



# MS Specialist Nursing in the UK 2018: Results from the 2018 MS Trust Nurse Mapping Survey

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## Executive Summary

- ▶ This work was run in parallel with an exercise mapping MS Specialist Nurses' (MSSNs) workload to establish a new sustainable caseload figure<sup>1</sup>.
- ▶ The whole time equivalent (WTE) number of MSSNs has increased by 4% from 2016, up to 250.
- ▶ There is an average of one nurse per 379 people with MS against 391 in 2016.
- ▶ There remains significant variation in caseloads of MSSNs across the UK, with 69% of people with MS living in areas where MSSNs have caseloads in excess of 315 (the new sustainable caseload figure, which was 358 in 2016).
- ▶ It is estimated that between 61 and 105 new MSSNs (depending on prevalence figures used, see section 4.1 below) are required to ensure that the average caseload is equal to or lower than the sustainable figure of 315.
- ▶ To produce these results an estimate of the number of people in the UK with MS was used that is likely to be at the lower end of the scale of the possible true figure. Using a higher figure some results presented here will change.
- ▶ These findings indicate that although there has been a welcome increase in numbers of MSSNs, this has not been rapid enough to counteract the lower sustainable caseload figure and increase in the number of people with MS.

## 1. Introduction

This report provides high-level findings from the 2018 MS Trust MS nurse mapping survey. It builds on previous work, in particular the 2016 MS Trust report which mapped MSSN capacity to populations across all clinical commissioning groups (CCGs) and Health Boards in the UK compared to the sustainable caseload figure<sup>2</sup>. Two years on, this report presents the findings of a follow up survey undertaken with all MSSN teams in the UK in 2018. It updates the 2016 picture and continues to make the case for fair access to an MSSN for every person with MS living in the UK.

Given increased challenges in working practices for MSSNs, particularly around monitoring requirements for patients on disease modifying drugs (DMDs), the existing sustainable caseload of 358 people with MS for each WTE MSSN was recognized as too high. Work recently commissioned by the MS Trust to update the sustainable caseload figure recommended 315 as more realistic<sup>1</sup>.

This report maps the provision of MS specialist nursing across the UK in the context of the revised sustainable caseload figure of 315 people with MS per WTE MSSN.



## 2. Survey methodology

The 2018 MSSN survey was based on the 2016 questionnaire, adapted with input from various MS nursing teams. We emailed a link to the online survey to one member of each MSSN team in the UK in July 2018, using the MS Trust's health professionals database. In some cases, organisations have merged or changed since the 2016 survey.

A final list of 164 MSSN teams was identified – 137 in England, 19 in Scotland, 4 in Wales and 4 in Northern Ireland. By the closing date in September, over 95% of teams had responded. Missing data was inserted using 2016 responses and validated by team members. This report therefore represents a snapshot of the MS nursing workforce at September 2018, and compares this to that of July 2016.

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

### 3.1 MS specialist nurses

MSSNs are at the core of MS teams, and are defined here 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>i</sup>.

#### Number and banding of posts

In 2018, there are 292 individuals in these roles, equating to 250 WTEs (due to part time working)<sup>ii</sup>. This is up from 241 WTEs in 2016, an increase of 4%. Figure 1 shows the breakdown of MSSNs by nation.

Figure 1 MS specialist nurses in the UK 2016 to 2018 (WTE)

	2016	2018	Increase/decrease (WTE)
England	193.1	204.07	11
Scotland	25.6	27.1	1.5
Wales	13.0	12	-1
Northern Ireland	9.5	7.15	-2.4
<b>UK Total</b>	<b>241.2</b>	<b>250.32</b>	<b>9.1<sup>iii</sup></b>

Figure 2 illustrates the growth in numbers of MSSNs by band and compares this between 2016 and 2018. The MS Trust believes that most MSSNs should be band 7 or above. 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 within larger teams to facilitate effective and efficient working.

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

<sup>ii</sup> This relates to MSSNs working with adults only. There are a small number of paediatric MSSNs who are excluded from the analysis.

