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).

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MSSN teams or commissioners interested in finding out more about the data behind the categories in this report are welcome to get in touch by emailing **gemss@mstrust.org.uk**

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Discussion Paper Briefing ➤ Report Consensus

MS Specialist Nursing in the UK 2014: The case for equitable provision

November 2014

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Executive Summary

- This report by the MS Trust follows up on its report, *MS specialist nursing in the UK - 2014,* which gives an overview of numbers of MS specialist nurses (MSSN) in the UK. It offers a more detailed picture of provision and states the case for MS specialist nursing care for everyone with a diagnosis of MS.
- MS is a disease of the central nervous system, commonly diagnosed between the ages of 20 and 40, giving rise to a range of symptoms and disabilities with an often unpredictable course. People with MS require access to disease modifying and symptomatic treatments, including medicines and expert multidisciplinary care.
- MS specialist nurses are highly valued by people with MS. They work across the whole disease trajectory, providing proactive case management to respond to acute deteriorations and relapses and to prevent secondary complications which can be disabling or life threatening and result in unscheduled care.
- Based on a sustainable caseload of 358 people with MS per whole time specialist nurse, there is currently a shortfall of 62 MSSNs across the UK, with significant shortfalls in England and Scotland and overall sufficient provision in Northern Ireland and Wales. 28% of people with MS, nearly 30,000, live in areas where MSSN caseloads are more than twice the level that is sustainable.
- In some areas, despite adequate provision, people with MS may still have to travel significant distances to reach services. This is notable in areas such as central Wales and Northern Ireland.
- The MS Trust GEMSS programme has worked with MSSNs to reach consensus on the patient outcomes they achieve through their interventions and is supporting them to evaluate their services against these. The results will be published in 2015.
- Whilst MSSN numbers overall are holding up, the current NHS context poses challenges including evidence of down-banding of posts in England, restrictions on maternity leave cover and on time available for training in all countries except Northern Ireland.
- There is a need for constructive dialogue between Commissioners/Health Boards, Providers and MSSNs, in consultation with people living with MS, to ensure that everyone with MS has access to an MSSN with a sustainable caseload.

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1. Introduction and objectives

In June 2014, the MS Trust published *MS Specialist Nursing in the UK – 2014*[1], giving an overview on the numbers of MSSNs by country, average caseloads and funding sources. This follow up report makes the case for the MS Specialist Nurse (MSSN) role and gives a more detailed picture of provision across the UK.

Specifically, the objectives are:

- to identify and explain the role of MSSNs in achieving health outcomes for people living with MS (section 2 of this report)
- to assess the current NHS context in which MSSNs are operating, and what this means for their posts (section 3 of this report)
- to map the provision of MSSNs by Clinical Commissioning Group (England) and Health Board (Scotland, Wales and Northern Ireland) and use the results of the MS Trust sustainable caseload model (reported separately[2]) to identify areas of under-provision, where a case can be made to strengthen the service to people with MS (section 4 of this report)

Three sources of data have been used for this report:

1. A survey of all MSSNs undertaken in March 2014[1] answered by 237 MSSNs (97% of the workforce) and 35 Neurology Specialist Nurses (NSNs) covering MS.
2. A supplementary survey of team leads in all MSSN and NSN teams across the UK, asking them about the CCG or Health Board areas they cover, the proportion of their time spent on MS (in the case of NSNs) and updating the information which they provided in the earlier survey. This survey was sent out in August 2014 and respondents were followed up until a 100% response rate was achieved.
3. The GEMSS (Generating Evidence in MS Services) programme‡ through which the MS Trust is supporting 16 MSSN teams across the UK to evaluate their services. Between them, the teams represent 40 nurses with a combined caseload of 17,500 patients. GEMSS teams have collected, or are currently collecting, a year's data about their caseloads, activity, performance against key process indicators and patient outcomes (measured through a patient survey, health professional survey and case studies). The final report on the programme will be published in late 2015, but interim analysis of GEMSS data has been used to inform the description of the MS specialist nurse role.

2. The role of MS specialist nurses in improving patient outcomes

2.1 The needs of people with MS

The provision of MS specialist nursing has arisen in recognition of the needs of people with MS for expert treatment, advice and support throughout the course of the condition.

The **range of symptoms and disabilities** caused by MS, and the **unpredictable course** of the disease, make it particularly complex and challenging to manage. MSSNs need to combine reactive care to respond to deteriorations, together with proactive case management and vigilance at key points in the journey.

‡ For more information about the programme, see www.mstrust.org.uk/gemss

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. MSSNs are well placed to provide support around these issues as well as concerns about work or training, negotiating changes in family relationships and can offer ante- and post-natal support.

There are three main types of MS. 85% of those people diagnosed have **relapsing-remitting** MS at onset.[3] 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 disability.[4] Many people with relapsing remitting MS are treated with disease modifying therapies (DMTs), typically beginning soon after diagnosis, to reduce the severity and frequency of relapses.[5] Until recently, most DMTs were administered by self-injection or IV infusion, but some newer treatments are given orally. Injectable DMTs require patients to be trained in their use, and all DMTs carry risks of side-effects, some of which are potentially very serious, and have an intensive schedule of monitoring for safety and efficacy.

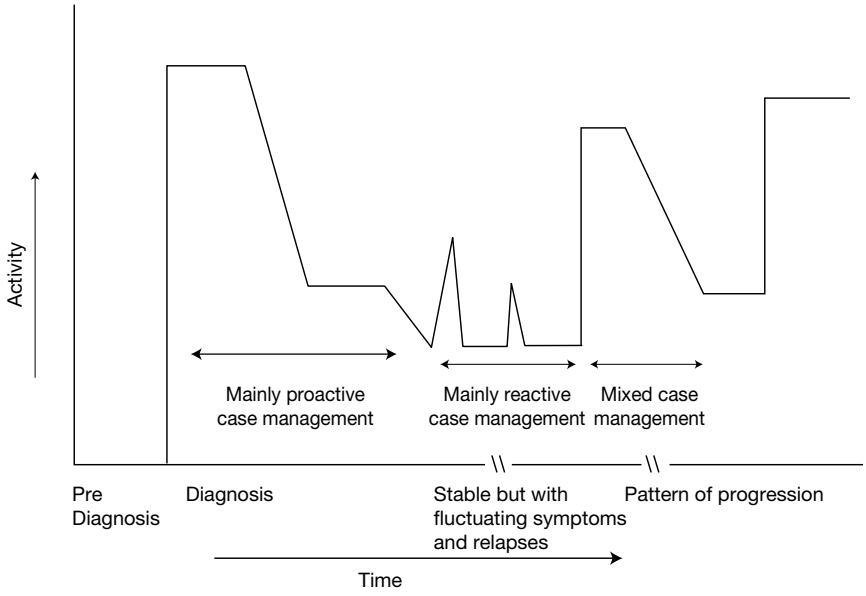
Relapsing remitting MS may develop into **secondary progressive MS**, where there is a sustained increase of disability, independent of relapses. 10-15% of people diagnosed with MS have **primary progressive MS**[6], where symptoms get progressively worse over time from the outset, rather than appearing as relapses. There are currently no disease modifying treatments that work in primary progressive MS and none have any effect on the gradual accumulation of disability in secondary progressive MS[7]. There are, however, a range of symptomatic treatments as well as interventions from nursing, physiotherapists, occupational therapists, rehabilitation physicians as well as other multidisciplinary services to help anyone with MS manage their symptoms. Those people who develop very 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. At this point, a co-ordinated, collaborative approach to patient care and the management of symptoms is essential.

