



# MS Specialist Nursing in the UK 2016: Report on progress towards equitable provision

## September 2016

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### Executive Summary

- This report by the MS Trust updates the findings from *MS Specialist Nursing in the UK 2014: the case for equitable provision*. It gives a revised overview of numbers of MS specialist nurses (MSSNs) in the UK as well as a summary of provision by clinical commissioning groups (CCGs) and Health Boards.
- MSSNs are highly valued by people with MS. They work across the whole disease trajectory, providing expert information and decision support as well as proactive case management to respond to acute deteriorations and relapses. Their interventions prevent secondary complications which can be disabling or life threatening and result in unscheduled care.
- The number of MS specialist nurses has increased by 12% since 2014 with a current workforce of 241 whole time equivalents (WTE).
- Despite the welcome increase in MS specialist nurse posts, there is significant variation across the UK in the caseloads of MSSNs. 64% of people with MS live in areas where MSSNs have caseloads in excess of the MS Trust sustainable caseload figure of 358 people with MS per WTE MSSN. Nearly a quarter of people with MS, more than 25,000 individuals, live in CCGs or Health Boards where caseloads are more than twice the sustainable level.
- 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.
- Our findings would be strengthened if there were a comprehensive MS register for the UK, or accurate prevalence data at local level.
- 62% of MSSNs have less than a day a week of non-clinical support to help with administration and coordination of their service, including 25% who have no admin support at all. This wastes money and reduces the availability of MSSNs for the skilled clinical tasks for which they are trained.
- Other challenges include patchy provision of other specialist services, particularly psychological support, and in some areas demands for all clinical nurse specialists to work regular ward shifts.
- The MS Trust remains committed to working with NHS 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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## I. Introduction

MS specialist nurses (MSSNs) are the key health professionals for people with MS, providing expert assessment, symptom management and psychological support, managing the provision and monitoring of disease modifying drugs (DMDs) and coordinating care with the rest of the multidisciplinary team<sup>1,2</sup>. They are experts in caring for people with MS, and deliver specialist care which contributes to improved outcomes for people with MS<sup>2</sup>. The MS Trust has been at the forefront of developing the MSSN role, from the establishment of the first posts in 1993 to supporting today's multidisciplinary workforce, of which the MSSN is a key part. The UK MS Specialist Nurse Association (UKMSSNA)<sup>iv</sup> and the MS Trust both play a major part in the professional development of MSSNs. The former provides a community of practice for sharing expertise and the latter a [residential induction course](#)<sup>v</sup> and an [annual multidisciplinary conference](#)<sup>vi</sup>.

In 2014, the MS Trust established, for the first time, a consensus on the number of people with MS whose care can be managed safely and effectively by a whole time MSSN, under defined conditions, using a sustainable caseload model<sup>3</sup>. Following this, the MS Trust published the first edition of this report<sup>2</sup> mapping MSSN capacity to populations across all clinical commissioning groups (CCGs) and Health Boards in the UK compared to the sustainable caseload figure.

The NHS faces unprecedented challenges to deliver value for money in the face of ever increasing demands and restrictions on spending. Since the publication of the first edition of this report, the MS Trust has been working hard with MSSNs to provide evidence of their value and make the case for strong, sustainable MS specialist teams with MS nurses at their heart. The report of the findings from the MS Trust's 'Generating Evidence in MS Services' (GEMSS) programme<sup>1</sup>, published in 2015, makes the case that MSSNs are a good investment in this context. They improve quality of life for people with MS and save costs elsewhere in the NHS, both by taking on roles which would otherwise need to be fulfilled by more expensive staff (mainly consultant neurologists) and by preventing complications caused by MS which can result in unscheduled care.

This report presents the findings of a follow up survey undertaken with all MSSN teams in the UK in 2016. It updates the 2014 picture and continues to make the case for equitable access to an MSSN for every person with MS living in the UK. Specifically, this report aims to:

- ▶ give an overview of the number of MSSNs working in the NHS today, compared to two years ago (section 3);
- ▶ highlight issues faced by MSSNs in the current NHS context which challenge their ability to work fully to their pay grade as specialists, and thus make the 'sustainable caseload' model unworkable (section 4);
- ▶ describe the methodology used to map the provision of MSSNs by CCGs (England) and Health Boards (Scotland, Wales and Northern Ireland), summarise the findings at country level and point to our online map which gives a local view of MSSN coverage (section 5);
- ▶ offer conclusions and recommendations for commissioners/Health Boards, provider organisations and MS nurses themselves (section 6).

<sup>iv</sup> A professional organisation which provides support, information and education to MS specialists in the UK. [www.ukmssna.org.uk](http://www.ukmssna.org.uk)

<sup>v</sup> A residential course for foundation training, accredited by Birmingham City University, which every MSSN has attended since its introduction in the late 1990s. [www.mstrust.org.uk/development-module](http://www.mstrust.org.uk/development-module)

<sup>vi</sup> [www.mstrust.org.uk/conference](http://www.mstrust.org.uk/conference)



## 2. Survey methodology

The survey of MSSNs was carried out as part of the MS Forward View programme, a one year project to identify the priority actions needed across the MS sector to enable MS services to deliver efficient, effective and equitable services for everyone with MS, in the context of changing treatment paradigms. Similar surveys of consultant neurologists, rehabilitation medicine consultants and neuro-pharmacists were also carried out<sup>vii</sup>.

The 2016 MSSN survey was based on the 2014 questionnaire, adapted with input from the MS Forward View advisory group.

The MS Trust emailed the survey to one member of each of MSSN team in the UK in February 2016, using the MS Trust's health professionals database. In some cases, organisations have merged or changed since the 2014 survey. A final list of 168 MSSN teams was identified<sup>viii</sup> – 141 England, 19 in Scotland, 4 in Wales and 4 in Northern Ireland. By the closing date in April, 94% of teams had responded. Missing data was inserted using 2014 responses and validated by team members. In June 2016, all team leads were emailed again to ask them for any permanent or long term changes to their team staffing establishment since the original survey, and their responses were incorporated. This report therefore represents a snapshot of the MS nursing workforce at July 2016, and compares this to the position articulated in August 2014.

<sup>vii</sup> The results of these surveys may be found at [www.mstrust.org.uk/ms-forward-view](http://www.mstrust.org.uk/ms-forward-view)

<sup>viii</sup> The 168 teams represent 139 employing organisations. The decision to count multiple teams within one employer was made where, first, there is no overlap of personnel or common leadership between the teams and, second, the teams cover distinct parts of the MS pathway and/or distinct geographic areas. This is a matter of judgment, but for example, we counted two Virgin Care teams (covering North West Surrey and South Surrey), and two Oxford University Hospitals NHS Trust teams (one at the John Radcliffe Hospital and one at the Oxford Centre for Enablement).