<sup>iii</sup> This is the total of adding the individual numbers for each country and does not represent the overall increase in WTE MSSNs (which is 4%)



Figure 2 UK MS specialist nurse workforce 2016 to 2018

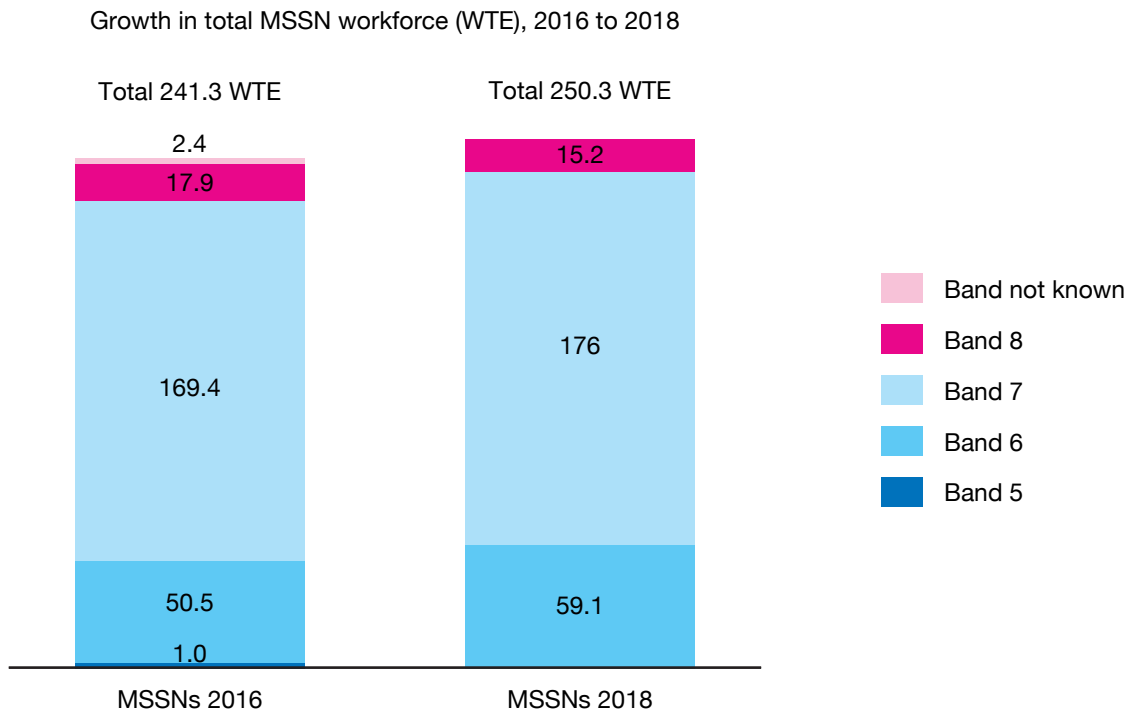
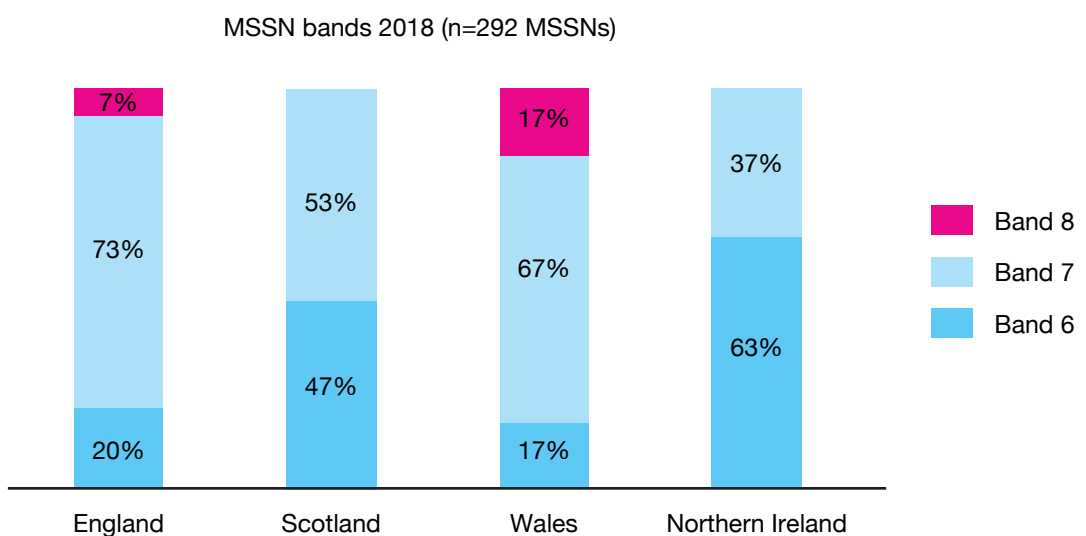


Figure 3 compares the banding of posts between UK nations. As in 2016, England and Wales on average employ MSSNs at a higher banding than Scotland and Northern Ireland, where a greater proportion of posts are at band 6.