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). Specialist expertise is needed to assess which symptoms are due to MS, treat symptoms effectively, and be vigilant to prevent secondary complications from developing as a result. 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.

2.2 The role of MS specialist nurses along the trajectory of MS

People with MS need to be able to access an MSSN directly and consistently across the disease trajectory but there are particular points in the MS disease pathway where support is needed most. The following diagram shows the intensity of nurse input over time for a typical course of MS.

Figure 1 - Typical MS Specialist Nurse activity pattern for a patient with Relapsing Remitting MS



Source: Leary, A, London Southbank University. MSSN Indicative optimum caseload study undertaken for MS Trust, presented at MS Trust nurses' meeting, March 2012

The periods of most intensive activity are:

- **at diagnosis**, where there is a great need for information and psychological support to enable people to make the adjustment, understand the possible course of the disease, develop self-management strategies and plan for the future. This investment of time in the early stages also sets the tone for the relationship and increases trust in the MSSN for when difficulties arise later.
- **when disease modifying drugs are prescribed** (often at, or soon after, diagnosis) where decision support, potentially injection training and ongoing information and monitoring are required.
- when people experience a **relapse or potential relapse**, where prompt accurate diagnosis is essential and symptomatic treatments (e.g. steroid therapy) may need to be prescribed.
- when there are **acute deteriorations in symptoms**, which may be around a relapse or when the disease has become progressive. Vigilance and prompt action are required to prevent secondary complications.
- when people require support to make choices **about key life events** that are impacted by their MS, such as disclosure of diagnosis, pregnancy and childbirth or issues related to work.
- when **care needs become complex**, and a wide range of care services need to be brokered.

The GEMSS project has identified and measured areas of MS specialist nurse activity[8], as illustrated in the following figure.

Figure 2 - MS specialist nurse interventions

Nursing interventions - physical

- Carrying out physical assessments and investigations (e.g. bladder scans) and requesting investigations (e.g. bloods, urine, radiology)
- Advising on the management of interrelated symptoms and reduction of risks (e.g. falls and infections), prescribing or recommending treatment
- Diagnosing relapses, prescribing or recommending treatment and following up
- Demonstrating and undertaking injections, administering IV drugs
- Monitoring disease modifying therapies, acting on safety issues, blood test results, identifying and managing adherence issues, recommending treatment escalation, switching or withdrawal
- Referring for specialist assessment or treatment by physiotherapists, occupational therapists, speech and language therapists, continence advisors and others
- Joint working with non-specialists (e.g. GPs and community nurses) and other specialists (e.g. neuro physiotherapists)

Nursing interventions - psychological and informational

- Assessing patients' psychological status
- Providing emotional support, especially at diagnosis and points of transition or distress
- Providing verbal and written information and education (individually and through group education), dispelling myths, signposting
- Supporting clinical choice and shared decision making about disease modifying therapies and other treatments – exploring timing and options
- Managing biographical disruption and providing life coaching (about work, leisure, family relationships)
- Guiding and supporting the wider family and carers
- Referring for psychological support

Nursing interventions - social

- Assessment of social situation i.e. family, support network, housing etc
- Providing advice and practical support
- Safeguarding vulnerable adults and children
- Mediating family and other relationships
- Anticipatory care planning and brokering additional social support through appropriate referrals

Liaison, case management and administration

- Liaising with, educating and up-skilling other healthcare professionals
- Brokering and planning care
- Initiating and contributing to case conferences
- Clinical administration
- Non clinical administration (minimised)

GEMSS teams have reached consensus on the patient outcomes they aim to achieve through these interventions, and they are evaluating their services against these. The outcomes have been organised into the five domains of the NHS outcomes framework for England, as shown in Figure 3. Those outcomes marked* also form part of the CCG Outcomes Indicator Set for 2014/15, against which Clinical Commissioning Groups are being measured.

Figure 3 - Outcomes of MSSN services mapped to the NHS England Outcomes Framework

Domain 1 Preventing people from dying prematurely

- Secondary complications (e.g. unusual infections, pressure ulcers, aspiration pneumonia prevented)

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

- People with MS feel supported to manage their condition*
- Enhanced health related quality of life for carers*
- Reduced impact of symptoms, e.g. pain, spasticity, cognitive problems, incontinence, swallowing problems, depression and anxiety
- High adherence to DMTs to maximise their effect in reducing relapses
- Avoidable unscheduled care and hospital admissions* (which most frequently arise in MS due to bladder and bowel problems, infections and falls prevented)
- Reduced unemployment and work absence
- People stay in their own home for longer

Domain 3 Helping people to recover from episodes of ill health or following injury

- Shortened recovery time from relapses and other episodes of ill health such as infections
- Reduced emergency readmissions to hospital in the 30 days after discharge*

Domain 4 Ensuring that people have a positive experience of care

- Positive experience of outpatient care*
- Improved hospital responsiveness to inpatients' personal needs*
- Greater coordination and integration of care*
- A responsive and timely service is provided
- The dignity and autonomy of people with MS is enhanced
- People with MS are supported in shared decision making
- Maximised independence and support for self-management
- Patients are offered care where they need it (close to or at home if necessary)

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

- Crises averted (rescue work)
- Risks identified and avoidable harms prevented (e.g. falls, pressure ulcers, injuries to carers)
- Adverse events with DMTs and other medications avoided through vigilance.

Further evidence of the role that MSSNs play in achieving these outcomes will be published by the GEMSS programme in 2015.

3. The NHS context: challenges and uncertainties

Since the first MS specialist nurse posts were established in 1993, the number of nurses has grown to around 245, covering (with variable caseloads) virtually all of the UK. A professional organisation (the UKMSSNA) provides a community of practice for sharing expertise and the MS Trust plays a major role in professional development, running a residential induction course§ for new MSSNs, bringing MSSNs together for an annual meeting and holding an annual multidisciplinary conference for all MS health professionals. The development of the role and education of MSSNs has been helped greatly by the support of the Department of Health Risk sharing scheme.

However, in 2014 we find MS specialist nurses working in a challenging and changing context.