### 3. Overview of findings on the size of the MS specialist nursing workforce

#### 3.1 MS specialist nurses

The mainstay of MS nurse teams are MS specialist nurses themselves, whom we have defined as professionals fulfilling a nurse role with a 100% MS caseload and the title 'MS specialist nurse', 'clinical nurse specialist in MS', 'MS nurse consultant' or 'MS practitioner'<sup>ix</sup>.

#### Number and banding of posts

In 2016, there are 282 individuals in these roles, equating to 241 WTEs (due to part time working)<sup>x</sup>. This is up from 216 WTEs in 2014, an increase of 12%. Figure 1 shows the breakdown of MSSNs by nation.

Figure 1 MS specialist nurses in the UK 2014 to 2016 (WTE)

	2014	2016	Increase (WTE)
England	173.2	193.1	20.0
Scotland	22.3	25.6	3.3
Wales	11.0	13.0	2.0
Northern Ireland	9.4	9.5	0.1
<b>UK Total</b>	<b>215.9</b>	<b>241.2</b>	<b>25.4</b>

Figure 2 illustrates the growth in the workforce over the past two years and compares the breakdown of MSSN posts by band between 2014 and 2016. The MS Trust's view is that most MS specialist nurses should be at band 7 or above, allowing for them to operate as autonomous specialists and manage whole episodes of care. Nevertheless, recruiting less experienced new MSSNs at band 6, where they can develop their skills, makes for sensible succession planning, providing they can move into band 7 roles in due course. Additionally, appointing some MSSNs at band 6 reflects the growing complexity of delivering a comprehensive service to individuals on DMDs and the need for greater skill mix to work effectively and efficiently. It would be a cause for concern if there were a systematic downgrading of posts to more junior grades as a result of pressures on NHS finances, but our survey data shows no evidence of such downgrading of posts. There are now 24 MSSNs working at band 8 (18 WTE), up from 18 posts in 2014. This includes four nurse consultants, reflecting the fact that the specialty is maturing and that there is now a cadre of very experienced nurses providing clinical leadership in the field.

<sup>ix</sup> A small number of MS practitioners come from an Allied Health Professional background, but fulfil the functions of an MS specialist nurse.

<sup>x</sup> This relates to MSSNs working with adults only. There is one paediatric MSSN based at Great Ormond Street Hospital who is excluded from the analysis.



Figure 2 UK MS specialist nurse workforce 2014 to 2016

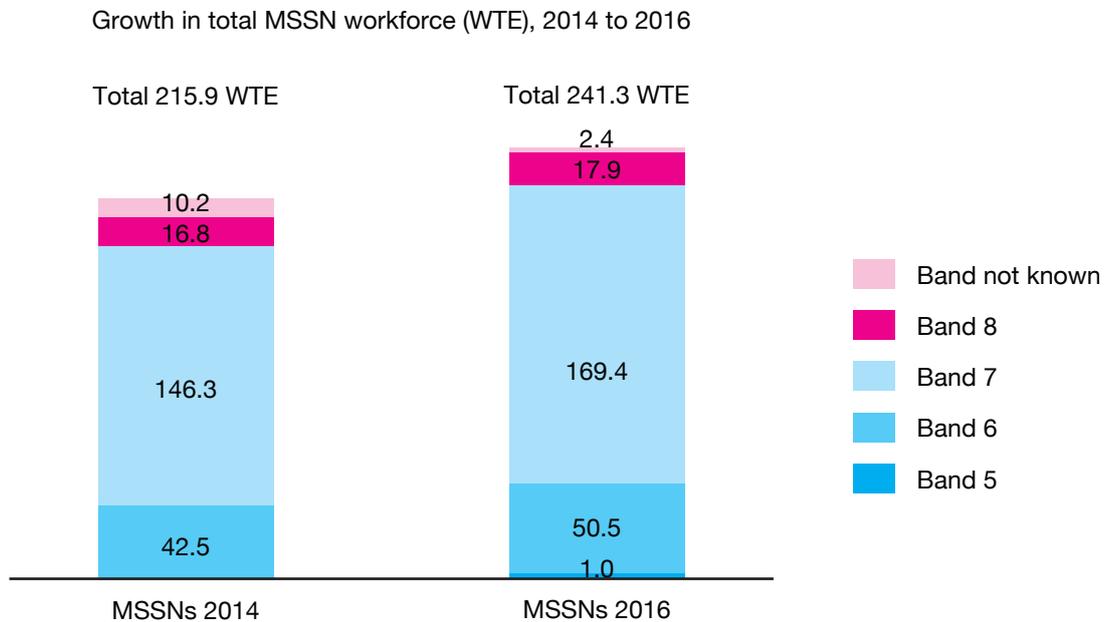
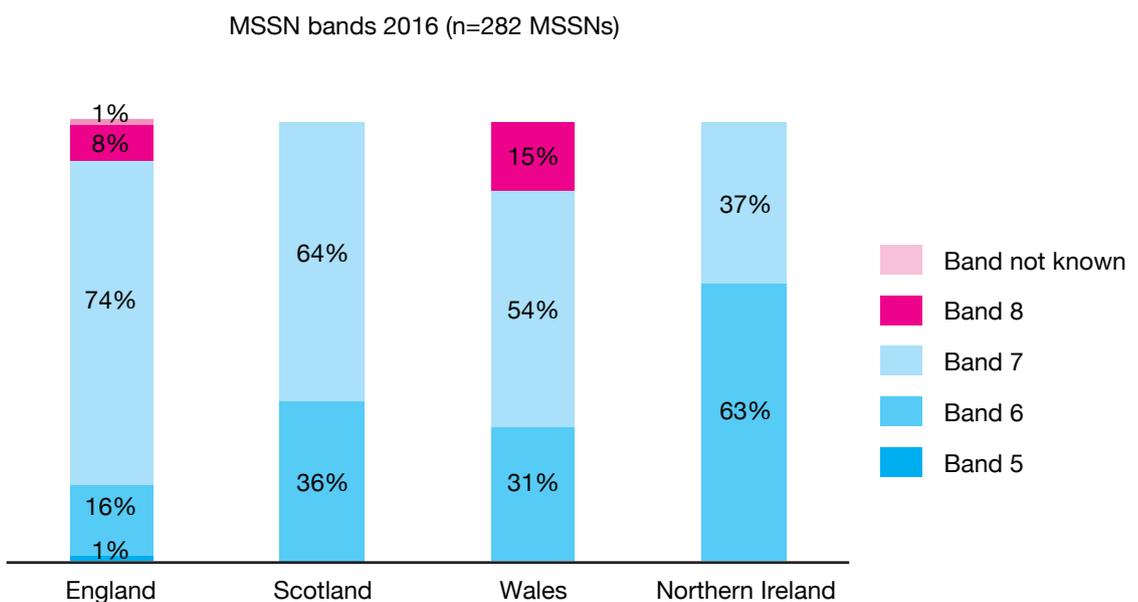


Figure 3 compares the banding of posts between the four nations of the UK. England and Wales on average employ MSSNs at a higher banding than Scotland and Northern Ireland, where a greater proportion of posts are at band 6<sup>xi</sup>.

