

Multiple sclerosis specialist nursing in the UK 2021: results from the MS Trust nurse mapping survey



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Executive summary

- This survey provides a snapshot of the MS specialist nurse workforce as at August 2021. The methodology and findings are discussed in detail within the body of the report below.
- There are 360 individual multiple sclerosis (MS) nurses employed across the United Kingdom (UK), equivalent to 298 whole time posts (WTEs). This is a significant increase since 2018, when there were 292 individual MS nurses, equivalent to 250 WTEs. This is partly due to new recruitment but also previously unfilled vacancies.
- Self-reported caseloads were used for the first time in this survey, with numbers of people with MS reported as higher than Public Health England (PHE) (2020) estimates across the country. The total number of people with MS (pwMS) on MS specialist nurse caseloads across the UK is estimated to be 140,633.
- The mean caseload per WTE MS specialist nurse is 472, representing a significant increase on previous surveys¹.
- 79% of people with MS live in areas where caseloads per MS specialist nurse team are higher than the sustainable caseload figure of 315 (Punshon et al, 2021). This is an increase from the 69% estimate reported in 2018 (Hannan et al, 2018).
- There is a shortfall of 149 WTE MS nurses across the UK, an increase on the reported shortfall of 105 MS specialist nurses in 2018 (Hannan et al).
- Approximately one third of MS specialist nurse services across the country are unable to provide either home visits or ward visits (36% and 33%, respectively), whilst 15 sites (12%) are unable to offer both, excluding people with the most advanced forms of MS living in those areas from accessing face-to-face MS specialist nurse care.
- Administrative support is essential to delivering an efficient and effective MS specialist nurse service, yet 18% of MS specialist nurse teams still have zero administrative support.
- The need for consistent data collection by MS specialist nurse teams is highlighted with only 53 teams (40%) reporting that they have an up-to-date database that covered all of their patients.
- Some 95.6% MS specialist nurse teams had returned to providing face-to-face outpatient appointments in August 2021, with 100% delivering telephone appointments.
- Effective workforce succession planning is imperative, with 14% (41) of respondents planning to retire in the next two years, and 36% (105) retiring in the next five years.
- The MS Trust is the leading provider of MS specialist education, with 89% of respondents having either attended or booked to attend the MS Trust Foundation Module. 71% respondents had attended the MS Trust Annual Conference during the preceding 3 years.

¹ Previous surveys utilised published prevalence figures rather than MS specialist nurse caseloads, which makes direct comparison of this metric difficult (379 per WTE in 2018 and 391 per WTE in 2016)



Introduction

This report presents the findings from the MS Trust mapping surveys carried out in 2021. The MS Trust has undertaken a biennial mapping of MS specialist nurse services across the UK since 2014 (Mynors and Bowen, 2014). This iteration of surveys should have taken place in 2020; however, due to the impact of the Covid-19 pandemic, we have only been able to implement the project in 2021.

Changes since 2018

Whilst we know that the pandemic has had, and continues to have, a huge impact on multiple sclerosis (MS) services across the board, there have been other notable changes since the last MS specialist nurse mapping report in 2018 (Hannan et al).

Significant changes across the commissioning landscape, particularly in England, have taken place in the last 12 months. Many smaller Clinical Commissioning Groups (CCGs) have merged to form single, larger CCGs. Integrated Care Systems (ICSs) are also becoming established across England. Hospitals and foundation trusts have also merged during that time.

This has inevitably had a significant impact on our methodology, which is described below.

Why MS specialist nurses?

MS specialist nurses are an essential part of the healthcare team for people with MS (pwMS), and everyone with MS should have access to an MS specialist nurse when and where they need it (NHS RightCare, 2019). The Optimum MS Pathway (Coles et al, 2019) also makes it clear that the MS specialist nurse is central to the care of pwMS, from diagnosis through to end of life.

However, MS specialist nurses are not the only essential member of the healthcare team that pwMS need to access. The MS Trust recognises the need to extend mapping to other key health professionals, particularly allied health professionals (AHPs) and neurologists, as they, too, are all hugely under-resourced. A survey conducted by the ABN in 2019 (Nitkunan et al, 2020), found that there were 958 consultant neurologists in the UK, equivalent to 1 WTE per 91,175 of the population, one of the lowest ratios amongst European countries. The MS specialist nurse workload and experience of the person with MS, are also directly impacted by the availability of the neurologist and of AHPs. Being able to access the combined skill mix and to seek neurological review in a timely way impacts significantly on MS specialist nurse workloads and patient outcomes.

The Optimum MS Pathway (Coles et al, 2019) recommends that pwMS should see a neurologist at diagnosis and when starting treatment but that otherwise, routine follow up should be led by the MS specialist nurse either virtually or face-to-face. The combination of having too few MS specialist nurses, too few neurologists and too few AHPs available to meet the needs of pwMS will impact on quality of care provided for pwMS throughout the UK.

The MS Trust does not have capacity to extend this survey to include other professions on this occasion; therefore, the focus of the survey and this report is the MS specialist nurse workforce.

The survey results will complement other published evidence demonstrating the value of MS specialist nurse roles, which is not yet available in the same way for AHP roles (for example: Leary et al, 2015; Mynors et al, 2016; Punshon et al, 2021).



Impact of Covid-19

There was widespread impact on NHS services as a result of Covid-19, and disruption to MS services was noted early in the pandemic (Portaccio et al, 2021). As a result, modifications to the timing and methodology of the mapping study were necessary, and our findings record changes to MS specialist nurse roles and services during this period.

This report maps the provision of MS specialist nurses across the UK, giving a snapshot of services as of August 2021.

Survey methodology

Survey of UK MS specialist nurse teams: methodology

The MS Trust has previously reviewed MS specialist nurse provision across the UK based on the CCG or Health Board covered by each team. The prevalence of pwMS in each CCG or Health Board was estimated using the most recently published prevalence data and local population estimates (Hannan et al, 2018). However, due to the reasons outlined below, the methodological approach employed for the 2021 mapping survey has been adapted to capture real-time data, to help us better understand MS specialist nurse services and workloads at both a service and individual level.

Area served

Each year, there are mergers across healthcare systems and changes to CCG configurations (Health Boards generally tend to be less affected); however, this year there are major changes across England, with the merging of many CCGs and the establishment of ICSs. The size of the newly merged CCGs and ICSs means that several MS specialist nurse teams are likely to work within each; therefore, applying a red, amber or green (RAG) rating

to them becomes less useful, obscuring much of the MS specialist nurse team-level detail. For instance, there are examples where two separate MS specialist nurse teams provide care to pwMS in a single ICS, with one team assigned a red RAG rating and the other a green. Combining the results from both teams would mean that the ICS would receive a green rating overall, entirely obscuring the fact that only half of the MS specialist nurse services it commissions are adequately resourced.