3.1 Working in a financially constrained NHS

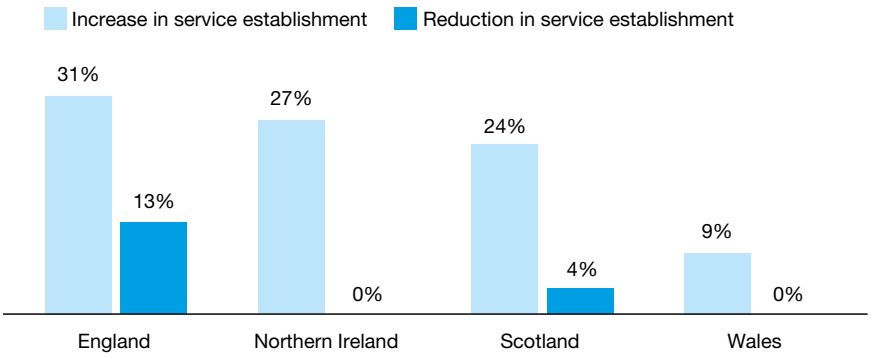
The NHS in all four countries of the UK is facing an unprecedented level of pressure to do more with less. The Royal College of Nursing (RCN) has identified a number of ways in which this is playing out in the nursing workforce[9], particularly in England, including a loss of senior posts, vacancy freezes and specialist nurses being partially redeployed into other roles such as ward work.

In order to see how MSSNs are being affected by the pressures, our March 2014 survey asked MSSNs about their experiences in the past twelve months. The questions were answered by 236 MSSNs (189 in England, 25 in Scotland, 11 in Wales and 11 in Northern Ireland), representing over 96% of all MSSNs at that time. Results for the four countries are reported separately, as funding and management arrangements differ significantly between them. All results in the following charts are shown as a percentage of respondents (not teams or centres).

In terms of the number of MSSNs employed, 28% of respondents (68 MSSNs, from 52 teams) reported an increase in service establishment over the past year. MSSNs from 43 teams in England, 3 in Northern Ireland, 5 in Scotland and one in Wales reported that posts had been expanded. Against this, MSSNs from 23 teams in England and 1 in Scotland reported reductions in establishment. Whilst this finding is broadly positive, there is no evidence of a significant change in overall nurse numbers between our last census in 2011[10] and today. In 2011, we identified 235 WTE (whole time equivalent) MSSNs, including a small number of NSNs, whereas the 2014 census found 216 WTE MSSNs and the equivalent of 15.9 WTE NSNs devoted to MS.

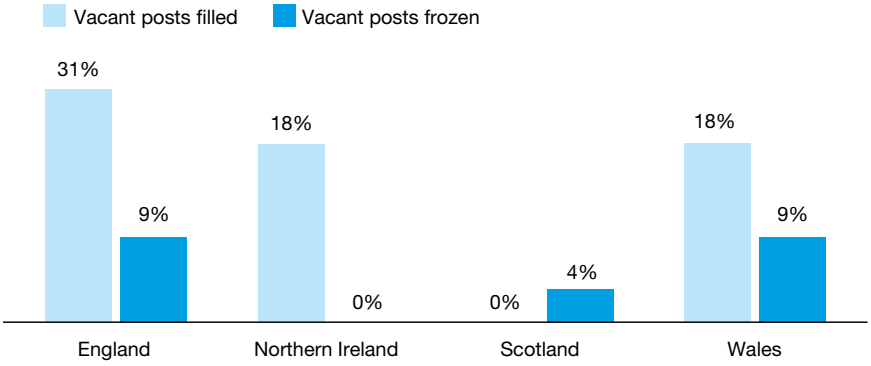
§ Accredited by Birmingham City University

Figure 4 - MSSN reported changes to service establishment within their teams in the past 12 months



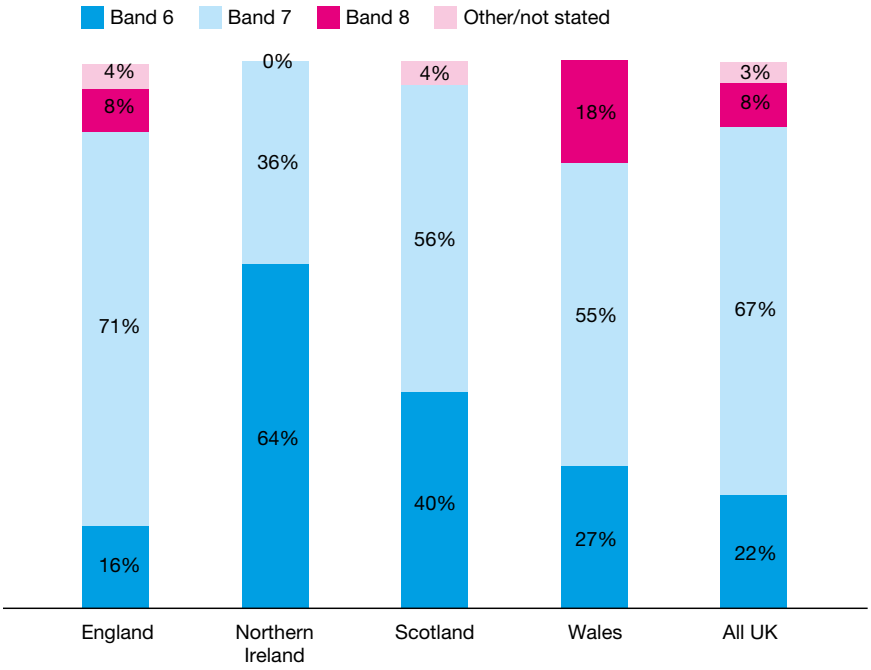
Similarly, most nurses who reported that they had had vacancies in their teams in the past 12 months had seen these filled, although 17 nurses in England and one in each of Scotland and Northern Ireland said they had seen a vacancy frozen.

Figure 5 - MSSN reported filling or freezing of vacant posts in their teams in the past 12 months



There are some differences between countries in terms of how posts with the title 'MS specialist nurse' are banded, according to the Agenda for Change bands used to evaluate and remunerate all nursing posts across the NHS[11]

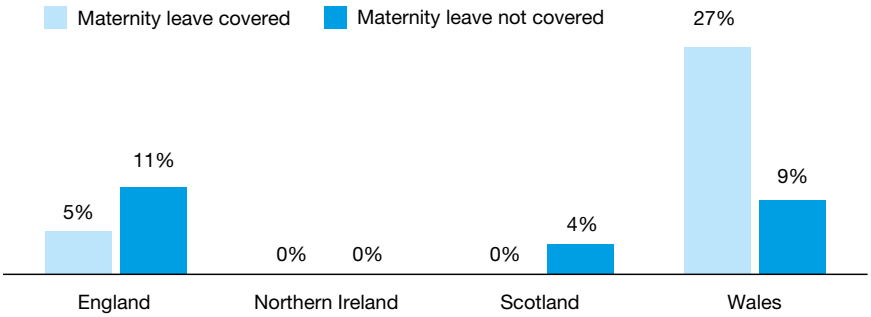
Figure 6 - MSSN respondents' reported pay banding by country



Of concern, 20 nurses (all of them in England) reported that in the past 12 months posts in their team had been down-banded, either when post holders left or when they were still in post. Only three nurses (two in England and one in Wales) reported that posts had been upgraded in their teams. Down-banding is not unique to MS services and has been challenged widely by the nursing community[9]. The earlier sections of this report have illustrated the level of specialist knowledge and skill and expert practice which MSSNs need to deploy in order to meet the complex needs of people with MS. The threat of posts being down-banded makes it all the more important that MSSNs collect data as a routine part of care in order to demonstrate the value of what they provide and the level at which they are practicing.