Figure 3 Proportion of MS specialist nurses by band, by country



<sup>xi</sup> It is worth noting that MS nurses in Northern Ireland are generally hired at band 6, and can only develop to a band 7 and have the job title 'MS specialist nurse' if they complete an additional year-long course in neurosciences. For the purposes of analysis in this report we have considered them to be MSSNs.



## Employer type and funding sources

Our data shows that over 95% of MSSNs are employed by the NHS. Six MSSNs are employed by private or social enterprise organisations delivering NHS services (such as Sirona Health and Virgin Care), and three are employed within charitably funded MS therapy centres.

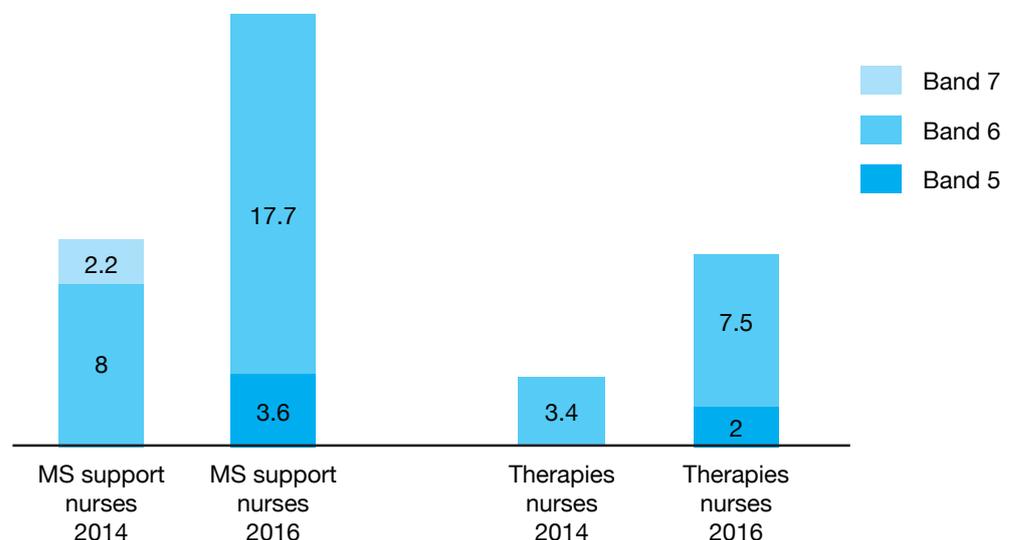
In 2014, we found that around 7% of MSSNs working in the NHS had their posts wholly or partly funded by pharmaceutical companies (c. 18 posts). Whilst we did not explicitly ask nurses this year about the source of funding for their posts, we know that this number has fallen substantially since the end of the [Department of Health Risk-sharing Scheme](#), with most funded posts now being taken on by the NHS. Our understanding is that only a handful of posts are still funded by the pharmaceutical industry.

## 3.2 MS support nurses and therapies nurses

Some 26 MS nurse teams (mainly in larger centres) include MS support nurses or MS therapies nurses (also known as DMD nurses). MS support nurses, mostly employed at band 6 and some at band 5, can free up time for MSSNs to focus on specialist tasks. These roles can also provide a useful development setting for aspiring specialist nurses. Therapies nurses are usually responsible for administering IV DMDs (though in many centres this is shared with or handled by infusion nurses based in an infusion suite rather than part of the MS team). There has also been growth in the number of both these roles, as shown in figure 4.

Figure 4 MS support nurses and therapies nurses

MS support nurses and therapies nurses (WTE) employed within UK MS teams (in 26 of 168 MSSN teams)



## 3.3 Neurology specialist nurses

In our 2014 report, we noted the presence of a small number of neurology specialist nurses covering more than one (and often several) neurological conditions. In a [separate discussion paper](#), we highlighted the challenges of specialist nurses covering multiple neurological conditions and concerns about dilution of MS expertise<sup>4</sup>. Our 2016 census has identified 38 neurology specialist nurses including MS within their caseload, equating to 16.9 WTEs (calculating estimated time spent on MS only) – this figure remains virtually unchanged from 2014. We also identified two palliative care neurology nurses who work with people with MS.



## 4. Challenges to the sustainable caseload

Three of the prerequisites for the MS Trust 'sustainable caseload model' were:

- availability of sufficient administrative support to enable MSSNs to focus on clinical tasks;
- availability of clinical supervision, most often achieved where MSSNs are not working in isolation but rather are part of a wider team. This also allows for cross cover for leave; and
- availability of the full multidisciplinary team for people with MS, so people with MS can access specialist input outside the scope of the MSSN role.

An additional challenge to the sustainable caseload is specialist nurses being asked to work shifts on inpatient wards in order to cover shortfalls and reduce spending on agency staff. Having received reports of this practice, we asked about this in the 2016 survey.