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





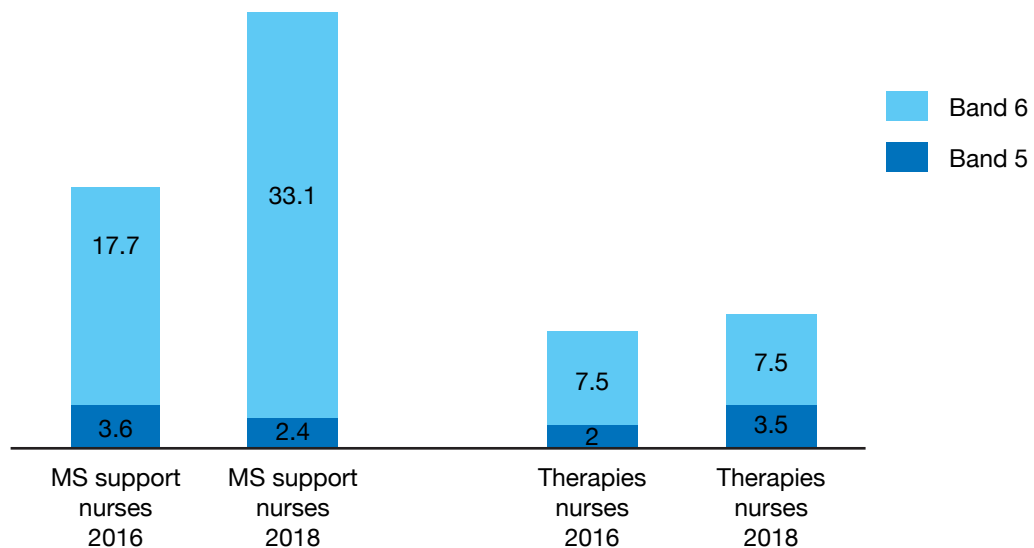
### 3.2 MS support nurses and therapies nurses

36 MS nurse teams 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, free up time for MSSNs to focus on more specialist tasks. These roles can also provide a useful development role for aspiring specialist nurses.

Therapies nurses are usually responsible for administering IV DMDs (though this may be shared with or delivered by infusion nurses rather than members of the MS team). There has 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 36 of 164 MSSN teams)



### 3.3 Neurology specialist nurses

The 2016 report highlighted the presence of a small number of neurology specialist nurses covering more than one (and often several) neurological conditions. The 2018 survey identified 36 neurology specialist nurses who include MS within their caseload, equating to 14.1 WTEs (calculating estimated time spent on MS only). This represents a small decrease from 2016 when this figure was 16.9 WTE. Two palliative care neurology nurses who work with people with MS were also identified.

The neurology specialist nurses were largely identified from previous surveys and are primarily in areas without MSSNs. However, the MStrust received anecdotal feedback that there may be additional neurology specialist nurses seeing people with MS in other areas, and so asked MS teams about this. This is something we need to understand better and will be investigating further.



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

The MS Trust set out to establish MSSN provision in each CCG and Health Board, repeating analysis undertaken in 2016. The following section describes the methodology used and summary findings at national levels. Further information, such as amount of administrative support, will be referenced in subsequent reports.

### 4.1 Methodology for allocating nursing posts to areas

Our survey established the WTE MSSN posts in each team. As in 2016 MS nurses, MS support nurses (band 6 and above) and neurology specialist nurses' time spent on MS were included in this analysis, whilst other posts, such as therapies, palliative care and continence nurses, were not.

The survey asked each nurse team to identify which CCGs or Health Boards their service covers, excluding areas comprising less than 10% of their caseload. At the time of publishing a very small number of queries with teams are outstanding, so no localised information is given (this will have minimal, if any, impact on national results). In an improvement to the previous methodology, teams were asked to indicate what proportion of their overall caseload is within each CCG or Health Board they cover. Previously, each team's WTE specialist nurses were divided equally across the CCGs or Health Boards they serve, which was not always a true reflection of the way the MSSN team worked.

In 2016 the MS Society consensus estimate of prevalence was used to estimate the number of people with MS in each CCG and Health Board, totaling 107,700 in the UK. A 2.4% year on year increase was applied to this, based on Mackenzie et al's work suggesting this annual growth rate<sup>3</sup>. This resulted in an estimated number of 113,013 people with MS across the UK, which was used in analysis. However, this figure is at the likely lower end of the scale of the true number of people with MS in the UK. Mackenzie estimated that the actual figure could have been closer to 127,000 in 2010 (the date of her analysis), so numbers below could change using this higher population figure.

Estimated prevalence of MS in each area was divided by the number of 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: 'green' meaning there are enough MSSNs for caseloads to be at or below 315 per WTE nurse; 'amber' where provision is between 50 and 100% of what it should be (between 316 and 630); and 'red' meaning provision is less than half of the sustainable amount (more than 630).