It should be noted that, throughout this report, 2021 figures relating to Wales cover only south Wales. MS specialist nurse teams covering mid and north Wales (predominantly The Walton Centre and The Royal Wolverhampton MS Services) are based in England and serve pwMS in both England and Wales and are included in the figures for England only.

Caseload

As detailed above, the 2021 MS specialist nurse mapping report employs a different approach to previous surveys, reviewing the data by MS specialist nurse team rather than CCG or Health Board. This, in turn, poses



its own particular challenges regarding estimating the local prevalence of MS, as it is much more challenging to calculate this for the area covered by an individual MS specialist nurse team rather than for a CCG or Health Board with a defined population. The most pragmatic approach to resolve this has been to ask each MS specialist nurse team to inform us of their caseload. Wherever possible, MS specialist nurse teams have provided us with figures taken from their database; however, not all teams have an up-to-date database, and, in these cases, an estimate has been supplied (40% of MS specialist nurse teams have an up-to-date database for all patients – see below). Where there were any apparent ambiguities or lack of clarity around a team's responses, we made every effort to contact them and clarify.

We recognise that there are limitations with this approach (as there are with using estimates of local prevalence based on published prevalence data). However, we believe that this methodology more closely reflects the workload of MS specialist nurse services, as it is based on the numbers of patients MS nurse teams are actually working with, as opposed to local prevalence estimates we have used in previous surveys. Previous surveys have assigned a caseload figure to each team based on these local prevalence estimates and the percentage workload each MS specialist nurse team reported per CCG/Health Board (Hannan et al, 2018) which does not necessarily correlate with self-reported caseloads.

Defining an MS specialist nurse

For the purposes of this survey, we have taken MS specialist nurses to be registered nurses at Band 6 or above, with a title that reflects a specialist approach to MS. We recognise that MS specialist nurses around the UK use several different titles (see Table 9 below); however, for the sake of ease, we will refer to all MS nursing roles as MS specialist nurses throughout the report.

Questionnaires

The survey questions were based on those used in previous years and adapted to reflect the change in approach outlined above. This has enabled some degree of comparison with previous surveys, although any comparisons should be applied with caution, given the change in methodology.

We also asked individual MS specialist nurses to complete a separate survey covering key areas such as succession planning and training, which are discussed below.

Links to both surveys were emailed to 536 health professionals recorded on the MS Trust database against the flags 'health professional', 'UK' and 'MS nurse' or 'MS nurse other' or 'neurology nurse' or 'nurse'. Some 11 bounce backs were received, giving a total of 525 valid emails sent (note: there is likely to have been some duplication within this, as some health professionals provide both their work and personal email addresses). From the initial mailing, 422 emails sent were opened, with a 50% click-through rate.

The link to the surveys was also included in two consecutive mailings of the monthly MS Trust Health Professionals email, which has a circulation figure of 1,239 health professionals.

Targeted, follow-up emails and phone calls were made to MS specialist nurse teams who did not respond to the initial emails.

Responses were received from 133 MS specialist nurse teams across the UK, and 176 individuals responded to the second survey.

The results of both surveys provide a snapshot of MS specialist nurse services as of August 2021.



Table 1: Numbers of MS specialist nurse teams responding to the 2021 survey across the UK

Country	No. MS specialist nurse teams responding	Notes
England	107	We were unable to collect data from one major prescribing centre ² but otherwise we have received responses from all the MS specialist nurse teams included in previous surveys.
Scotland	21	
South Wales	2	People with MS In north Wales receive care from either the MS specialist nurse team employed by The Walton Centre (2 whole time equivalent MS specialist nurses) or the MS specialist nurse team based at The Royal Wolverhampton Hospital – both teams’ data has been reported within England’s figures.
Northern Ireland	3	
UK	133	164 teams were identified across the UK in the 2018 survey, we know that some of these are no longer extant ³ . Responses were received from all acute centres and prescribing centres bar one.

² There was no data available for the missing Prescribing Centre from 2018 or 2016 surveys, so they have not been included.

³ GIRFT (2021) reports that 43 Neuroscience Sites across England have no MS specialist nurse capacity.



Overview of findings

Section 1

MS specialist nurse workforce and caseloads

One of the main aims of the MS Trust mapping survey is to establish the number of MS nurses working across the UK and their associated caseloads.

Each MS specialist nurse team provided details of the number of individual nurses working in their team (Band 6 and above), the whole time equivalent (WTE) per nurse and the percentage of time each nurse was allocated to work with pwMS each week. Using these figures, we calculated the whole time equivalent MS specialist nurses per team, as well as the actual number of individual MS specialist nurses (or 'headcount'). We were then able to calculate the mean caseload per WTE by both team and country.

Tables 2a and 2b provide an overview of MS specialist nurse caseload and WTEs by country in 2021 compared to 2018.

Key findings:

- There are 360 individual MS specialist nurses working across the UK, compared to 292 in 2018 (a 23.3% increase)
- This equates to 298 WTE MS specialist nurses (compared to 250 WTEs in 2018)
- The total reported MS specialist nurse caseload across the UK is 140,633
- The mean caseload per WTE MS specialist nurses in the UK is 472, 50% higher than the recommended caseload per WTE⁴.

Table 2a: Overview of MS specialist nurse caseload and whole time equivalents in Aug 2021

2021 Data	Total reported caseload	Actual number MS specialist nurses 2021	No. whole time equivalent MS specialist nurses	Mean caseload per whole time equivalent(range)
England	112,451	304	251.1	447.8 (127-1,490)
Scotland	18,182	36	28.1	647 (105-1,000)
S Wales	4,000	12	11	363 (333-400)
N Ireland	6,000	8	7.5	800 (450-1,100)
UK	140,633	360	297.9	472.1 (105-1,490)

Table 2b: Overview of MS specialist nurse caseload and whole time equivalents in Sept 2018

2018 Data	Total reported caseload	No. whole time equivalent MS specialist nurses	Mean caseload per whole time equivalent
England	89,030	223.5	398
Scotland	11,190	27.9	401
Wales	4,260 ⁵	13.8 ⁶	309
N Ireland	3,220	10.1	319
UK	107,700	275.3	391

⁴ 315 (Punshon et al, 2021).

⁵ The 2018 figure is for the whole of Wales.

⁶ The 2018 figure includes one MS specialist nurse from north Wales.



Section 1.2

Caseload vs prevalence

From these results, it can be seen that the number of pwMS across the UK is significantly higher than that reported in the 2018 mapping survey (Hannan et al, 2018). The 2018 figure was based on estimates of prevalence published at that time (MacKenzie et al, 2014), which have since been updated by Public Health England (PHE), 2020. The most current published prevalence figures from PHE are listed below for information:

- England: 105,450
- Scotland: 15,750
- Wales: 5,600
- N Ireland: 4,830
- UK: 131,720.

