 above for specific examples). Of these, 47 provided the number of hours that they work each week. This averaged 25.9 (range 10-55 hours).

There are clear economic benefits to helping people with MS to remain in employment besides the positive impact on their life satisfaction and opportunities for social contact. First, to them and their families, employment brings significant financial benefits. Using UK 2014 average gross earnings of £13.08 per hour^{rr}, the overall benefit across a MSSN caseload of 358 people based on 5.9% of the caseload remaining in employment at 25.9 hours per week would be £372k in earnings paid to pwMS. An additional benefit of pwMS remaining in employment is a benefit to the state in not having to pay out of work benefits. Benefit/Personal Independence Payment levels vary between individuals, but at the rate of £100 per week, the cost to the state of benefits across 5.9% of an MSSN caseload would be £110k.

The suggestion is not that MSSNs alone achieve these types of savings, but MSSNs, as brokers and coordinators of care and working with colleagues in Occupational Therapy and vocational medicine can make a major contribution to reducing the societal economic burden of disabilities caused by MS.

^{rr} Office for National Statistics, Annual Survey of Hours and Earnings, provisional results 2014



Chapter 7: Conclusions, challenges and opportunities for MS specialist nursing

This report has presented, using the GEMSS data, information on the caseloads MSSNs work with, the activities they undertake, the outcomes they achieve for people with MS and the economics of their services. Overall, based on the evidence, the value of MS specialist nurse to people living with MS and to the NHS is clear and compelling.

For people with MS	MS specialist nurses are the health professionals most consulted about MS and play a vital role in the overall coordination of care. Their specialist expertise and continuity of availability enables them to improve outcomes for pwMS across all five domains of the NHS outcomes framework.
For other health professionals in the NHS	MS specialist nurses make a major contribution to increasing the capacity of other staff (particularly neurologists) and to building the skills and knowledge of other, less specialist professionals working with pwMS, including GPs, social care staff, other nurses and therapists, indirectly improving outcomes for PwMS.
For NHS commissioners	MS specialist nurses save costs elsewhere in the health system, both in ambulatory care costs (GP, A&E visits and neurology outpatient attendances) and prevention of unplanned hospital admissions resulting from complications of MS including MS relapses, bladder and bowel problems, respiratory infections and other issues.
For wider society	MS specialist nurses improve quality of life for pwMS and thereby help them to live full and active lives, including staying in work where this is possible. This benefits the economy and is of wider value to the families and carers of pwMS.

At the same time, this report recognises that MSSNs are not the whole story: they are essential members of a wider multidisciplinary team which is needed for specialist care of the many facets of MS.

The GEMSS project has also revealed challenges to MS specialist nurse services and opportunities for them to develop further.

7.1 Challenges facing MSSN services

The pressures on MS specialist nurses are growing, and a number of factors are contributing to increasing workloads:

- The challenge of safely managing disease modifying drugs is growing as the range of DMDs grows and the risks and complexity of monitoring them continues to increase. New treatment paradigms, aimed at earlier and more proactive treatment, offer new hope for people diagnosed with MS²¹, but the workload associated with them is significant. This poses challenges to ensuring an equitable service for everyone on the caseload.



- MS nurse caseloads continue to rise, in line with other demands on the NHS, due to the fact that people are living longer. The number of people with MS is increasing by around 2.4% per year, but MSSN caseloads would seem to be rising at a faster rate than this, as discussed in section 3.3 above. As more people with MS are living to an older age, the associated complexities of co-morbidities will contribute to rising workloads.
- There is a limit to the number of MS neurologists across the UK and evidence that the neuro-specialist Allied Health Professional and psychology services needed by pwMS are under strain and in some cases being reduced^{30, 31}. This puts additional pressure on MS specialist nurses to fill the gap, particularly for those pwMS who have progressive disease and therefore complex needs, but who do not benefit from DMDs.
- MSSNs are working in an NHS environment where the advent of electronic health records (with some exceptions) is not yet enabling MSSNs to collect data on caseload and activity in a way that could really help them to plan their services and undertake proactive caseload management.