### 4.2 Results summary

Figure 5 shows the total number of WTE MS nurses, which includes WTE MS support nurses and neurology specialist nurses' time spent on MS. This figure is 298, an increase of 22.7 WTE nurses from 2016. This gives an average of one nurse per 379 people with MS (based on the estimated number of people with MS at 113,013) compared to 391 in 2016.

In order for the average caseload to be at the sustainable level of 315 a total of 359 WTE specialist nurses would be required, an increase of 61 on the current figure (403 WTE nurses would be required using the higher figure of 127,000 people with MS). These figures indicate that although progress has been made in the last two years there is still a lot more to do, and that if the higher figure for people with MS is confirmed then progress needs to be even more rapid.



Figure 5 Number of MS nurses included in analysis of provision

	Estimated number of people with MS	WTE specialist nurses (including support nurses and NSNs time on MS)	Average caseload per WTE nurse
England	93,376	243.8	383
Wales	4,467	13.2	338
Scotland	11,794	30.7	384
Northern Ireland	3,376	10.35	326
<b>TOTAL</b>	<b>113,013</b>	<b>298</b>	<b>379</b>

Despite the welcome increase of 22.7 WTE specialist nurses, and the overall reduction in average caseload per WTE nurse, 69% of people with MS live in areas where caseloads are in excess of the sustainable caseload figure ('reds' and 'ambers' combined), an increase from 64% in 2016. Nearly a quarter of people with MS (over 26,000) still live in CCGs or Health Boards where caseloads are more than twice the sustainable level ('reds'). Thus it is clear that many more MS nurses are still needed. These deficits would increase significantly if the higher estimate of 127,000 people with MS in the UK is confirmed. Using this figure 77% of people with MS live in areas where caseloads are in excess of 315 per WTE MSSN.

There remains wide variations in provision across CCGs and Health Boards. Figure 6 shows the number of CCGs and Health Boards in England, Scotland and Wales rated as 'red', 'amber' or 'green' according to the above criteria. Northern Ireland as a whole is in the 'amber' category, whereas it was 'green' in 2016. Overall the proportions of CCGs and Health Boards in each of the three categories have remained relatively stable in the last two years (e.g. although there are fewer 'greens' in England in 2018 compared to 2016 this is partly due to fewer numbers of CCGs, following mergers, with proportions of green CCGs in 2018 and 2016 being very similar 38% and 39%). Using the higher population figure of 127,000 the proportion of 'green' areas reduces to 31% (69 in total).

Figure 6 Number of CCGs and Health Boards by level of MS nurse provision, 2018 vs 2016 (2016 figures in brackets)

	Red	Amber	Green
England	46 (45)	84 (87)	73 (77)
Scotland	1 (2)	5 (4)	8 (8)
Wales	1 (1)	1 (1)	5 (5)
Northern Ireland		1	(1)



## 5. Conclusions

This report summarises and updates data on the current provision of MSSNs in the UK. Although there has been an increase in the numbers of MSSNs, this has not been enough to counteract the increased demand on MSSN time, or the likely increase in the number of people with MS.

This data suggests that between 61 and 105 new MSSNs are required to ensure that average caseload is at or below the sustainable figure of 315. There remains considerable variation across the UK in terms of how adequate the levels of nursing provision are in each CCG and Healthboard. If higher population estimates are used there will be evidence of even more significant impact on resource pressures. More work is required to analyse the additional data collected in this survey with subsequent reports published early in 2019.

## References

1. Leary, A and Punshon, G. Optimum Caseload Calculations: MS Specialist Nurses (upcoming). London, 2018.
2. Mynors G, Bowen A and Doncaster, D. MS specialist nursing in the UK 2016: Report on progress towards equitable provision: MS Trust; 2016.
3. Mackenzie I, Morant S, Bloomfield G, MacDonald T, O'Riordan J. Incidence and prevalence of multiple sclerosis in the UK 1990-2010: a descriptive study in the General Practice Research Database. *Journal of Neurology, Neurosurgery, and Psychiatry*. 2014;85(1):76-84.

## Acknowledgements

We would like to thank all the MS and neurology specialist nurses who responded to the MS Trust nurse survey in 2018.



## About the MS Trust

The MS Trust is a UK charity that believes that no one should have to manage MS alone. We produce trusted MS information and support MS health professionals.

Access to specialist services, and in particular MS nurses, is essential if people living with MS are to receive the full range of support they might need.

We work hard to produce evidence to identify what is required and demonstrate the value of specialist services.

We also work to ensure everyone affected by MS can access good quality, specialist care. We provide specialist education and continuing professional development for health and social care professionals to ensure high quality services are maintained.

We produce practical, evidence based information for people living with MS. All our information is free, online or 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 or NHS 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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