The caseload figures reported for 2021 are based on MS specialist nurse reported caseloads, as detailed above.

Whilst there are some limitations to using MS specialist nurse reported caseload figures, there are also recognised methodological limitations with any epidemiological study of prevalence (as detailed by the authors MacKenzie et al, 2014; PHE, 2020), which are always, inevitably, an underestimate of true prevalence. This is caused by a number of different factors including the time lag between an individual developing symptoms of MS and receiving a diagnosis; there may be restricted access to services in different areas at different times and some people are just reluctant to seek a diagnosis at all. The accuracy and timeliness of databases recording people with a diagnosis of MS at any stage is also a particular challenge given the lack of a single MS Register across the UK.

The caseloads reported by MS specialist nurse teams in response to this survey will more accurately reflect the workload each team is facing than previous surveys that utilised estimates of prevalence.

There is a great deal of anecdotal evidence that many people with MS are unable to access MS nurse care⁷ (see Croft et al, 2016; Roberts et al, 2016) suggesting that the MS specialist nurse caseloads are themselves underestimates of the actual number of pwMS in the UK as they only include pwMS known to MS services.

These discrepancies in prevalence figures highlight the need for a UK-wide agreement on core datasets that need to be collated by each MS service and for a single, comprehensive UK MS Register. People with advanced MS, who make up to 30-40% of the MS population (Roberts et al, 2016), are particularly vulnerable in this regard.

In the Getting It Right First Time (GIRFT) report for Neurology, Fuller (2021) makes a series of recommendations about the need for a neurology dashboard, 'building on routinely collected data, to enable monitoring of key metrics to support continual quality improvement'. If this could be coordinated across all MS specialist nurse teams and include epidemiological data, this would be a great step forwards in facilitating commissioning of MS services able to meet the needs of everyone with MS.

Section 1.3

Caseload per WTE MS specialist nurse

The recommended, sustainable caseload figure per WTE MS specialist nurse is 315 pwMS (Punshon et al, 2021). This figure is based on comprehensive workforce modelling and assumes a mixed rural/urban geography, a caseload that covers everyone with MS from diagnosis to end of life, with administrative support of 0.6 WTE per WTE MS specialist nurse. Where these conditions are not present, the sustainable caseload figure should be reduced. We have used a caseload figure of 315 per WTE MS specialist nurse in our calculations throughout this report.

⁷ For example, an evaluation of the impact of the addition of a new MSSN post to the MSSN team at Leicester General Infirmary as part of the MS Trust Specialist Nurse Programme in 2018, found that there were more than 700 pwMS in the area who had been lost to follow up, 400 of these were contacted and re-engaged with the MSSN service during the evaluation period. (MS Trust, data on file).



As shown in Table 3a, mean caseloads per WTE MS specialist nurse are all significantly greater than 315. The mean caseload across the UK is 50% higher than the recommended caseload. This inevitably means that MS specialist nurses are having to leave work undone and will be unable to meet all the needs of every pwMS on their caseloads. The work by Punshon et al (2021) identified psychological interventions, physical assessments, social interventions/benefits, and recommending or prescribing medications as the most likely areas of work necessarily left undone by MS specialist nurse teams with caseloads higher than the recommended 315 per WTE. This will inevitably impact negatively on outcomes for pwMS and lead to increased use of unscheduled care services and increased costs for the NHS⁸.

The range of mean caseload per WTE within each country is marked and reflects something of the differences between MS specialist nurse services and local resources. However, this should be viewed in context. For example, the

site with the lowest reported caseload per WTE (105) is one that is particularly remote and rural, has no easily accessible hospital site and which has no administrative support at all. The site with the largest reported caseload per WTE (1,490) is one where there have been a lot of recent staff changes and where recruitment was temporarily suspended.

Section 2 MS specialist nurse banding by country

Table 3a lists the total numbers of WTE MSSNs by country and across the UK as a whole. Numbers from the 2018 survey are provided in Table 3b for comparison.

Figures indicate an overall rise, predominantly at Band 6, which is the entry level to MS specialist nursing. The change in methodology should not impact on numbers of MS nurses identified; therefore, direct comparison between 2018 and 2021 is valid.

Table 3a: Whole time equivalent MS specialist nurses at each Banding in 2021

2021	England	Scotland	S Wales	N Ireland	Total
Band 8c	1				1
Band 8b	2				2
Band 8a	15.55		2		17.55
Band 7	144.12	16.4	5.8	3	169.32
Band 6	88.46	11.7	3.2	4.5	108

Table 3b: Whole time equivalent MS specialist nurses at each Banding in 2018

2018	England	Scotland	Wales ⁹	N Ireland	Total
Band 8c	1				1
Band 8b	2				2
Band 8a	14.3		2		16.3
Band 7	149	14.3	8	2.6	173.9
Band 6	40.8	12.7	2	4.4	59.9

⁸ Emergency admissions for pwMS rose 15.6% between 2016 and 2019 (Raising the Bar, 2020)

⁹ 2018 figures cover the whole of Wales.



Key findings:

- The number of Band 7 WTEs has decreased slightly (by 4.58 WTEs) since 2018, while the number of MS specialist nurses at Band 6 has increased significantly (by 48.1 WTEs)
- There has been no real change in number of WTEs in Scotland or Northern Ireland
- The shift in ratio of Band 7 to Band 6 MS specialist nurses will inevitably impact on the balance of skills and experience available within MS specialist nurse teams.

Section 3 MS specialist nurse teams and provision of a sustainable workload

Punshon et al (2021) calculated the sustainable caseload for an MS specialist nurse as 315 pwMS per WTE. It is expected that if an MS specialist nurse is carrying a sustainable caseload, they will be able to deliver proactive, holistic care to everyone on their caseload, minimising the need for unscheduled care amongst pwMS and thus improving their outcomes and reducing costs and burden on the NHS (Leary et al, 2015)¹⁰.

In response to the survey, each MS specialist nurse team has provided their team caseload and the number of MS specialist nurses within their team. We have calculated the WTE MS specialist nurses per team, as detailed above. This has enabled us to calculate the mean caseload per WTE for each team. As in previous surveys, we have then allocated a traffic light rating of red, amber or green (RAG) for each team, the higher the caseload per WTE, the less likely the MS nurse team is to be able to deliver proactive care to everyone on their caseload:

- RED:** Mean caseload per WTE is more than twice the sustainable caseload (ie >630 per WTE)
- AMBER:** Mean caseload per WTE is > than 315 and less than or equal to 630
- GREEN:** Mean caseload per WTE is 315 or less

Section 3.2 A pragmatic interpretation

We recognise that the differentiation between each of the RAG ratings is very stark; in practice, a team with a mean caseload per WTE of 340 (for example) would, most likely, be able to meet the needs of everyone with MS on their caseload. However, it should be noted that, when calculating the RAG rating per team, we have only taken into account the mean caseload per WTE; we have not factored in the amount of administrative support, the team's caseload mix or geographical setting, all of which contribute to the sustainable caseload figure for that team.