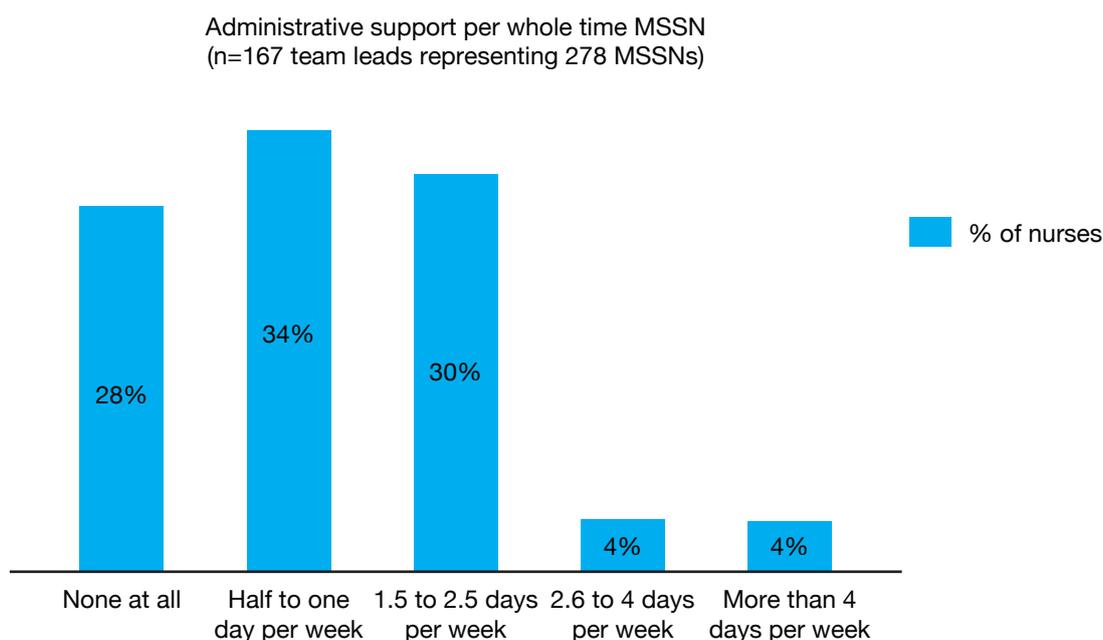
The caseload model also identified that having more MSSN prescribers could make processes smoother for people with MS by allowing MSSNs to manage MS symptoms and relapses independently.

These issues were examined by the 2016 survey and the results are as follows.

### 4.1 Availability of administrative support

Administrative support is vitally important to MS nurse teams, particularly given the complexity of scheduling the delivery and monitoring of DMDs. The roles which an able administrator can play are described in detail in the [GEMSS MS specialist nurse evaluation final report](#)<sup>1</sup>. Our 2016 survey asked nurse teams to state how much administrative support they had within their teams, and the results are shown in figure 5. It is disappointing to note that more than a quarter of MS specialist nurses have no administrative support at all within their teams, and a further third have less than a day a week of support per WTE nurse.

Figure 5 Availability of administrative support for MS specialist nurses





The inevitable consequence of this deficit is that MSSNs in many teams are spending a large amount of their time carrying out non-clinical tasks, as shown in figure 6. For example:

- In 55% of teams, MSSNs are answering all incoming calls, even those of a non-clinical nature (such as people checking appointment times).
- In 27% of teams, MSSNs are typing all their own letters and reports.
- In 57% of teams, MSSNs are doing all the scheduling of DMD monitoring appointments.
- In 82% of teams, MSSNs are responsible for all liaison with the ward/infusion suite to book beds for IV DMD administration.

We asked team leads to state whether they thought they had enough administrative support within their teams to enable MS specialist nurses to focus on clinical tasks. Of those who replied, 78% said 'no'. As shown in figure 7, the 22% who said they **did** have sufficient administrative support on average had 0.57 WTE administrative staff per nurse within their team (ie approximately three days of administrative support per WTE nurse). Our conclusion is that this level is required for efficient practice, and that without sufficient support the sustainable caseload model simply does not hold.

Figure 6 Who performs administrative roles within MS nurse teams

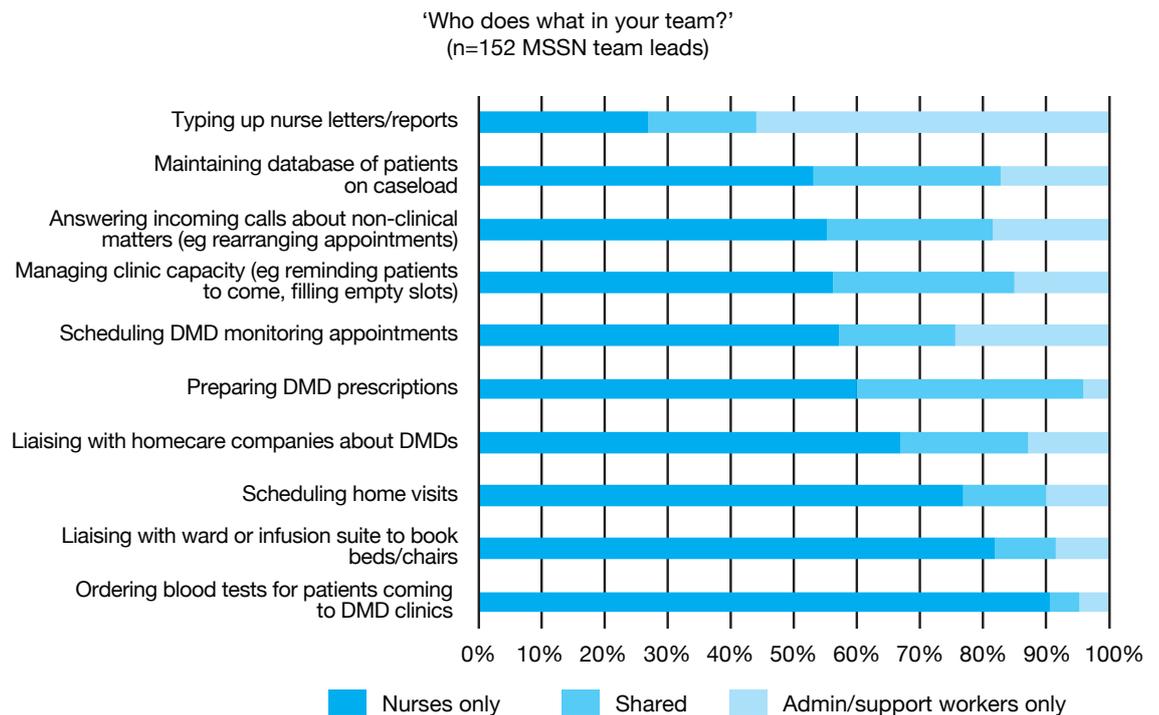
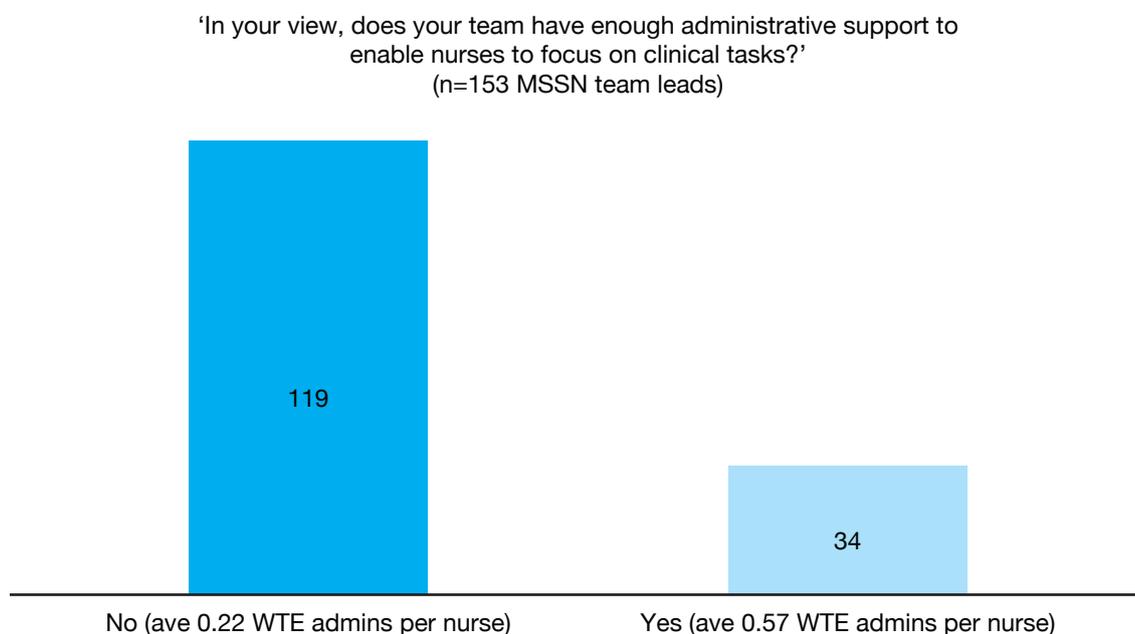