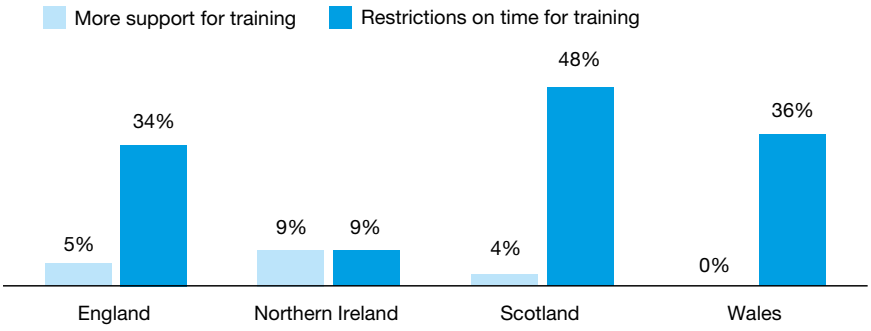
Maternity leave cover is often a point of pressure for MSSN teams. In England, 20 nurses (11% of respondents) reported that a maternity leave in their team had not been covered during the past year, leading to additional pressures.

Figure 7 - MSSN reported level of cover for maternity leave in the past 12 months



Finally, we asked about training, and the responses here were the greatest cause for concern. Over a third of nurses in England and Wales, and nearly half in Scotland, reported that they had seen additional restrictions on time available for training imposed in the past twelve months.

Figure 8 - MSSN reported changes to time available for training in the past 12 months



Overall, therefore, there is a mixed picture of how the NHS financial pressures are affecting MS specialist nurses. There is case for cautious optimism around the number of posts, but an ongoing need to ensure that vital training time, post banding and coverage of maternity leave do not become casualties of the need to contain costs or introduce significant risk to service quality and safety.

3.2 Changes to disease modifying therapies

The MS specialist nurse role has developed alongside the introduction of disease modifying therapies for MS, but the pace of change in this area has increased markedly in the past year. As described above, MSSNs play a key role in supporting people with MS to make decisions about disease modifying drugs, initiating treatment (including training on self-injection where appropriate) and treatment monitoring.

From 2002-11, all DMTs were either self-injected or administered by IV infusion in hospital (in the case of natalizumab, licensed in 2006). However, three new oral DMTs have more recently been approved for use on the NHS: fingolimod (Gilenya) in 2011 and teriflunomide (Aubagio) and dimethyl fumerate (Tecfidera) in 2014. Two further DMTs have been approved this year (2014): alemtuzumab (Lemtrada), given by IV infusion and peginterferon beta-1a (Plegridy), given by injection. All DMTs have different dosing schedules, delivery routes, monitoring regimes and side effect profiles and the protocols around them are evolving as knowledge of the newer medicines increases. Many patients remain on the injectable therapies and, for some, there may be a decision to be made about switching. The impact of these new treatments on MSSN workload is, as yet, unclear and needs careful monitoring.

3.3 The appointment of neurology specialist nurses

In a small, but possibly growing number of areas, condition-specific MS specialist nurses are being replaced with neurology specialist nurses covering more than one (and sometimes several) neurological conditions. In a separate discussion paper, the MS Trust has highlighted real concerns about the creation of these roles without a recognition of the additional support which specialist nurses fulfilling them will need.[12]

3.4 The impact of multi-disciplinary working and new models of integrated care

The 2014 NICE Clinical Guideline for MS[13] identifies caring for people with MS using a coordinated multidisciplinary approach as a key area for implementation and that this should be delivered by a range of professionals with expertise in MS, including MSSNs. The value of multidisciplinary care for people with MS is undisputed, however it will be important for MSSNs to clarify their distinctive role within the team and demonstrate the impact of the nursing interventions they provide. Having a flexible multidisciplinary service should not be confused with roles being interchangeable and nurses need to be vigilant that their unique contribution is recognised. Additionally, the concurrent development of generic integrated care services, focused on avoiding hospital admissions and addressing the rising needs of an ageing population with multiple co-morbidities could divert investment from specialist community services. MSSNs must collaborate effectively with local service innovations whilst continuing to assert the vital role of specialist nursing.

3.5 Commissioning arrangements in England

NHS services in England are now commissioned by two distinct routes. 'Local commissioning' is undertaken by GP led Clinical Commissioning Groups, and 'specialised services commissioning' by NHS England. MS services straddle these two mechanisms, with community services falling under local commissioning and services based in neuroscience centres generally commissioned as part of specialised services. The boundaries of which services are commissioned by which route are changing, with many services (as described in our 2012 report[10]) still commissioned as part of block contracts which do not explicitly define what is being commissioned as an MSSN service. The result is a confusing landscape of commissioning decision makers for MSSN services. This can be difficult for services to negotiate when wanting to evidence the outcomes they achieve or argue for additional resources or service reconfiguration.

Overall, these contextual factors are making it more important than ever that MS specialist nurses collect and present evidence about the value of their roles and that the MS Trust and others highlight what is needed to bring services to the level that they should be throughout the UK.

4. Mapping sustainable caseloads against current provision

The MS Trust set out to establish, by CCG or Health Board, and (for England) by Area Team, where MSSN provision is currently sufficient and where there are shortfalls.

4.1 Methodology

The following approach was used:

- A complete database of all MSSNs and Neurology Specialist Nurses working in the UK, including their WTE was established by the MS Trust, as outlined in the earlier report[1].
- In a supplementary survey of MSSNs and NSNs carried out in August 2014, team leads were asked to say which CCGs or Health Boards their service covers (from a list of CCGs or Health Boards in the geography around their base). Respondents were told to exclude from their list any commissioning areas from where they saw only a small number of patients, comprising less than 10% of their caseload, and where they were not the main provider of services to that area. The data provided was checked against the MS Trust database and anomalies queried and corrected.
- The supplementary survey also asked NSNs to estimate the proportion of their time that they spent on MS. (The results are reported in detail separately).[12]
- The WTE MSSNs and NSNs dedicated to MS in each team were divided equally between each of the CCGs or Health Boards that they said they serve.
- The prevalence of MS in each of the four countries was taken to be at the level estimated by the MS Society in 2014[14], based on a study by McKenzie et al at the University of Dundee[15] but adjusted downwards to reflect potential over-recording of diagnoses in GP data. The prevalence rate estimated by the MS Society for each country was used to calculate an estimate of the number of people with MS in each CCG/ Health Board.
- The number of MSSNs required for each commissioner was then calculated using the 'sustainable' caseload of 358, derived from the MS Trust's model of sustainable caseload.