When combined with unsustainable and inequitable caseloads for MSSNs across many areas of the country¹⁴, and inadequate support for MSSNs in terms of administrative systems and staff, there are real risks to the services they are able to offer:

- Services may concentrate effort on the pressing need for DMD initiation and monitoring, diminishing the amount of time available for people with progressive disease and complex disabilities who may be less visible to services.
- Teams may be forced to offer episodic, reactive care in response to pwMS calling in crisis, as opposed to proactive case management and review. This may result in problems escalating rather than being dealt with at an early stage, resulting in needless complications and unscheduled care. A reactive approach also risks focusing on those people with MS who ask for help, at the expense of those who tend to suffer in silence.
- MSSNs, in their attempt to keep up with an unmanageable workload involving pwMS with very challenging problems, may themselves suffer from stress and burn-out, leading to the risks of sickness absence and loss of valuable members of the profession.

These challenges and risks point again to the need to ensure that nurse numbers are sufficient to allow for sustainable caseloads, but also the need for MS specialist nurses to work smarter rather than just harder.

7.2 Recommendations for developing MSSN services

The GEMSS project has highlighted a number of ways in which MS specialist nurses can work differently to improve their productivity, make their roles more effective and enable them to make an even greater contribution to outcomes.

The findings in this report are relevant for commissioners, providers and MS specialist nurses themselves. All have a part to play in taking forward this valuable workforce. The MS Trust intends to continue to play a key role in supporting MS specialist nurse services going forward. Specifically, the following actions are needed by a community of practice, working together:



7.2.1 Increase the MSSN workforce so that MSSN caseloads are sustainable

As highlighted in our 2014 report, the NHS across the UK needs an additional 62 WTE MSSNs to add to the 234 WTEs in post, to enable all MSSNs to have caseloads within the 'sustainable' level of 358 pwMS. The findings in this report have demonstrated the impact of excessive caseloads for pwMS themselves, with a substantial minority saying that they had insufficient support and many reporting feeling abandoned, despite having symptoms and needs which could be ameliorated by MSSN input. An increase in the available workforce of MSSNs remains a priority, along with therapists and others who provide pwMS with badly needed support.

7.2.2 Focus on service equity so everyone with MS has access to care

GEMSS has revealed that although the proportion of people on the MSSN caseload with RRMS and those with progressive disease is roughly equal, the resources of the MSSN service are often pulled toward those with RRMS. Section 4.1 highlights that those on DMDs are getting more contact with MSSNs. The demands associated with supporting people with RRMS to choose, start and receive the appropriate monitoring and review for DMDs is resource-intensive for MSSN services. A service-wide commitment to ensuring that there is equitable access to MSSNs for everyone with MS is required, along with strategies to use the multidisciplinary MS team effectively to ensure that those with progressive disease are not disadvantaged.

7.2.3 Describe and create more rational funding models for services

The very complex commissioning landscape for MS services in England, described briefly in section 6.2, makes it very challenging to identify funding flows for MSSN services. Commissioning arrangements do not necessarily incentivise providers to invest in services, even if they would reduce NHS costs elsewhere, or to improve the productivity of services which already exist. Further work is needed to understand these funding flows and then to simplify and apply them more consistently across the NHS.

7.2.4 Increase autonomy and advanced practice amongst MSSNs

There are opportunities for MS specialist nurses to work more consistently at advanced practitioner level. Relatively few MS specialist nurses within GEMSS are prescribers, and this limits their ability to manage whole episodes of care, particularly in assessing and prescribing treatment for infections, MS symptoms like spasm, and relapses. More could be done to up-skill MS specialist nurses in these areas and support them to take on new roles. At the same time, MSSNs need to be freed from spending large amounts of time on tasks which do not require their training – such as non-clinical administration and more basic clinical tasks. Delegating some of these clinical roles to more junior members of teams and broadening the skillmix of teams will have an added benefit of aiding succession planning for MSSNs.

7.2.5 Effect a step-change increase in support for self management

GEMSS has revealed that people with MS are keen to be as skilled and knowledgeable as they can be in managing their own condition and recognising when they do, and when they don't, need to seek specialist help. Although most of the GEMSS nurses are



involved in delivering self-management programmes, such as courses for people who are newly diagnosed or symptom management sessions to address common issues such as fatigue and low mood, the number of people reached by these programmes is small relative to overall caseloads, and there is significant unmet demand from pwMS. Delivering self-management and group support needs to be seen as a core part of the MSSN role, rather than an occasional add-on to be done in their own time. With the right programme materials available to deliver 'off the shelf', help from local AHPs, and sufficient admin support to organise programmes and invite participants, much could be achieved in this area.