Figure 7 Team leads' views about the sufficiency of administrative support



#### 4.2 Availability of cross cover: team size analysis

The size of MS nurse teams is shown in figure 8<sup>xii</sup>.

Figure 8 Number of nurses per team

Nurses in team	Number of teams	% of teams	Number of nurses in these teams	% of nurses in these teams
5+	12	7%	76	22%
3-4	26	16%	86	26%
2	48	29%	96	28%
1	81	48%	81	24%

This shows that more than half of MSSNs are working alone or in a very small team of two. Single-handed working presents challenges because nurses working alone are not supported by MS specialist colleagues who can provide cross cover, mutual support and peer review.

<sup>xii</sup> The number of nurses is the headcount of MSSNs, MS support nurses and neurology specialist nurses in each team. Note that this is not directly comparable to our table in the 2014 report because we have defined teams slightly differently. Palliative care and paediatric teams are excluded.

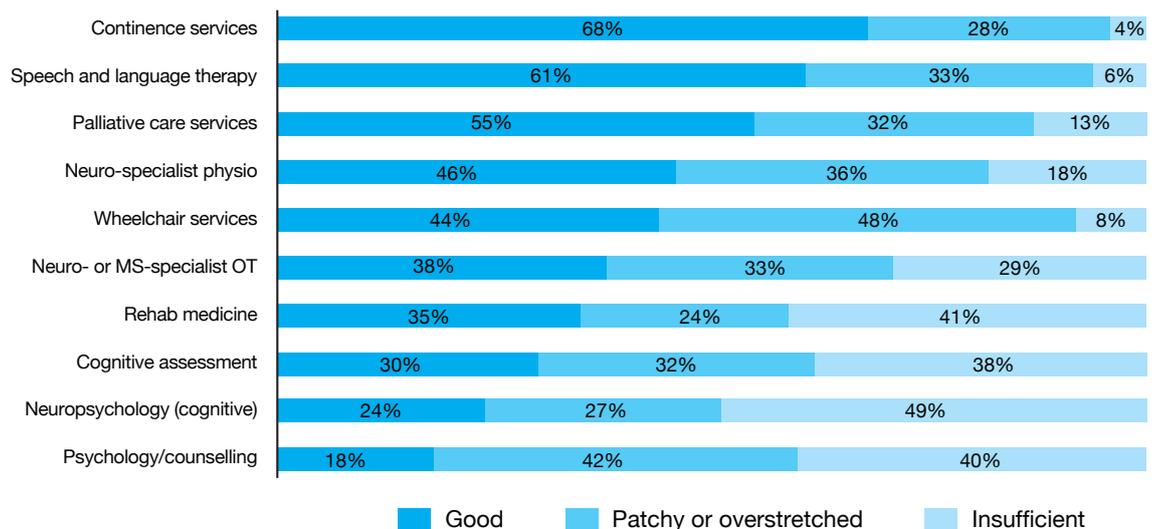


### 4.3 Availability of the full multidisciplinary team

People with MS may need input from a wide range of specialist health professionals during the course of their disease. MSSNs, as care coordinators, need to be able to consult with and make referrals to these professionals when needed<sup>5</sup>. Our survey asked MS specialist nurse team leads to assess how readily available other specialist services were around them, and the results are shown in figure 9. Whilst only indicative of the situation, the results suggest that the majority of other services needed by people with MS are patchy at best. MSSNs based in larger centres reported that provision of community and rehabilitation services is good in parts of the area they serve, but poor in others. There appears to be a particular shortage of psychological services, including cognitive assessment, neuropsychology and counselling services. The absence of these vital services will inevitably place a greater burden on MSSNs to provide psychological support – something which they are only partially trained to do, and which is exceedingly time consuming.

Figure 9 Availability of other specialist services which people with MS may need

‘How would you rate the availability of these services for people with MS in the area you serve?’  
(n=147 MSSN team leads)



### 4.4 MS specialist nurses asked to work on wards

Following anecdotal reports of MSSNs being asked to work regular shifts on inpatient wards, we asked teams to state whether they had been asked to do this during the past year. 26% of MSSN team leads in England and one of the four teams in Northern Ireland said that they had<sup>xiii</sup>, citing reasons including ‘winter pressures’, ‘black alerts’, ‘staff shortages in the discharge lounge’ and ‘all clinical nurse specialists are asked to rotate onto wards’. However, free text comments indicated that a number of these teams had successfully demonstrated that working on wards would damage the MS service and had resisted the request. In contrast, no teams in Scotland or Wales reported that they had been asked to work on wards. Clearly, taking days out of the MSSN role to do ward work disrupts the service and is likely to mean that people with MS miss out on review appointments.