CCGs and Health Boards are grouped into three categories of coverage:

Green	There are enough MSSNs for them to have caseloads at or below 358 per WTE.
Amber	Provision is between 50 and 100% of what it should be. Caseloads are estimated to be between 358 and 716 people with MS per WTE MSSN. Given the limitations of the data, provision may be sufficient, although it is likely that MSSNs are overstretched.
Red	Provision is below 50% of what it should be. Caseloads are estimated to be more than 716 people with MS per WTE MSSN, indicating an insufficient level of provision for everyone with MS in the area.

4.2 Limitations in the data and analysis

It is important to recognise the limitations in the data and analysis, specifically:

- The data, both on WTE and commissioning groups covered, is self-reported by MSSNs and NSNs themselves, and hence potentially subject to some degree of error. To reduce the risk of error as far as possible, MSSNs and NSNs were presented with an up to date list of CCGs/Health Boards in the vicinity of their service to choose from when saying which they served.
- The prevalence of MS in the UK is the subject of debate, as there is currently no comprehensive registry. In our earlier report[1], data was presented based on two possible levels of MS prevalence, an older estimate of 100,000, and the estimate made by the Mackenzie study[14] of 127,000. As described, we have used a compromise figure that lies between these two levels.
- We have applied a single prevalence rate in each of the four countries of the UK, as detailed in the Appendices. However, in practice we know that prevalence within the countries of the UK is variable, with particularly high rates in the north of Scotland[16]. These have not been accounted for. In the Western Isles, for example, the model gives an estimated number of people with MS as 56, when we know from the GEMSS programme that it is at nearly twice this level.
- The UK population is constantly changing. In this model, we have used CCG and Health Board population data from a number of reliable sources[17-20], which together give a UK population of 63.1m, 1 million less than latest ONS figures[21]. This difference will mean that we have underestimated the total prevalence of MS and need for MSSNs by some 1.6%.
- The approach to dividing WTE MSSNs equally between commissioning areas is somewhat crude, but was the most realistic approach given that many teams do not have detailed data about the share of their time that they spend with people with MS from different areas.
- The analysis says nothing about how far people with MS have to travel to reach an MS specialist nurse clinic. Some areas may be relatively well provided for by nurses in numerical terms, but if this distance is unmanageable then access may be relatively poor unless outlying clinics and home visits are provided.

As described elsewhere,[2] MSSNs working in exceptionally rural areas will not be able to handle a caseload of 358: a figure around 250 is more realistic. Given that this is not an exact science, and for consistency, the 358 figure has been applied to the whole of the UK, but CCGs and Health Boards with a population density of less than 2 people per hectare are marked with a *. In these areas, a level of provision denoted as 'sufficient' may in fact not be.

In the small number of areas where people with MS are looked after by Neurology Specialist Nurses covering multiple conditions, we have assumed that they can handle the equivalent caseload as a condition-specific MSSN for the share of their time spent on MS. This may not in fact be the case due to the professional development required to keep up to date across several conditions.[12]

4.3 Results

The analysis shows, across the UK, a shortfall of MS specialist nurses of 62 against a workforce of 234 whole time equivalents (see figure -).

Across the four countries of the UK, we see different levels of provision with significant shortfalls in MSSNs in England and Scotland, and overall a sufficient level of provision in Wales and Northern Ireland.

Figure 9 - Number of specialist nurses covering MS - current and needed

	Estimated number of people with MS	WTE specialist nurses available	WTE specialist nurses needed	Shortfall (-) or excess (+)
England	87,686	189.3	244.9	-55.7
N. Ireland	3,188	10.4	8.9	1.5
Scotland	11,119	21.8	31.1	-9.2
Wales	4,235	12.9	11.8	1.1
UK total	**106,228**	**234.4**	**296.7**	**-62.3**

Within countries, there are also large variations, with some CCGs or Health Boards being relatively well provided for and others less so. Figure 10 shows the number of CCGs and Health Boards in England, Scotland and Wales rated as 'red', 'amber' or 'green'. Northern Ireland as a whole is in the 'green' category.

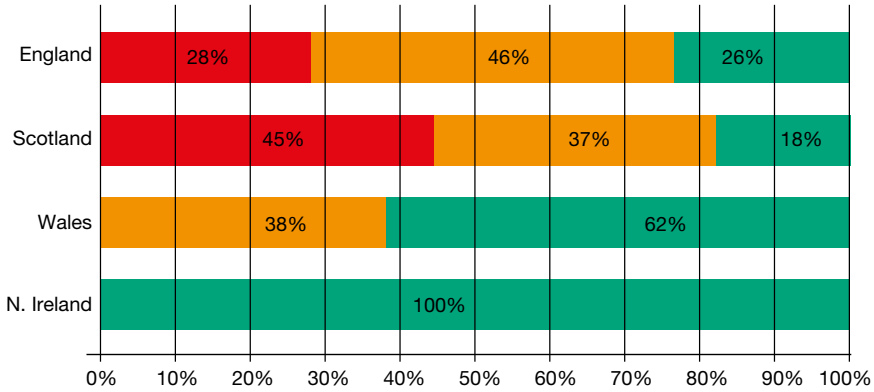
Figure 10 - Number of CCGs and Health Boards by level of provision

	Red	Amber	Green
England	57	91	63
Scotland	3	5	6
Wales		2	5

Details of the individual CCGs and Health Boards falling into each category are given in the Appendices.

For people with MS, the consequence of this variation is an inequitable pattern of provision across the UK. The analysis suggests that some 28% of people with MS, nearly 30,000 individuals, live within areas where provision is 'red', or in other words less than half of what it needs to be for caseloads to be sustainable. This may mean that a proportion of people in those areas are not known to their nearest MS specialist nurse service at all, or that some are receiving much less input than they really need – potentially a less proactive service, less able to prevent complications and difficulties. The breakdown of people with MS by country, according to the level of provision in their local CCG or Health Board, is shown in figure 11.

Figure 11 - Proportion of people with MS in each country by level of provision in their local CCG/Health Board



5. Conclusions and recommendations

This report identifies and explains the role of the MSSN and their unique contribution to achieving improved outcomes for people with MS across the UK, with more data still to come from the GEMSS programme in 2015 to provide tangible evidence of this.

Whilst we can be cautiously optimistic that MS specialist nurse posts are holding up well within the current NHS climate, there is no reason for complacency. Nurses are under ever increasing pressure to do more with less, and there is evidence that this is already playing out in restrictions on the amount of time available for training and professional development and (in some areas) in vacancies being frozen and posts down-banded. This makes it more important than ever that nurses demonstrate the value of their roles with tangible data.

This report shows that the provision of MS specialist nursing remains highly variable across the UK, with some areas relatively well provided and others with wholly inadequate provision. In all parts of the UK, there is a need for a constructive discussion between service providers and commissioners (England) or Health Boards to ensure that people with MS at all points in the disease trajectory are receiving the specialist care required to achieve safe, effective, high quality health outcomes.

Recommendations for Commissioners and Health Boards

- Review local data to **determine true local prevalence of MS** (which may differ substantially from the estimates generated through UK wide epidemiological studies).
- **Clarify the commissioned outcomes** that apply to MS specialist nurses and specify how these can meaningfully be measured.
- Work with providers to **agree the most appropriate model and pathways of care for the local area,** taking into account the rurality of the geography and local configuration of neuroscience and community services.
- Determine and then commit to **fund the required capacity** needed to achieve a high quality MSSN service.