This means that, while some of the teams assigned an amber RAG rating due to lower caseloads per WTE may be able to deliver proactive care to everyone on their caseload, some teams with a green RAG rating may be operating in a very remote and rural area, with no administrative support, and are therefore unable to provide the required level of care. It should be said that any MS specialist nurse team with a red RAG rating will be unable to deliver proactive care to everyone with MS on their caseload.

Calculating RAG ratings for every team using this level of detail is beyond the scope of this report. We have, therefore, decided not to publish individual team data. Individual team RAG ratings released without context can be misleading and potentially unhelpful. However, we would encourage individual MS teams/commissioners to approach us to request their local data, which we can provide while clarifying the local context and challenges. Every MS service is different, as each has to work within the resources available and must meet local needs. These will be very different for an MS specialist nurse working in the Scottish Highlands compared to a team working in central London, for example.

Other resources that can help MS specialist nurse teams identify their capacity and resource needs can be found in the Resources section of this report.

¹⁰ Leary et al (2015) demonstrated that introduction of proactive, specialist nurse led management and a rapid response service around unscheduled care use for pwMS reduced emergency bed days from a mean of 2,700 per year to 198 per year.



Section 3.3 RAG ratings across the UK

The results of the RAG rating attributions can be seen in Table 4.

64% of MS specialist nurse teams are having to work with caseloads above the recommended sustainable figure (comparison with previous surveys for this metric is not possible due to the changes in methodology).

By calculating the number of people with MS on the caseload of each of the MS specialist nurse teams identified as red, amber or green, we can calculate the number of pwMS seeking care from MS specialist nurse teams within each category (Table 5).

Key findings:

- 64% of MS specialist nurse teams are having to work with caseloads above the recommended sustainable figure

- 79% of people with MS are living in areas where MS specialist nurses have caseloads in excess of 315. This compares to 69% of pwMS in 2018
- 447 WTE MS nurses are required across the UK to be able to meet the needs of everyone on their caseloads
- The current total of 298 WTE MS specialist nurses means that there is a shortfall of 149 WTE MS specialist nurses across the country. This correlates with the findings of the recent survey carried out by Rog et al (2021)¹¹.

Therefore, despite the increase in numbers of WTE MS specialist nurses since 2018, the reported increase in caseloads (ie, using self-reported caseload figures rather than estimates of prevalence) has offset the gain, and it is evident that MS specialist nurses are having to work harder than ever while likely meeting the needs of fewer pwMS than in previous years.

Table 4: Number of red, amber and green MS specialist nurse teams by country¹²

Country	Red	Amber	Green
England (n= 105)	20	43	42
Scotland (n=15)	3	9	3
S Wales (n=2)	0	2	0
N Ireland (n=3)	2	1	0
UK (n= 125) ¹³	25	55	45
UK %	20%	44%	36%

Table 5: Number of people with MS under the care of MS specialist nurse teams working within the red, amber and green definitions of caseload size

Country	Red	Amber	Green	Total people with MS
England	39,418 (35%)	46,584 (41.4%)	25,664 (22.8%)	112,451
S Wales	0	4,000 (100%)	0	4,000
Scotland	4,300 (23.6%)	11,237 (61.8%)	295 (1.6%)	18,182
N Ireland	5,100 (85%)	900 (15%)	0	6,000
Total	48,818 (34.7%)	62,721 (44.6%)	25,959 (18.5%)	140,633

¹¹ Rog et al (2021) determined a shortfall of 150 MSSNs across the 70 largest MS centres using PHE estimates of prevalence.

¹² No direct comparison available with previous surveys, as they all calculated the RAG rating by CCG and Health Board rather than by team.

¹³ Not every team who submitted responses supplied sufficient data to enable a RAG rating to be applied.



Section 4 Administrative support

Sufficient administrative support for an MS specialist nurse team is vital in order to ensure letters, referrals and so on are typed and dispatched in a timely and efficient manner. Support is also required to ensure MS specialist nurse appointments are booked, managed and recorded effectively, as well as (in some cases) triaging telephone calls to the team.

In addition to this type of secretarial support, MS specialist nurse teams who prescribe a range of disease modifying drugs (DMDs) also require a DMD coordinator who will assist in tracking DMD monitoring, prescription management, maintaining databases, and so on.

Previous work by the MS Trust has determined that every MS specialist nurse team should have 0.6 WTE administrative support per 1.0 WTE MS specialist nurse in order to optimise productivity (Mynors et al, 2016). Fuller (2021) has also highlighted the negative impact lack of administrative support can have on clinical time across the whole team.

Administrative support and DMD/MS coordinators are recommended as an essential member of the MS team within the NHS RightCare Progressive Neurological Conditions

Toolkit (2019). Paying a Band 6 or 7 MS specialist nurse to type letters and book appointments is an extremely inefficient use of resource.

Table 6 provides an overview of the administrative support available to MS specialist nurse teams as reported by respondents in the survey.

Key findings:

- Only 15.7% of teams have adequate administrative support equivalent to, or greater than, 0.6 per 1.0 WTE MS specialist nurse. These are almost exclusively in England
- 18.2% of MS specialist nurse teams have zero administrative support where MS specialist nurses are solely responsible for writing their own letters, etc
- Total administrative support available to MS specialist nurse teams across the UK is 99.6 WTE for 298 WTE MS specialist nurses; the required number of administrative staff/DMD coordinators for this number of MS specialist nurses is 178.8 WTE, giving a shortfall of 79 administrative roles across the UK. As numbers of MS specialist nurses increase, so must the number of administrative/coordinator roles in addition to addressing the current shortfall.

Table 6: Administrative and DMD coordinator support

	Total whole time equivalent administrative support	Total whole time equivalent DMD coordinators	No. teams with zero admin	No. teams with \geq 0.6 admin/DMD
England (n=102)	58.02	32.2	18 (17.6%)	17 (16.7%)
Scotland (n=14)	3.25	0.7	4 (28.6%)	0
S Wales (n=2)	0.8	0.7	0	1 (50%)
N Ireland (n=3)	2.8	1	0	1 (33.3%)
Total (n=121)	64.87	34.6	22 (18.2%)	19 (15.7%)



Section 5

Types of appointment offered by MS specialist nurse teams

Respondents to the survey were asked to indicate the type of appointments they currently offered to pwMS on their caseload.

The Covid-19 pandemic has significantly altered the type and proportions of different appointments that are offered by MS specialist nurse teams, with much higher numbers of telephone clinics and video consultations available than pre-pandemic. Some teams added comments to their responses to indicate that the number of home visits and/or satellite clinics they were currently able to offer have been reduced or stopped due to the impact of the pandemic on services.