7.2.6 Improve use of information and undertake proactive case management

As we have described in GEMSS, service models have evolved differently in different areas, sometimes in response to local needs and priorities but not always in a strategically planned way. The ways in which people with MS are managed are not always codified through pathways and protocols, but may have developed around individuals' skills and practices. There is an opportunity to improve the consistency of care by greater use of pathways and proactive case management. The requirement for a structured annual review for everyone with MS within the NICE guideline in England offers a timely opportunity for the contents of an annual review to be defined.

At a minimum, to ensure that people can be proactively reviewed and managed, every MS service needs a register of everyone on their caseload which is consistently updated, and local protocols about how people will be reviewed and kept informed about services available. As a longer term priority, better data at national and local level about the prevalence of MS and the population with it is essential to ensure that services can be properly planned and people who are out of contact with services do not fall through the service net.

7.2.7 Improve the productivity of MS specialist nurses

As described in [Chapter 4](#), GEMSS revealed wide variations in the number of pwMS seen by MS specialist nurses working in different settings. The levers identified to improve productivity: using MSSNs only for specialist tasks, smart scheduling, a focus on maximising use of capacity, limiting the number of home visits and using succinct structured written communications with other professionals, can all help specialist nurses to make the most of their time. Improving hospital information systems and electronic health records systems so that they are user-friendly and record useful information about pwMS once, at the point of care, is essential if MSSNs are to make best use of their time. Effective administrative support for MS nurses is perhaps one of the most important factors contributing to improved productivity.

7.2.8 Make full and effective use of the multidisciplinary team

MS specialist nurses work in a variety of settings with varying access to multidisciplinary services with expertise in MS. Within the GEMSS teams there are examples where the presence of AHPs with MS expertise enhances coordination of care, ensures access to specialist support for complex symptoms, provides an expert focus on employment and participation and promotes a more comprehensive MS service tailored to the needs of the individual. Multidisciplinary models of MS care are essential, but first, it is



essential that a complete team of practitioners is available in all areas, without major gaps and secondly, MSSNs and their AHP colleagues need proactively to define ways of joint working, knowledge sharing and referral pathways that ensure close teamwork and minimise duplication of activities between team members.

Since the first posts were established more than 20 years ago, MS specialist nursing has grown and developed into a powerful enabler of better outcomes and improved quality of life for people with MS. We hope that the GEMSS project, and this report, will herald a new chapter in MS specialist nursing in the UK.



Appendix A: Overview of GEMSS evaluation tools

The table below summarises the tools that were developed to collect data as part of the GEMSS project. Appendices B, C and D provide further information about the GEMSS patient survey, the health professional survey and the Dorset Specialist Neurological Intervention Audit Tool. A separate report¹¹ describes in more detail the facilitation process used during GEMSS and the impact of participation on the GEMSS teams and their services.

Figure 43: Summary of GEMSS data collection tools

What was measured	Form of the tool	Data collection frequency	Data in this report therefore represents
Service activity	Excel data collection tool (data collected manually or via a PAS request)	Monthly	15 GEMSS teams (excluding Dorset who have wider neurology caseload)
Performance against Key Performance Indicators on service responsiveness	Excel data collection tool (data collected manually then entered)	Monthly	Data included only within local team reports
Caseload number and characteristics	Excel database provided by GEMSS team or existing database (e.g. Merck IMed system, Access database, Graphnet Health) if already in place	Initial caseload database collated over the first 2-4 months of the year, then continuously updated ^{ss}	All teams apart from Walton Centre ^{tt}
Patient experience, service utilisation and patient reported outcomes	GEMSS patient survey, posted out to representative sample of caseload. Replies returned to MS Trust for entry and analysis (online entry for pwMS also available)	Implemented once during 2014-15 (most teams in summer of 2014)	All teams apart from Walton Centre, Poole and Dorset. ^{uu} 1254 pwMS
Stakeholder/professional colleagues' views of the service	Online survey sent to colleagues identified by the MSSN team	Implemented once (autumn 2015)	11 GEMSS II teams only