Recommendations for Providers:

- **Ensure that every person with MS in your area has access to a MSSN** who has a sustainable caseload.
- **Employ enough MSSNs** to meet your local prevalence at a Band that reflects the level of clinical specialism required to achieve agreed service outcomes.
- **Agree a dataset with MSSN teams** to demonstrate achievement of MSSN service standards and key outcomes agreed with Commissioners.
- **Implement the conditions for effective service delivery[2]** that are required to support sustainable MSSN caseloads.
- **Support specialist professional development** for MSSNs.

Recommendations for MSSNs:

- **Audit your service** against the conditions for effective service delivery[2] needed to support a sustainable caseload.
- **Engage with local Commissioners** to highlight the role of the MSSN and to agree realistic and achievable service outcomes.
- **Collect accurate and relevant data** about how your service delivers against standards and key service outcomes.
- **Survey your caseload using a validated tool**** to monitor patient experience of the MSSN service and provide evidence of impact.

The MS Trust will continue to support specialist nurse services in making the case for equitable provision to people with MS across the UK.

** Such as the Patient Experience Survey developed through the GEMSS team and offered as a service by the MS Trust.

Appendix A – Provision in England

Key points from the analysis

- It is estimated that 87,686 people in England have MS – a prevalence rate of 1 person in every 606.
- There are 172.5 MSSNs in England, and 16.8 WTE NSNs (looking just at the share of time they spend on MS), giving a total of 189.3 WTE.
- An increase of 29% (55.7 nurses) is needed to allow each WTE MSSN to have a sustainable caseload of 358 people with MS or fewer.
- Of England's 212 CCGs, 31 could be considered very rural (population below 2 people per hectare) and may require more nurses than shown in the analysis below for caseloads to be sustainable.

Figure 12 - Analysis of MSSN provision by Clinical Commissioning Group (England)

Area team	CCG	Very rural?	Estimated number of people with MS	MSSNs needed (WTE)	Current level of provision
LONDON					
London	NHS Barking and Dagenham		309	0.86	Green
	NHS Barnet		590	1.65	Green
	NHS Bexley		384	1.07	Green
	NHS Brent		516	1.44	Amber
	NHS Bromley		513	1.43	Green
	NHS Camden		363	1.02	Red
	NHS Central London (Westminster)		260	0.73	Green
	NHS City and Hackney		420	1.17	Green
	NHS Croydon		602	1.68	Amber
	NHS Ealing		560	1.56	Amber
	NHS Enfield		518	1.45	Amber
	NHS Greenwich		422	1.18	Amber
	NHS Hammersmith and Fulham		301	0.84	Amber
	NHS Haringey		422	1.18	Red
	NHS Harrow		397	1.11	Green
	NHS Havering		393	1.10	Amber
	NHS Hillingdon		455	1.27	Red
	NHS Hounslow		421	1.18	Green
	NHS Islington		341	0.95	Green
	NHS Kingston		265	0.74	Green
	NHS Lambeth		503	1.40	Amber
	NHS Lewisham		457	1.28	Amber
	NHS Merton		331	0.92	Amber
	NHS Newham		513	1.43	Red
	NHS Redbridge		465	1.30	Red
	NHS Richmond		310	0.86	Green
	NHS Southwark		477	1.33	Amber
	NHS Sutton		316	0.88	Amber
	NHS Tower Hamlets		423	1.18	Red
	NHS Waltham Forest		429	1.20	Green
	NHS Wandsworth		508	1.42	Amber
	NHS West London (Kensington and Chelsea, Queen's Park and Paddington)		364	1.02	Amber

Area team	CCG	Very rural?	Estimated number of people with MS	MSSNs needed (WTE)	Current level of provision
MIDLANDS AND EAST OF ENGLAND					
Arden, Herefordshire and Worcestershire	NHS Coventry and Rugby		689	1.93	Red
	NHS Herefordshire	*	303	0.85	Green
	NHS Redditch and Bromsgrove		294	0.82	Green
	NHS South Warwickshire		427	1.19	Amber
	NHS South Worcestershire		480	1.34	Amber
	NHS Warwickshire North		310	0.86	Amber
	NHS Wyre Forest		162	0.45	Green
Birmingham and the Black Country	NHS Birmingham CrossCity		1180	3.29	Amber
	NHS Birmingham South and Central		327	0.91	Green
	NHS Dudley		517	1.44	Green
	NHS Sandwell and West Birmingham		777	2.17	Amber
	NHS Solihull		342	0.95	Green
	NHS Walsall		445	1.24	Amber
	NHS Wolverhampton		413	1.15	Red
Derbyshire and Nottinghamshire	NHS Erewash		156	0.43	Green
	NHS Hardwick		179	0.50	Green
	NHS Mansfield and Ashfield		317	0.89	Red
	NHS Newark & Sherwood	*	190	0.53	Red
	NHS North Derbyshire		449	1.25	Red
	NHS Nottingham City		502	1.40	Amber
	NHS Nottingham North and East		241	0.67	Red
	NHS Nottingham West		181	0.51	Red
	NHS Rushcliffe		184	0.51	Red
	NHS Southern Derbyshire		846	2.36	Amber
East Anglia	NHS Cambridgeshire and Peterborough		1388	3.88	Green
	NHS Great Yarmouth and Waveney		351	0.98	Green
	NHS Ipswich and East Suffolk	*	652	1.82	Red
	NHS North Norfolk	*	277	0.77	Green
	NHS Norwich		315	0.88	Red
	NHS South Norfolk	*	385	1.07	Amber
	NHS West Norfolk	*	282	0.79	Green
	NHS West Suffolk	*	363	1.01	Green
Essex	NHS Basildon and Brentwood		411	1.15	Amber
	NHS Castle Point, Rayleigh & Rochford		283	0.79	Green
	NHS Mid Essex		624	1.74	Amber
	NHS North East Essex		515	1.44	Amber
	NHS Southend		288	0.80	Green
	NHS Thurrock		261	0.73	Amber
	NHS West Essex		474	1.32	Amber