Table 7 shows the number of MS specialist nurse teams offering different types of appointment.

Key findings:

- 100% of MS specialist nurse teams are offering telephone consultations
- 95.6% are offering face-to-face outpatient department (OPD) appointments (ie, 6 MS specialist nurse teams in England were not able to offer face-to-face OPD appointments at the time of answering the survey)

- 100% of Scottish MS specialist nurse teams are offering video consultations, compared to only 62% of English MS specialist nurse teams
- Less than two-thirds (64.5%) of MS specialist nurse teams across the UK are able to offer home visits
- 15 sites (12.4%) are unable to offer either home visits or ward visits, which inadvertently excludes people with the most advanced types of MS¹⁴ from being able to access face-to-face MS specialist nurse care and support.

This data shows that almost all MS specialist nurse teams were back to providing face-to-face outpatient appointments in August 2021, with 100% delivering telephone appointments.

36.5% of teams were unable to deliver home visits, and 33.1% were unable to offer ward visits. 12.4% of sites are unable to offer either home visits or ward visits, effectively excluding people with the most advanced MS from accessing face-to-face specialist care.

MS specialist nurse teams who are unable to provide home visits or ward visits have reported to us that this is due to either local NHS Trust policies and/or due to lack of capacity within their service¹⁵.

Table 7: No. of MS specialist nurse teams offering each type of appointment by country in August 2021

	OPD face-to-face	Telephone consult	Video consult	Home visit	Ward visit	Satellite clinic ¹⁶
England (n=102)	97	102	63	63	68	41
Scotland (n=14)	14	14	14	11	10	6
S Wales (n=2)	2	2	1	2	2	1
N Ireland (n=3)	3	3	1	2	1	2
Total (n=121)	116 (95.9%)	121 (100%)	79 (65.3%)	78 (64.5%)	81 (66.9%)	50 (41.3%)

¹⁴ ie, people who are housebound as a result of their MS.

¹⁵ Personal communications: MS Trust.

¹⁶ A satellite clinic is one delivered by MS specialists in a centre separate from their base. Most commonly, this would be an MS team from an acute NHS Trust delivering a clinic in a local community health centre or DGH, enabling people with MS in the locality to access their specialist care closer to home.



Section 6 Availability of other services

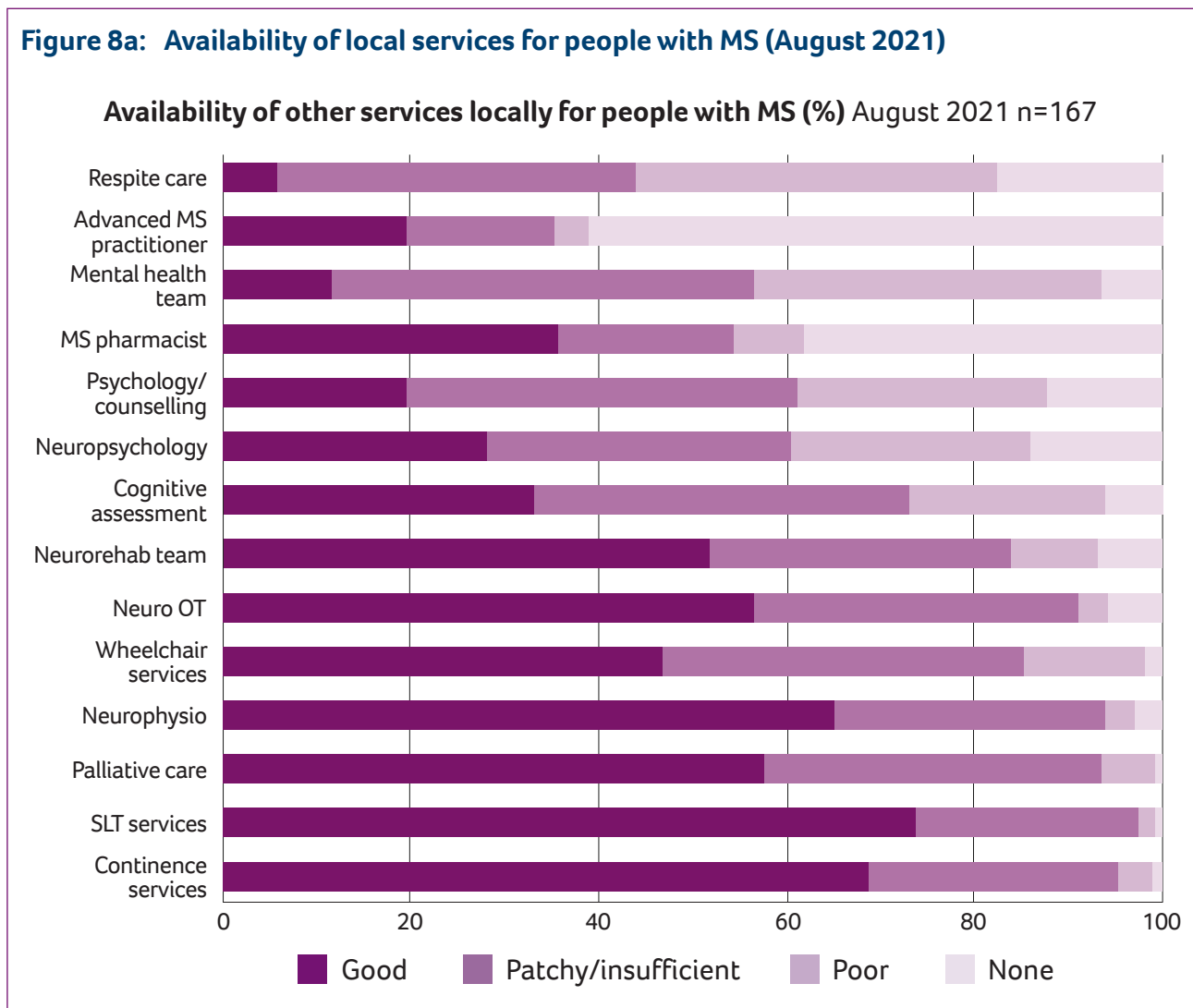
While the MS specialist nurse role is evidently critical in delivering the care that people with MS need, theirs is not the only role with a vital part to play in providing that care. There are a large number of other health and social care roles that are crucial to ensure all the needs of pwMS can be met as and when they arise. However, it is notoriously difficult to map other health professionals in the same way that we have done with MS specialist nurses.

In the 2016 mapping report (Mynors et al, 2016), a question included in the MS specialist nurse survey enquired about the availability of other roles locally. We have repeated this

in 2021 with a question incorporated within the individual MS specialist nurse survey (see below for methodology).

Respondents were asked to rate the availability of a list of services for pwMS in their locality. 167 respondents provided a rating for every service listed. The percentage of respondents for each rating is given, and numbers have been rounded to one decimal place.