<sup>xiii</sup> Excluding those who were asked to do so as a result of the junior doctors’ industrial disputes.

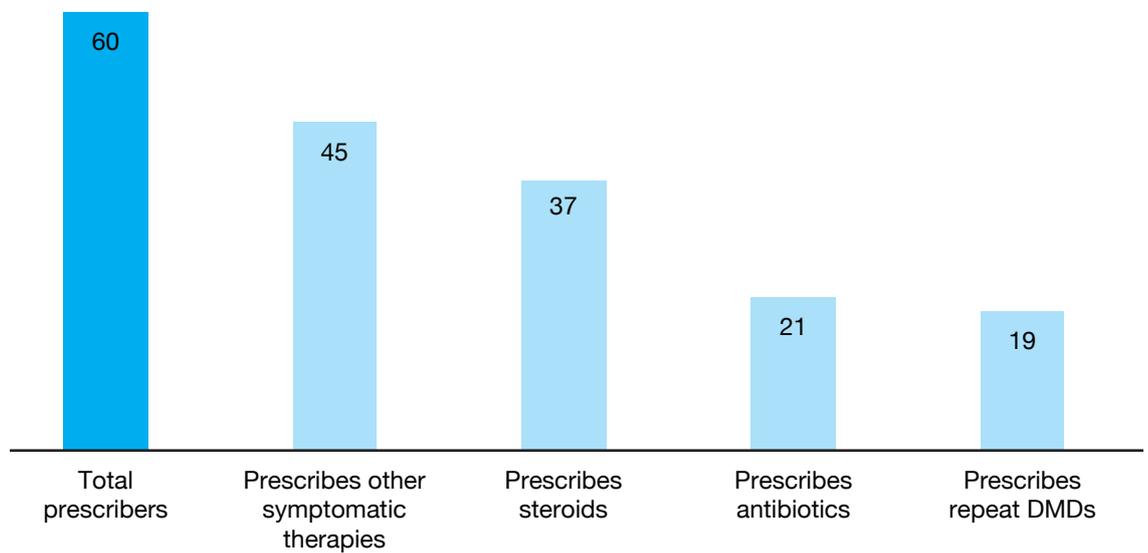


#### 4.5 MS specialist nurse prescribing

As highlighted by the 2014 edition of this report, the opportunity for some MSSNs to manage more episodes of care by becoming independent nurse prescribers could be beneficial to the efficiency of the service and streamline pathways for people with MS. According to our data, only 60 MSSNs (less than a quarter) are independent prescribers. Figure 10 shows how many MSSNs prescribe which treatments.

Figure 10 MS specialist nurse independent prescribers and what they prescribe

Number of MS nurse independent prescribers in the UK 2016, and what they prescribe





## 5. Comparing MS specialist nurse provision to the sustainable level across the UK

The MS Trust set out to establish, by CCG or Health Board, and (for England) by NHS England area, where MSSN provision is currently sufficient or otherwise, repeating the analysis undertaken in 2014. This year, the results are presented in an online 'heatmap' which is available at [www.ms-trust.org.uk/msfv-map](http://www.ms-trust.org.uk/msfv-map), and the following section describes the methodology used and summary findings at national levels.

### The fast paced change in DMD prescribing – is the MS Trust sustainable caseload model still right?

DMDs are developing rapidly, with new options available, an emphasis on early treatment, and escalation of treatment as necessary to eliminate disease activity as far as possible<sup>6</sup>. The MSSN's key roles of supporting people with MS to make decisions about DMDs, initiating treatment, monitoring for adverse effects and reviewing effectiveness is becoming ever more complex and time consuming. This calls into question whether our sustainable caseload model is still right. To test the model with revised assumptions, we assumed that:

- People with MS who are starting on or switching DMDs need an extra two consultations with an MSSN in the first year (on top of two and a half already built into the model).
- Currently, around 28% of people with MS are on DMDs
- Over the next five years, we would expect this to rise to 40% (ie 80% of those with relapsing remitting (RRMS) disease).
- Around 80% of people newly diagnosed with RRMS start on DMDs in the first year of diagnosis.

Applying these assumptions to the MSSN workload does reduce the sustainable caseload, but not by much – from 358 people with MS per WTE nurse to 342. There is much that can be done to manage DMD treatment more efficiently (for example, through effective use of administrative support in DMD coordinator roles). This issue is being examined in detail through the MS Trust's MS Forward View programme, due to report in November 2016. In the meantime, we stand by the 358 figure for analysis purposes.

### 5.1 Methodology for allocating nursing posts to areas

Our survey established the WTE MSSN posts in each team. As in 2014, posts were included and excluded from the analysis based on the following criteria:

#### Included

- MSSNs, MS practitioners and MS nurse consultants
- MS support nurses (band 6 and above only)
- Neurology specialist nurse posts in areas where there is no MSSN (self reported % of time spent on MS)
- Vacant posts in the above categories which are planned to be filled

#### Excluded

- Infusion nurses, therapies nurses
- MS support nurses and support workers below band 6
- Community neurology nurses
- Research nurses
- Palliative care nurses (5)
- MS continence nurse (1)
- MSSN in training (supernumerary) (1)
- Paediatric MS nurse (1)



The survey asked each nurse team to identify which CCGs or Health Boards their service covers, excluding areas where they see only a small number of patients (comprising less than 10% of their caseload), and where they are not the main provider of services to that area. The data provided was checked against the responses from the 2014 survey and anomalies queried and corrected.

The WTE MS and neurology specialist nurses dedicated to MS in each team were divided equally between each of the CCGs or Health Boards that they serve.

The [MS Society consensus estimate of prevalence](#)<sup>7</sup> was used to estimate the number of people with MS in each CCG and Health Board. This is an updated version of their 2014 estimate (which related to 2012) and it sums to 107,700 people with MS across the UK (up from 106,700 in the 2014 analysis). This revised estimate takes account of population changes in each area since 2014, but not potential changes to the prevalence of MS within the population.

The estimated prevalence of MS in each area has been divided by WTE nurses available to give an estimated caseload per MSSN in each CCG or Health Board.