Area team	CCG	Very rural?	Estimated number of people with MS	MSSNs needed (WTE)	Current level of provision
Hertfordshire and the South Midlands	NHS Bedfordshire		683	1.91	Amber
	NHS Corby		102	0.28	Green
	NHS East and North Hertfordshire		885	2.47	Amber
	NHS Herts Valleys		934	2.61	Amber
	NHS Luton		336	0.94	Green
	NHS Milton Keynes		422	1.18	Green
	NHS Nene		1018	2.84	Red
Leicestershire and Lincolnshire	NHS East Leicestershire and Rutland		526	1.47	Red
	NHS Leicester City		544	1.52	Red
	NHS Lincolnshire East	*	376	1.05	Amber
	NHS Lincolnshire West	*	372	1.04	Amber
	NHS South Lincolnshire	*	232	0.65	Red
	NHS South West Lincolnshire	*	200	0.56	Red
	NHS West Leicestershire		611	1.71	Red
Shropshire and Staffordshire	NHS Cannock Chase		218	0.61	Green
	NHS East Staffordshire		204	0.57	Green
	NHS North Staffordshire		352	0.98	Amber
	NHS Shropshire	*	507	1.42	Red
	NHS South East Staffs and Seisdon Peninsular		367	1.03	Green
	NHS Stafford and Surrounds	*	248	0.69	Green
	NHS Stoke on Trent		424	1.18	Amber
	NHS Telford and Wrekin		275	0.77	Amber
NORTH OF ENGLAND					
Cheshire, Warrington and Wirral	NHS Eastern Cheshire		322	0.90	Amber
	NHS South Cheshire		291	0.81	Red
	NHS Vale Royal		169	0.47	Red
	NHS Warrington		335	0.93	Red
	NHS West Cheshire		375	1.05	Red
	NHS Wirral		528	1.48	Red
Cumbria, Northumberland, Tyne and Wear	NHS Cumbria	*	835	2.33	Green
	NHS Gateshead		331	0.92	Red
	NHS Newcastle North and East		230	0.64	Amber
	NHS Newcastle West		231	0.65	Amber
	NHS North Tyneside		332	0.93	Red
	NHS Northumberland	*	522	1.46	Green
	NHS South Tyneside		245	0.68	Amber
	NHS Sunderland		455	1.27	Red

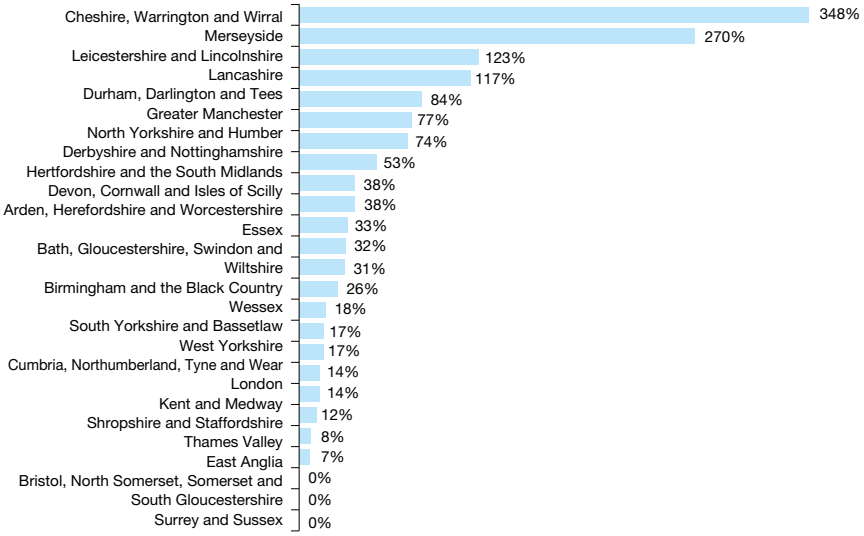
Area team	CCG	Very rural?	Estimated number of people with MS	MSSNs needed (WTE)	Current level of provision
Durham, Darlington and Tees	NHS Darlington		174	0.49	Green
	NHS Durham Dales, Easington and Sedgefield	*	451	1.26	Amber
	NHS Hartlepool and Stockton-on-Tees		469	1.31	Red
	NHS North Durham		396	1.11	Amber
	NHS South Tees		452	1.26	Red
Greater Manchester	NHS Bolton		458	1.28	Red
	NHS Bury		306	0.86	Amber
	NHS Central Manchester		297	0.83	Amber
	NHS Heywood, Middleton and Rochdale		350	0.98	Amber
	NHS North Manchester		270	0.75	Amber
	NHS Oldham		372	1.04	Amber
	NHS Salford		387	1.08	Amber
	NHS South Manchester		264	0.74	Amber
	NHS Stockport		468	1.31	Red
	NHS Tameside and Glossop		418	1.17	Amber
	NHS Trafford		375	1.05	Amber
	NHS Wigan Borough		525	1.47	Red
Lancashire	NHS Blackburn with Darwen		244	0.68	Amber
	NHS Blackpool		235	0.66	Amber
	NHS Chorley and South Ribble		275	0.77	Red
	NHS East Lancashire		613	1.71	Red
	NHS Fylde & Wyre		273	0.76	Red
	NHS Greater Preston		333	0.93	Red
	NHS Lancashire North		258	0.72	Amber
	NHS West Lancashire		183	0.51	Amber
Merseyside	NHS Halton		208	0.58	Red
	NHS Knowsley		241	0.67	Red
	NHS Liverpool		769	2.15	Red
	NHS South Sefton		264	0.74	Red
	NHS Southport and Formby		189	0.53	Red
	NHS St Helens		290	0.81	Red
North Yorkshire and Humber	NHS East Riding of Yorkshire	*	517	1.45	Amber
	NHS Hambleton, Richmondshire and Whitby	*	252	0.70	Amber
	NHS Harrogate and Rural District	*	262	0.73	Red
	NHS Hull		423	1.18	Red
	NHS North East Lincolnshire		264	0.74	Green
	NHS North Lincolnshire	*	277	0.77	Amber
	NHS Scarborough and Ryedale	*	182	0.51	Amber
	NHS Vale of York	*	566	1.58	Red

Area team	CCG	Very rural?	Estimated number of people with MS	MSSNs needed (WTE)	Current level of provision
South Yorkshire and Bassetlaw	NHS Barnsley		383	1.07	Green
	NHS Bassetlaw	*	187	0.52	Green
	NHS Doncaster		499	1.39	Amber
	NHS Rotherham		426	1.19	Green
	NHS Sheffield		911	2.54	Red
West Yorkshire	NHS Airedale, Wharfedale & Craven	*	261	0.73	Green
	NHS Bradford City		135	0.38	Amber
	NHS Bradford Districts		549	1.53	Red
	NHS Calderdale		337	0.94	Green
	NHS Greater Huddersfield		392	1.10	Red
	NHS Leeds North		328	0.92	Amber
	NHS Leeds South and East		389	1.09	Amber
	NHS Leeds West		522	1.46	Red
	NHS North Kirklees		306	0.86	Green
	NHS Wakefield		539	1.51	Amber
SOUTH OF ENGLAND					
Bath, Gloucestershire, Swindon and Wiltshire	NHS Bath and North East Somerset		290	0.81	Green
	NHS Gloucestershire		988	2.76	Amber
	NHS Swindon		355	0.99	Red
	NHS Wiltshire	*	783	2.19	Amber
Bristol, North Somerset, Somerset and South Gloucestershire	NHS Bristol		707	1.97	Amber
	NHS North Somerset		335	0.94	Green
	NHS Somerset	*	878	2.45	Amber
	NHS South Gloucestershire		435	1.21	Amber
Devon, Cornwall and Isles of Scilly	NHS Kernow	*	885	2.47	Red
	NHS North, East, West Devon	*	1426	3.98	Amber
	NHS South Devon and Torbay		449	1.25	Amber
Kent and Medway	NHS Ashford		196	0.55	Amber
	NHS Canterbury and Coastal		327	0.91	Amber
	NHS Dartford, Gravesham and Swanley		407	1.14	Green
	NHS Medway		437	1.22	Green
	NHS South Kent Coast		334	0.93	Red
	NHS Swale		176	0.49	Green
	NHS Thanet		222	0.62	Amber
	NHS West Kent		760	2.12	Amber