Figure 8a: Availability of local services for people with MS (August 2021)





The same data was collected in the 2016 mapping survey. These results are shown in Figures 8a and 8b (the list of services rated in 2021 includes additional services to those listed in 2016).

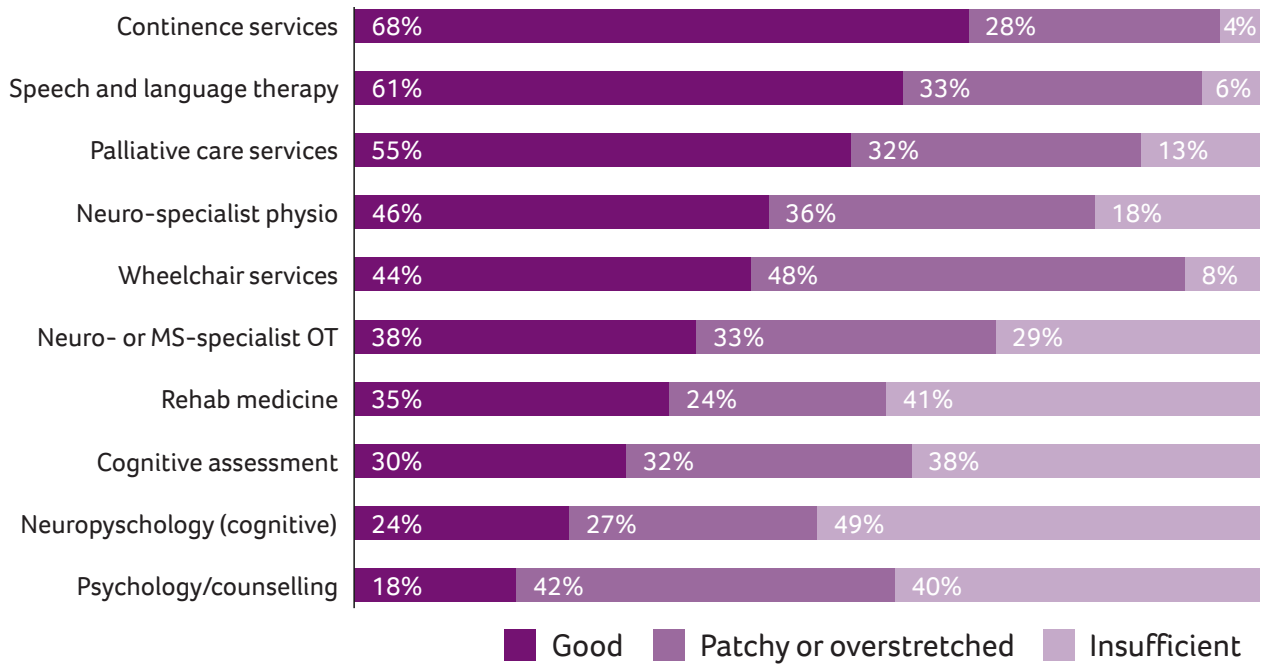
A question of this type can only give an indication of the availability and provision of the other services that pwMS need to be able to access. Further work to accurately map availability and capacity of these services is required.

Key findings:

- Speech and language services provided good access in both 2016 and 2021
- Continence services appear to be consistently well provisioned
- Access to psychology for pwMS was poor in 2016 and remains so in 2021, with only 20% of respondents reporting good access
- Access to respite services was not surveyed in 2016; however, with only 5.9% of teams reporting local access as good in 2021, current provision is clearly unacceptable.

Figure 8b: Availability of local services for people with MS (Mynors et al, 2016)

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



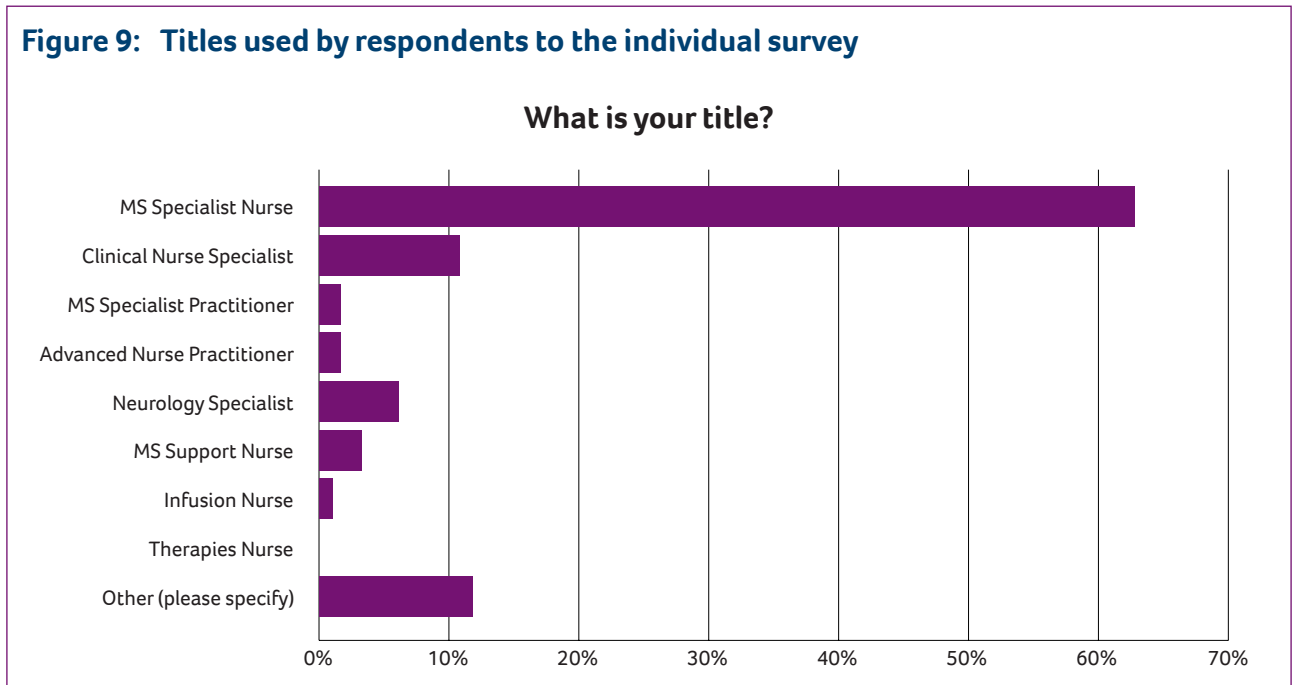


Individual survey results

Methodology

Questions were posed with the aim of developing greater understanding about succession planning requirements and training and development needs within MS specialist nurse teams. Data about the availability of other health professionals was also sought through this questionnaire, based on the 2016 mapping report (see Section 6 above). This survey was separate and subsidiary to the main survey and was instead aimed at individual MS specialist nurses.