Interventions carried out during consultations	Dorset Specialist Neurological Intervention Audit Tool (SNIAT), used over 3 weeks	Used for all consultations during snapshot period spring 2015	5 GEMSS II teams ^{ww} plus Dorset Neurology Service (a GEMSS I team) and East Staffordshire Adult Ability Team ^{www} ; 451 consultations carried out by 9 MS specialist nurses with pwMS
Activity against capacity in job plans	Capacity planning tool developed for GEMSS 'sustainable caseload model' ¹³	Used with facilitator support during analysis phase using 2014/15 activity	8 teams
Case studies	GEMSS case study template and writing guide	Collected by participants throughout the year	All teams

ss Apart from the Leicester team, where the data analysed represents a snapshot at July 2015.

tt Data completeness at the Walton Centre was insufficient for the caseload to be included in the meta analysis.

uu The Walton Centre used a different methodology for distributing their patient survey, giving it to pwMS attending clinics rather than posting it to a randomly selected sample of the caseload. The Poole and Dorset services did not repeat their patient survey during 2014/15 (having used it in 2012, although they are repeating it in 2015/16) and hence are not included.

ww Mid Essex, North Devon, Shrewsbury & Telford, Western Isles and Calderdale & Huddersfield (Calderdale MSSN only).

www East Staffs Adult Ability Team also agreed to use the SNIAT to give a broader cross section of AHPs using it; the results of AHP use of the tool are reported separately¹².



Appendix B: The GEMSS Patient Survey

The GEMSS patient survey was developed by the MS Trust GEMSS facilitators and participating teams in 2012. It was piloted with people with MS (recruited through the MS Trust), to ensure it was understandable, acceptable, useful and straightforward to complete, in around 15-20 minutes.

Within each participating organisation, the MSSN team obtained local information governance and/or audit approval to carry out the survey and had the option to add one or two local questions. The surveys were identical save for minor differences^{xx} and the results reported have been adjusted accordingly.

The surveys were posted out during June 2014^{yy} to a randomly selected sample of people registered with the MS nurse service inviting them to participate in the survey. A covering letter assured them of their anonymity in participating and explained the background to the project. In some areas, the survey and the GEMSS project were also publicised via the local MS Society branch newsletter in order to encourage invited respondents to take part. A web address providing access to the survey online (at Survey Monkey) was included in the letter for those who found it easier to complete the survey in this way, as pilot testing had shown that this was easier for some people with MS with dexterity problems. Those who completed the survey on paper were invited to return it to the MS Trust in a freepost envelope.

The teams set the number of people they sent the survey to with a view to getting back a minimum of 50 responses (for one nurse), 80 responses (for two nurses) or 100 responses (for 3 or more nurses) based on an expected 50% response rate. Where time and budgetary constraints allowed, a larger number of surveys was sent out.

A three week deadline for the return of the survey was given, although responses received up to a month after the deadline were included (and no additional responses were received after that time). Paper surveys received were entered into Survey Monkey by the GEMSS administrator at the MS Trust and analysis of the data was undertaken by the GEMSS facilitators. Initial analysis of each team's data was carried out using Excel and each team participating in the project received an individual report of their own survey results.

The data from all the teams was imported from Survey Monkey into 'R' statistical analysis software, and further analysis undertaken on a meta-level to create this report. The responses to four qualitative survey questions were also analysed:

- "Please use this box to provide any examples of the positive difference your MS nurse team has made to you in the past 12 months."

^{xx} The Mid-Essex version of the survey did not include the question about employment, the Northumbria team did not include the question about the number of times respondents had seen each type of health professional about their MS in the past year and omitted one of the 'benefits' of the MS nurse service (medication advice and prescribing), and the Royal Devon team added an additional local question to the survey about the value of copying letters to patients (not included here).

^{yy} With the exception of the Northumbria and Dudley teams who sent out their surveys in February 2014 and December 2014 respectively. The Walton Centre team gave surveys out to pwMS attending clinics, and their results are not included in the meta-analysis.



- “If you hadn’t had access to an MS nurse service over the past 12 months, what difference do you think it would have made to you? (Tick all that apply).”
- “Is there anything that the MS nurse service has done particularly well over the past 12 months?”
- “Is there anything that the MS nurse service could have done better or done more of over the past 12 months?”