Area team	CCG	Very rural?	Estimated number of people with MS	MSSNs needed (WTE)	Current level of provision
Surrey and Sussex	NHS Brighton and Hove		451	1.26	Amber
	NHS Coastal West Sussex		781	2.18	Green
	NHS Crawley		177	0.49	Green
	NHS East Surrey		288	0.80	Amber
	NHS Eastbourne, Hailsham and Seaford		298	0.83	Amber
	NHS Guildford and Waverley		337	0.94	Amber
	NHS Hastings and Rother		299	0.83	Amber
	NHS High Weald Lewes Havens	*	274	0.77	Green
	NHS Horsham and Mid Sussex		366	1.02	Amber
	NHS North West Surrey		555	1.55	Amber
	NHS Surrey Downs		464	1.29	Amber
	NHS Surrey Heath		154	0.43	Green
Thames Valley	NHS Aylesbury Vale	*	319	0.89	Green
	NHS Bracknell and Ascot		218	0.61	Amber
	NHS Chiltern		522	1.46	Amber
	NHS Newbury and District	*	173	0.48	Amber
	NHS North & West Reading		164	0.46	Green
	NHS Oxfordshire		1059	2.96	Amber
	NHS Slough		232	0.65	Green
	NHS South Reading		174	0.49	Green
	NHS Windsor, Ascot and Maidenhead		227	0.63	Amber
	NHS Wokingham		256	0.71	Amber
Wessex	NHS Dorset		1231	3.44	Green
	NHS Fareham and Gosport		321	0.90	Amber
	NHS Isle of Wight		229	0.64	Green
	NHS North East Hampshire and Farnham		340	0.95	Green
	NHS North Hampshire		353	0.99	Green
	NHS Portsmouth		339	0.95	Green
	NHS South Eastern Hampshire		344	0.96	Amber
	NHS Southampton		389	1.09	Green
	NHS West Hampshire		894	2.50	Red

The following chart shows how many additional MSSNs would be needed in each England area team area to bring caseloads to 358 per WTE nurse, providing a priority list of areas where an increase is most urgently needed.

Figure 13 - Increase in MSSN FTE needed by Area Team for sustainable caseloads - England, %



Appendix B – Provision in Scotland

Key points from the analysis

- It is estimated that 11,119 people in Scotland have MS – a prevalence rate of 1 person in every 470.
- In some parts of Northern Scotland (such as Western Isles, Shetland Islands and Orkney), prevalence is significantly higher. For example, we know (from the GEMSS programme) that the number of people with MS in Western Isles is around twice the number shown in the analysis below.
- There are 21.3 WTE MSSNs in Scotland, and 0.5 WTE NSNs (share of time spent on MS), giving a total of 21.8 WTE.
- An increase of 42% (9.2 WTE nurses) is needed to allow each WTE MSSN to have a sustainable caseload of 358 people with MS or fewer.
- Of Scotland's 14 Health Boards, 10 could be considered very rural (fewer than 2 people per hectare) and may require more nurses than shown in the analysis for caseloads to be sustainable.

Figure 14 - Analysis of MSSN provision by Health Board (Scotland)

Health Board	Very rural?	Estimated number of people with MS	WTE MSSNs needed	Current level of provision
Western Isles	*	56	0.16	Green
Highland	*	662	1.85	Green
Shetland	*	48	0.13	Green
Orkney	*	43	0.12	Green
Dumfries and Galloway	*	316	0.88	Green
Borders	*	240	0.67	Amber
Tayside	*	857	2.39	Green
Forth Valley††	*	625	1.74	Red
Grampian	*	1172	3.27	Amber
NHS Ayrshire & Arran	*	781	2.18	Amber
Lanarkshire		1198	3.35	Amber
Fife		777	2.17	Amber
Lothian		1782	4.98	Red
Greater Glasgow and Clyde		2563	7.16	Red

†† post currently vacant but NSN post advertised

Appendix C – Provision in Wales

Key points from the analysis

- It is estimated that 4,235 people in Wales have MS – a prevalence rate of 1 person in every 710.
- There are 12.9 MSSNs in Wales, which overall should be a sufficient number to provide for sustainable caseloads.
- Powys Health Board could be considered very rural (fewer than 2 people per hectare) and may require more nurses than shown in the analysis for caseloads to be sustainable.
- MSSN provision in Wales is heavily concentrated in the south (predominantly) and the northeast, so although overall the figures for Wales appear adequate, people with MS who live away from these areas are likely to have to travel significant distances to attend face to face clinics.
- A proportion of provision to people with MS in Wales is provided by teams based across the border in England. This improves ease of access for people with MS living nearer to these services than services in Wales. However, some of the English services involved are among the most overstretched in terms of caseloads, and English provider Trusts should ensure that these services are properly funded by the NHS in Wales to ensure that they do not compromise equity of access for people living in England.

Figure 15 - Analysis of MSSN provision by Health Board (Wales)

Health Board	Very rural?	Estimated number of people with MS	WTE MSSNs needed	Current level of provision
Powys	*	185	0.52	Green
Cardiff and Vale		656	1.83	Amber
Hywel Dda		528	1.47	Green
Abertawe Bro Morgannwg		711	1.99	Green
Cwm Taf		409	1.14	Green
Betsi Cadwaladr		956	2.21	Amber
Aneurin Bevan		791	2.39	Green

Appendix D – Provision in Northern Ireland

Key points from the analysis

- It is estimated that 3,188 people in Northern Ireland have MS – a prevalence rate of 1 person in every 574.
- There are 10.4 WTE MSSNs in Northern Ireland, which should be sufficient to provide sustainable caseloads overall.
- However, although MS services in Northern Ireland, particularly provision and monitoring of DMTs, are considered strong, access to specialist nurse services across the country is variable[22]. Health services in Northern Ireland are commissioned centrally and provided by five Health and Social Care Trusts. There are MSSNs based in four of these (Belfast, the Northern, Southern and Western), but services are relatively concentrated at the Royal Victoria Hospital in Belfast. The Western Health and Social Care Trust, in particular, covers a large, rural area and people may have to travel for 2.5 hours or more to reach their MS nurse. A review of the distribution of MS services by the Health and Social Care Board is underway.
- Furthermore, the prevalence of MS in Northern Ireland (as in the rest of the UK) is uncertain. A study in 2004[23] suggested that prevalence in the North-east of Northern Ireland was some 32% higher than than the estimate we have used. If applied to the whole of Northern Ireland, this would push provision from the 'green' to the 'amber' category.

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