Links to both surveys were emailed simultaneously to the 536 health professionals recorded on the MS Trust database. The links were also included in two consecutive mailings of the monthly MS Trust Health Professionals email, which is sent to 1,239 people. 176 responses were received.





Individual survey: overview of findings

Section 7

Demographics of respondents to the individual survey

Of the 176 respondents, 89% worked in England, 1% in Northern Ireland, 6% in Scotland and 4% in Wales.

63% of respondents used the title MS specialist nurse. The other titles used by respondents are shown in Figure 9.

- Respondents were asked to give their Banding:
 - » Band 6: 23%
 - » Band 7: 67%
 - » Band 8 (a, b and c): 9%
- 54.5% of respondents were working full time, with the range of contracted hours varying between 14-37.5 per week
- 89% of respondents work solely with pwMS. Of those who covered more than one condition, these included epilepsy, Parkinson's disease, motor neurone disease, Huntington's and multiple system atrophy (MSA)/progressive supranuclear palsy (PSP)
- Median reported caseload per respondent (n = 160) was 440 (range 50-1,200).

Section 8

Non-medical prescribing

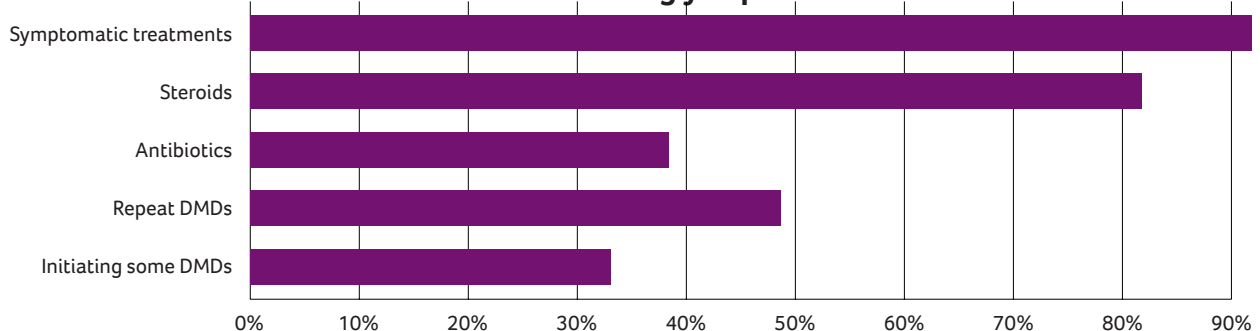
Respondents were asked whether they were qualified as, or training to be, a non-medical prescriber. 44 respondents (25%) reported that they were currently registered non-medical prescribers, with a further 8 respondents (4.5%) training to become one. However, only 39 of the 44 MS specialist nurses who are registered non-medical prescribers are currently prescribing.

This represents a decrease in numbers since 2016 (Mynors et al, 2016), when 60 respondents were qualified non-medical prescribers. It is unclear from the data collected why there has been such a significant reduction in the number of MS specialist nurses registered as non-medical prescribers, although this could be as a result of the number of experienced MS specialist nurses who have retired from MS nursing over the last 5 years. The Optimum MS Pathway (Coles et al, 2019) recommends routine prescribing should be carried out by non-medical prescribers, acknowledging that this will require an increase in the number of MS specialist nurses.

Non-medical prescribers reported that they prescribe a range of different treatments, as shown in Figure 10. Over 80% of MS specialist nurse non-medical prescribers prescribe predominantly symptomatic treatments and high-dose steroids to help manage relapse. Smaller numbers of MS specialist nurses prescribe antibiotics or are involved in writing DMD prescriptions.

Figure 10: Types of medications prescribed by MS specialist nurse non-medical prescribers (n=39)

If you are a qualified non-medical prescriber please indicate which of the following you prescribe



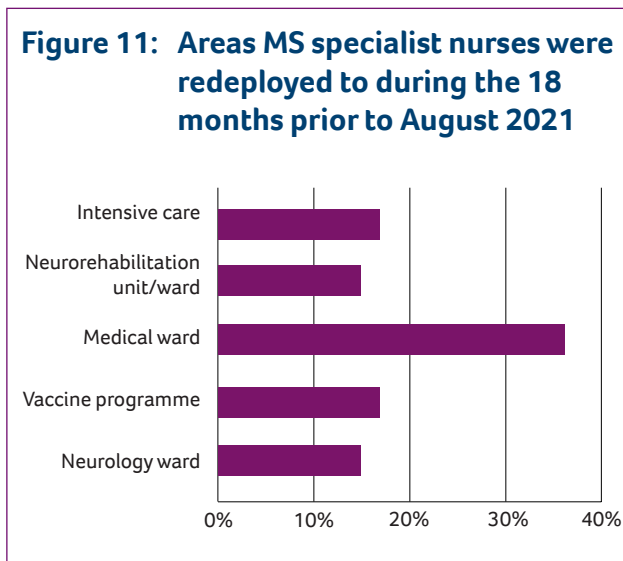


Section 9 Redeployment during Covid-19 pandemic

Many MS nurse teams were impacted by redeployment during the peak of the Covid-19 pandemic in 2020-21.

73 (41.5%) respondents reported being redeployed during the 18 months prior to August 2021. Figure 11 shows the areas these MS nurses were redeployed to, with the majority being redeployed to medical wards.

Of those who were redeployed, the mean time spent away from the MS specialist nurse service was 11.2 weeks per respondent, although this varied from a few hours to full-time working elsewhere for a number of months.



This reduction in MS specialist nurse workforce at a time when pwMS were struggling to access services can only have exacerbated the difficulties pwMS were already facing.

Given the extensive backlog now being faced by MS specialist nurse services (Fuller, 2021; MS Society, 2021), it is strongly recommended that MS specialist nurses are not redeployed away from MS care in future.

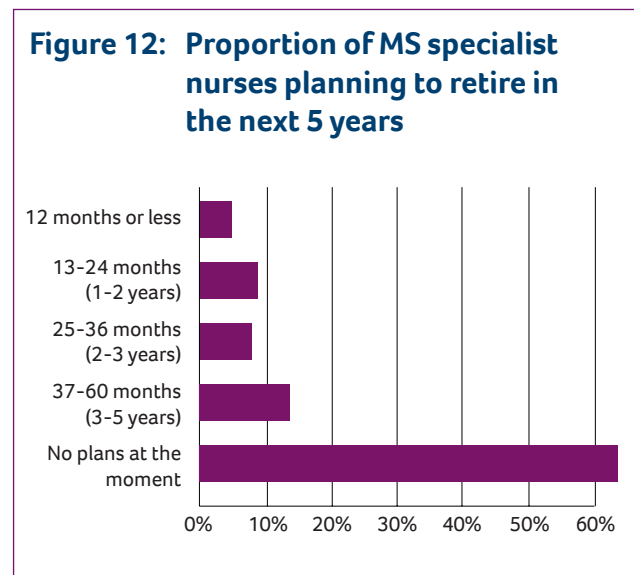
Section 10 Training and development needs

As well as intermittent episodes of redeployment, MS specialist nurse services are facing high numbers of staff departures over the next 2-3 years.