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

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

## 5.2 Limitations in the data and analysis

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

- ▶ The data, both on WTEs and commissioning areas covered, is self-reported by nurse teams, and hence potentially subject to some degree of error. To reduce the risk of error as far as possible, team leads were presented with an up to date list of CCGs/Health Boards in their local area to choose from when saying which they served.
- ▶ The prevalence of MS in the UK remains a subject of debate as there is currently no comprehensive registry of people with MS. Some estimates suggest the number is higher than the 107,700 used in our analysis. For instance, a [study by Mackenzie et al](#)<sup>8</sup> suggested a UK prevalence of 127,000 in 2010, with an annual growth rate of 2.4% per year as life expectancy increases for people with MS. Whilst the estimate we have used is the best available consensus, it remains open to challenge.
- ▶ We have applied the MS Society's consensus prevalence to each of the four nations of the UK uniformly, except for the very high prevalence areas of the Western Isles<sup>xv</sup> and Orkney and Shetland<sup>9</sup>, where more accurate estimates have been used. However, in practice we know that prevalence within the countries of the UK is variable<sup>8</sup>.

<sup>xv</sup> Actual caseload of the MSSN used.



- ▶ The approach to dividing WTE MSSNs equally between commissioning areas is somewhat crude, but is a pragmatic 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 does not take into account how far people with MS have to travel to see an MSSN. 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. The sustainable caseload model notes that MSSNs working in exceptionally rural areas will not be able to handle a caseload of 358 due to long travel times for home visits – a figure around 250 is more realistic.

### 5.3 Results summary

As figure 11 shows, across the UK, there is now a total of 275.3 WTE MS nurses (including MS support nurses and neurology specialist nurses' time on MS), up from 234.4 WTE in 2014, giving an average of one nurse per 391 people with MS. However, despite the welcome increase in staffing since 2014, there remain wide variations in provision, with some CCGs or Health Boards being relatively well provided for and others less so. Caseloads per nurse in the bottom quintile CCGs and Health Boards remain well in excess of 750 people with MS per nurse. Figure 12 shows the number of CCGs and Health Boards in England, Scotland and Wales rated as 'red', 'amber' or 'green' according to the criteria in section 5.1. Northern Ireland as a whole is in the 'green' category.

Figure 11 Number of MS nurses included in analysis of provision

	Estimated number of people with MS	WTE specialist nurses (including support nurses and NSNs on MS)	Average caseload per WTE nurse
England	89,030	223.5	398
Wales	4,260	13.8	309
Scotland	11,190	27.9	401
Northern Ireland	3,220	10.1	319
<b>TOTAL</b>	<b>107,700</b>	<b>275.3</b>	<b>391</b>

Figure 12 Number of CCGs and Health Boards by level of MS nurse provision, 2014 vs 2016

2014	Red	Amber	Green
England	57	91	63
Scotland	3	5	6
Wales		2	5
Northern Ireland			1

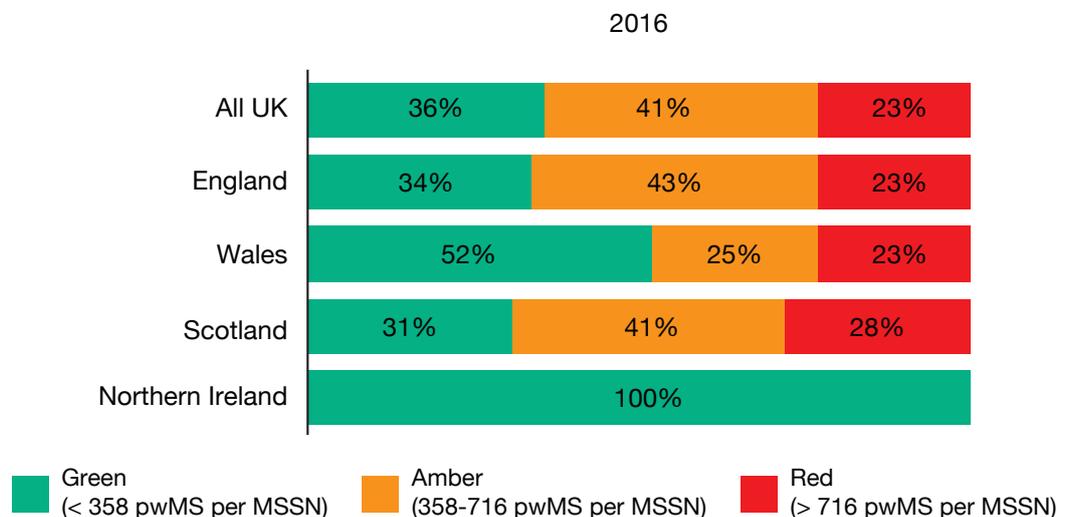


2016	Red	Amber	Green
England	45	87	77
Scotland	2	4	8
Wales	1	1	5
Northern Ireland			1

Details of the individual CCGs and Health Boards falling into each category are shown on the online map at [www.mstrust.org.uk/msfv-map](http://www.mstrust.org.uk/msfv-map).

For people with MS, the consequence of this variation is an inequitable pattern of provision across the UK. The analysis suggests that some 24% of people with MS, more than 25,000 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 MSSN service at all, or that some are receiving much less input than they really need. This may equate to a less proactive service, which is less able to prevent complications and difficulties.

**Figure 13 Proportion of people with MS by level of MS nurse provision in their CCG/ Health Board**



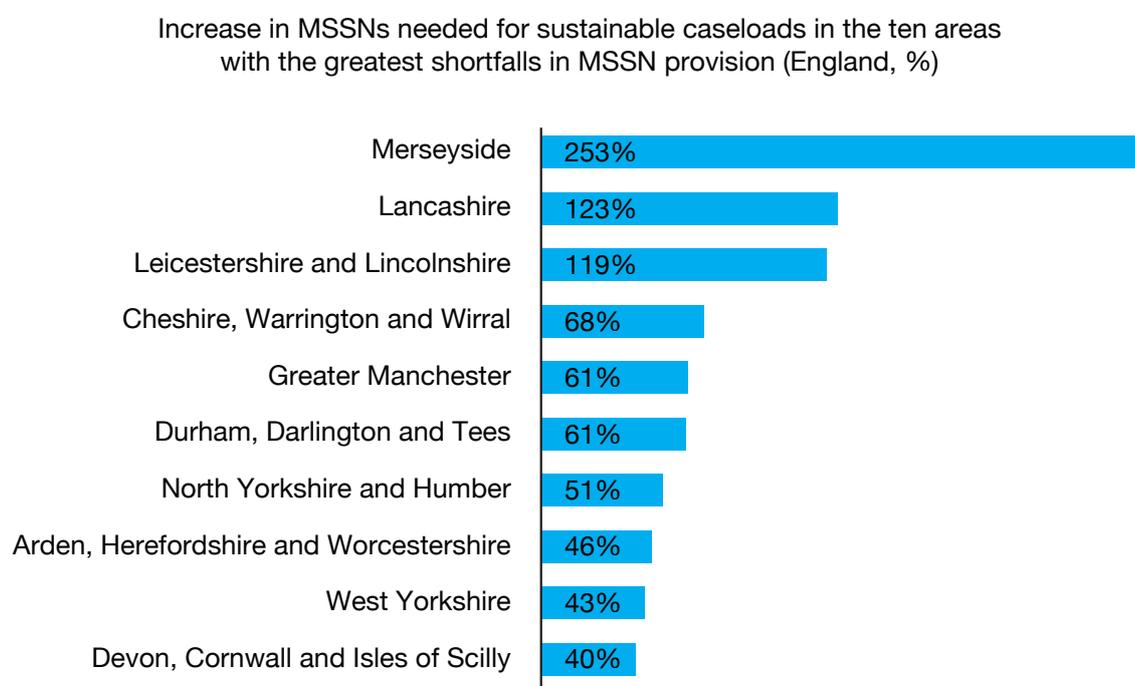
#### 5.4 Number of additional MS specialist nurses still required to meet shortfalls