The responses to these questions were imported into Excel and coded thematically under the following headings:

- Positive impacts of the MSSN service
- Reasons why the MSSN service made no positive difference
- Perceived consequences if the MSSN service had not been there
- Features or attributes of the MSSN service and/or the MSSNs themselves which pwMS particularly liked or appreciated
- Suggestions for improvements to services

The number of surveys sent out and the response rate by team is shown in figure 44.

Figure 44: Patient survey response rate by team

Team	Number of surveys sent out	Surveys returned	Response rate
Calderdale and Huddersfield	300	125	42%
Dudley	150	72	48%
Leeds	200	105	53%
University Hospitals of Leicester	500	230	46%
Mid Essex	196	97	49%
Northern Devon	100	62	62%
Northumbria	80	46	58%
Exeter	150	80	53%
Salford Royal	350	151	43%
Shrewsbury & Telford	180	85	47%
Tayside	350	157	45%
Western Isles	92	44	48%
TOTAL	2648	1254	47%



Appendix C: GEMSS Survey of Health Professionals

As an additional source of information about services, each team administered a brief online survey of health professional colleagues who work with people with MS who use their service. The aims of the survey were:

- To find out what difference the service has made to people with MS, in the experience of other health and social care professionals working with them.
- To find out whether other health practitioners think that the service has had any benefits for them in their own role.
- To obtain any suggestions for improving the service.

The MSSN teams emailed a link to the online survey to practitioners whom they worked with in January 2015. They were encouraged to cast the net as widely as possible and to include neurologists, GPs, district nurses, Allied Health Professionals, ward nurses and social workers they had interacted with. The covering email explained that the survey was being used as part of the GEMSS project and encouraged practitioners to respond honestly and assured them of anonymity.

Results were collated and analysed by the GEMSS administrator and facilitators at the MS Trust and fed back to each team. The response rate to the survey varied widely, with some teams generating as few as six responses and others as many as 46. As a result of this variation and the self selected nature of the respondents, the results have not been analysed statistically across teams; however, the qualitative comments made were in many cases very helpful to the teams in understanding their relative strengths and areas for improvement in working with other colleagues. The quotations from the survey used in this report are purely illustrative.



Appendix D: The Dorset Specialist Neurological Intervention Audit Tool (SNIAT)

To model the work and complexity of specialist nursing practice in MS, five teams participating in the GEMSS project piloted the Dorset SNIAT, a rapid data collection tool developed by the MS teams at Dorset Neurology Service and Poole Hospitals NHS Trust.

The tool records the ways in which the MDT (Specialist Nurses and Allied Health Professionals) prevent long term complications which can lead to poorer outcomes and unscheduled care (including emergency hospital admissions) through the interventions that they undertake with people with long term neurological conditions. These interventions are recorded based on how serious, or urgent, the problems are at the time using a simple colour scheme of green, amber and red.

Level of specialist input	Nature of intervention
Green	<ul style="list-style-type: none"> ■ Providing planned specialist treatments and investigations (e.g. administering medication, blood tests) ■ Recognising and <u>actively</u> monitoring/asking about signs of problems (and documenting this) ■ Providing information and advice to prevent these from escalating
Amber	<ul style="list-style-type: none"> ■ Identifying a problem which has the potential to cause harm ■ Undertaking specialist assessment to identify the source and remedies to the problem ■ Initiating treatments/care to address a specific problem ■ Referral to/liaison with other healthcare professionals to address a specific problem
Red	<ul style="list-style-type: none"> ■ Identifying a crisis or potentially life threatening or life-limiting problem ■ Initiating urgent referral for an immediate treatment package or hospital admission

By recording a sample of their work and analysing it, practitioners can show:

- The range of interventions that they undertake – demonstrating specialist practice.
- Differences in the roles played by different members of the team in terms of the domains they cover; which could be a useful source of discussion about increasing continuity of care and reducing duplication of work.
- The domains in which people with MS typically present with or which are brought up in consultations – this may highlight areas which should be being covered in review consultations but which may not be.



- The seriousness or urgency of issues addressed. Complications of MS cannot always be prevented, but we might expect to see that teams which are better resourced and more proactive in their approach cover a wider range of domains in each consultation and have fewer patients needing the 'red' level of input.

The tool is entirely anonymous – patient identifiable data is not recorded. The tool is **descriptive and retrospective** – designed to capture what happened during consultations, not to prescribe what should take place or act as a checklist for practitioners to follow.