Analysis of the shortfall in provision is required at a geographic level greater than that of a CCG, given that most teams cover multiple CCGs. We therefore analysed this for England at the level of the 27 NHS England areas<sup>xvi</sup>. This shows that there are 17 NHS areas (out of 27) with shortfalls in provision, down from 22 in 2014. Figure 14 ranks the areas of shortfall in terms of percentage increase in nurses required for sustainable caseloads in the ten areas of greatest shortfall. Even within the areas with no overall shortfall, there are still individual CCGs with shortfalls in provision, balanced out by other CCGs within the area. The online heatmap [www.mstrust.org.uk/msfv-map](http://www.mstrust.org.uk/msfv-map) gives further detail at local level.

<sup>xvi</sup> NHS area teams were integrated into the four NHS England regional teams in 2015. However, analysis at area level allows for direct comparison with our 2014 report, and is a geographically meaningful unit of analysis.



Figure 14 Increase in MS nurses needed in the ten England areas with greatest shortfall



Within Scotland, there are five Health Boards with shortfalls in provision (out of 14), as shown in figure 15. Of these, Lothian and Lanarkshire have by far the greatest shortfalls. Provision in Greater Glasgow and Clyde remains insufficient but has increased significantly since 2014.

Figure 15 Increase in MS nurses needed by Health Board for sustainable caseloads in Scotland

Health Board	Additional nurses required
Lothian	3
Lanarkshire	3
Greater Glasgow & Clyde	1
Grampian	1
Ayrshire & Arran	1
<b>TOTAL</b>	<b>9</b>

Within Wales, there are just two Health Boards (out of seven) with a shortfall of nurses, as shown in figure 16.



Figure 16 Increase in MS nurses needed by Health Board for sustainable caseloads in Wales

Health Board	Additional nurses required
Betsi Cadwaladr	2
Cardiff and Vale	1
<b>TOTAL</b>	<b>3</b>

Northern Ireland does not have an overall shortfall in MSSNs although, as noted in our 2014 report, the relative concentration of services in Belfast, particularly for DMD services, has meant long travel times for people with MS to access them.



## 6. Conclusions and recommendations

This report summarises and updates data on the current provision of MSSNs in the UK. Whilst we are encouraged that there are more MSSNs in post now than in 2014, the strain on services continues to increase and many MSSNs struggle to meet the demands of their specialist role. This is primarily due to lack of basic support to help administer and coordinate their service. Teams are under mounting pressure to keep pace with complex monitoring regimes for DMDs, which require them to manage significant clinical risk. They are trying, with increasing difficulty, to balance these service demands with the needs of the rest of their caseload, which often has a high level of complexity and disease burden.

As we found in 2014, this report shows that the provision of MS specialist nursing is highly variable across the UK, with some areas relatively well provided for and others with wholly inadequate provision. Those areas with the poorest levels of provision must urgently address their local shortfall in order to ensure that everyone with MS has equitable access to high quality services and that they do not continue to lag behind other areas in achieving the best health outcomes.

Recommendations for commissioners and Health Boards:

- ▶ **Understand** your local MS prevalence and the proportion who have seen an MSSN in the past year. There will be people who are out of touch with the local MS service.
- ▶ **Challenge** providers on the extent to which the MSSNs have adequate support to coordinate their service, so that they can focus their time on specialist nursing work.
- ▶ **Question** whether the needs of those with greater disease burden are being over-shadowed by the demands of delivering a safe DMD service and how this can be addressed.

Recommendations for providers:

- ▶ **Improve value for money** by ensuring that the MSSNs have adequate support for coordinating their service, so that they can focus on clinical work.
- ▶ **Commit resources** so that people with MS have fair and equitable access to MSSNs.
- ▶ **Monitor** MS service provision to ensure a sustainable caseload can be achieved.

Recommendations for MSSNs:

- ▶ **Build your case** for more resources to help you achieve a sustainable caseload.
- ▶ **Get to know your local commissioners** and help them understand how MSSNs make a difference for everyone with MS.
- ▶ **Collect accurate and relevant data** about your service and use it to highlight the impact of variation and the importance of equity.
- ▶ **Survey people with MS on your caseload** using a validated tool<sup>xvii</sup> to help drive your service improvement agenda.

The MS Trust remains committed to supporting specialist nurse services and making the case for equitable provision for people with MS across the UK. Learn more about our work at [www.mstrust.org.uk/GEMSS](http://www.mstrust.org.uk/GEMSS).

<sup>xvii</sup> Such as the patient experience survey developed through the GEMSS programme and offered as a service by the MS Trust. [www.mstrust.org.uk/gemss-patient-survey](http://www.mstrust.org.uk/gemss-patient-survey)



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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](mailto:gemss@mstrust.org.uk).

## About MS Forward View

[MS Forward View](#) is a one year project, launched in November 2015, to identify the priority actions needed across the MS sector to enable MS services to deliver efficient, effective and equitable services for everyone with MS, in the context of changing treatment paradigms. MS Forward View is looking at how MS services can make better use of current resources and skills, and how best to measure the quality and equity of access to services for everyone with a diagnosis of MS. We are bringing together clinicians, specialised and local commissioners, professional bodies, experts in workforce planning, multidisciplinary educators, people with MS and patient organisations, to produce a sector-wide consensus on how to optimise the provision of equitable, evidence-based care for everyone with MS. This plan will also help define future education programmes for health professionals working in MS.



## About the MS Trust

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

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

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

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

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

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

Visit [www.mstrust.org.uk](http://www.mstrust.org.uk)

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