Seven of the teams taking part in GEMSS 2014/15, together with the East Staffordshire Adult Ability team, used the tool over a three week period during 2015. During this time they recorded all their consultations with patients, both face to face and by telephone. A User Guide and training session were provided by the GEMSS facilitators so that staff were confident in their ability to record data accurately and consistently. Each team member carried around with them a paper data collection sheet for each day, showing the matrix, and simply kept a tally of interventions undertaken. This was then transferred at the end of the data collection period to Survey Monkey, and analysed by the GEMSS facilitators.

The aggregated results of the SNIAT data collection across both nurses and Allied Health Professionals have been submitted for publication¹². The data presented in this report refers to the MS specialist nurse consultations with people with MS only.



Appendix E: Acknowledgements and the GEMSS Advisory Group

The GEMSS programme would not have been possible without the commitment and enthusiasm of the **GEMSS leads** in each of the participating teams, together with all the other team members who collected data:

Audrey Owen, Denise Winterbottom	Calderdale & Huddersfield NHS FT
Gale Metcalfe, Julie Taylor	Leeds Teaching Hospitals NHS Trust
Helen Willis, Julie Webster	Mid Essex Hospital Services NHS Trust
Carol Turner	Northern Devon Healthcare NHS Trust
Louise Jarrett	Royal Devon and Exeter NHS FT
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Rachel Morrison	NHS Western Isles
Caroline Chandler, Cheryl King	Poole Hospital NHS FT
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Tracy Dean	The Dudley Group NHS FT
Michelle Davies, Tracy Evans	Dorset Healthcare University NHS FT
Daisy Cam, Helen Parry	Sheffield Teaching Hospitals NHS FT



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Amy Bowen (Chair)		Director of Service Development	MS Trust
Juliet Ashton	From Dec 14	Sapphire Nursing Consultant – Epilepsy Commissioning	Epilepsy Society
Pam Bostock	From Dec 14	Consultant Neuro Occupational Therapist	Staffordshire and Stoke on Trent Partnership NHS Trust
Dr Peter Brex		Consultant Neurologist	Kings College Hospital
Amanda Cheesley		Long Term Conditions Advisor	RCN
Michelle Davies	From Mar 13	Clinical Specialist Neuro-Physiotherapist	Dorset Neurology Service
David Foster		Deputy Director of Nursing	Department of Health
Rosie Grove		Policy Advisor	UKMSSNA
Karen Harrison Denning		Director Admiral Nurse	Dementia U.K.
Sally Hughes		Programme Director – Policy and Influencing	MS Society
Prof Alison Leary		Professor of Workforce Modelling	South Bank University
Vicki Matthews	To Nov 13		'MS Pro', and RIMS
Jane Nicklin		Independent Health Consultant / Physiotherapist	
Debbie Quinn		MS Specialist Nurse / MS Trust Nurse Advisor (until summer 2014)	Northamptonshire
Julie Rigby	To Jul 13	Quality Improvement Programme Lead	NHS England
Helen Sandell	To Dec 14	Co-Chair	Therapists in MS Group
Delyth Thomas		Co-Chair	UKMSSNA



Dr Ben Turner	From Jan 15	Consultant Neurologist	Barts and the London Hospitals NHS Trust
Karen Vernon	To Dec 14	MS Nurse Consultant	Salford Royal Hospital
Sarah Vibert	To Dec 14	Head of Development and Policy	Epilepsy Society
David Yeandle		Person with MS	
Geraldine Mynors		GEMSS Programme Manager and Facilitator	Mynors Suppiah Ltd. / MS Trust
Jane Suppiah		GEMSS Facilitator	Mynors Suppiah Ltd.

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For further information on this report and work by the MS Trust on MS specialist nursing and other services, please contact Amy Bowen, Director of Service Development (amy.bowen@mstrust.org.uk).

About the MS Trust

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

We work to make sure everyone affected by MS can access good quality care from specialists with an interest in MS, and offer education and professional development. Through our innovative GEMSS programme, we support evidence-based service improvement in MS care. Our approach is always to work in partnership with health professionals and people affected by MS to improve MS services now and in the future.

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

We rely on donations to fund our vital services.

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

Visit www.mstrust.org.uk

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