25 (14.2%) respondents are planning to retire in the next 2 years, with a further 39 (22.2%) over the next 5 years (in total, over one-third of the current workforce). In addition to those MS specialist nurses who are planning to retire, 9 (5.1%) are actively looking for a role outside MS, with a further 33 (18.8%) considering a move.

While it is expected that, as each post becomes vacant, recruitment will be prompt and effective to ensure minimal lack of provision for pwMS, there is inevitably going to be a significant loss of expertise from the MS specialist nurse workforce. The need for support for new MS specialist nurses, in terms of their training and development, will become increasingly important over the next few years.

Induction and training for the new MS specialist nurse is paramount to ensuring they are able to develop their skills, knowledge and expertise as they develop from novice to expert MS specialist nurses.





MS nurse training

The MS Trust runs a week-long *Foundation in MS Care* course aimed at all new in post MS specialists (nurses and therapists). The course is accredited at Level 6 and 7 with Birmingham City University, and students who register with the University gain 20 credits towards their BSc or MSc degree. This training is aimed at helping novice MS specialists gain knowledge and confidence to progress towards becoming specialist practitioners.

Some 149 (81.4%) respondents have attended the MS Trust Foundation Module, with a further 14 (8%) booked to attend in the 12 months from August 2021.

The MS Trust will have trained 163 (89.4%) respondents by November 2021.

Feedback from MS specialists who attended the Foundation in MS Care in March 2021:

“Overall, it was an amazing learning experience with top-quality lecturers. Precise and updated information that we all appreciated.”

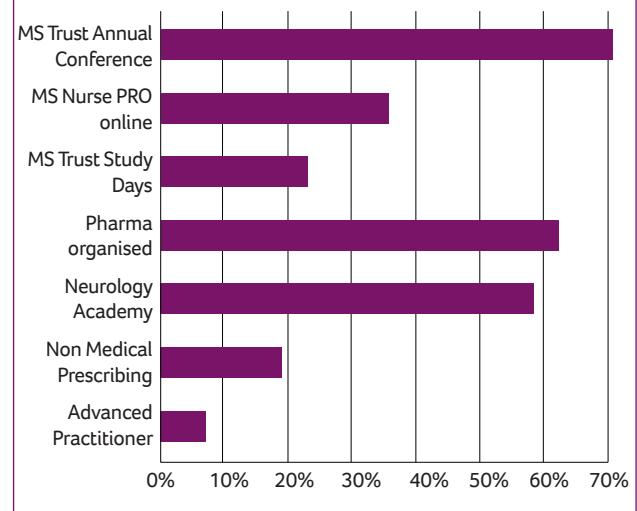
“By far the best training/educational programme I have ever been fortunate enough to go on.”

“So impressed with the breadth of topics covered – really comprehensive and relevant – as well as being practical enough to be able to utilise. Has helped me grow in confidence.”

“Thank you so, so much. I never knew how much the MS Trust does. It’s an amazing organisation that we (as healthcare professionals) and our patients are lucky to have.”

There are an increasing number of other training providers aiming courses at MS specialist nurses (this is less the case for therapists). However, the MS Trust remains the leading provider of MS specialist education, with 125 (71%) respondents reporting they have attended the MS Trust Annual Conference during the preceding 3 years (Figure 13). This is a higher proportion of MS specialist nurses than have attended any of the other training available.

Figure 13: Training attended by respondents in the last three years





How the MS Trust are responding to the findings of this survey

As is evident from the findings of this report and that of others that have been recently published (Fuller, 2021; MS Society, 2021; Rog et al, 2021), there remains a lot of work to be done to ensure that everyone living with MS has access to the specialist care and support they need at the right time and in the right place.

The MS Trust is working hard to ensure that no one has to manage MS alone.

Our initiatives include:

Specialist nurse programme

- The MS Trust Specialist Nurse Programme funds MS specialist nurse posts, providing training and supporting service improvement across sites where a permanent, additional MS specialist nurse post is established
- To date, we have funded 8 sites, with a further 2 sites expected to be established before July 2022
- The Specialist Nurse Programme targets sites with the greatest need, i.e., those with the highest caseloads per WTE MS specialist nurse.

Advanced MS champions pilot

- Following on from the findings of MS Forward View (Croft et al, 2016) the MS Trust established a pilot programme, funding 6 advanced MS champion roles across the UK. These roles have been filled by MS nurses and therapists
- The impact of these roles has been evaluated and a report will be published in early 2022
- There is already interim evidence that the advanced MS champion roles not only improve outcomes and quality of life for people with advanced MS and their families, but are also financially viable, saving the NHS approximately £225,000 per annum in avoidable admissions alone.

Business case support

- The MS Trust is always keen to support MS teams in developing their services and writing business cases. There is a list of online resources that the MS Trust have developed to help MS teams with this (see below)
- The MS Trust Health Professionals team also provide ad-hoc one-to-one support for MS teams in this regard (email us at: hpteam@mstrust.org.uk).

MS specialist nurse competencies

- The MS Trust is working with the UK MS Specialist Nurse Association (UKMSSNA) to write and publish a set of MS specialist nurse competencies. These are expected to be published during the first half of 2022
- The MS Trust has also worked with the Therapists in MS group (TiMS) to facilitate publication of a set of allied health professional competencies (TiMS, 2020).

MS Trust annual conference

- Training, networking and keeping up to date for MS specialists (therapists as well as nurses) is vital in such a fast-moving speciality. The MS Trust is the leading provider of MS specialist education and has continued to deliver the Annual Conference every year, even during the worst period of the pandemic. We have approximately 300 delegates attending each year
- Funding is made available to the majority of delegates through MS Trust bursaries.

Study days

- The MS Trust holds at least one virtual study day each year. These are offered free of charge to health professionals and cover a wide range of topics
- Recent topics have included *Mental health and Palliative care in MS*.

Foundation module

- The MS Trust Foundation in MS Care module is highly regarded and always oversubscribed. We deliver a week-long,



residential course for all new in post MS specialists, giving them the knowledge and expertise to move from novice towards confident specialist

- The course is accredited by Birmingham City University for students who choose to go on and do the assignment, giving them 20 credits at either Level 6 or 7
- The MS Trust funds between 15-18 places on each course for MS specialist nurses and therapists.

Enquiry team support

- The information and enquiry team produce a great deal of information, which is used by people living with MS as well as health professionals. This includes booklets that can be ordered or downloaded from the website, free of charge, as well as constantly updated and comprehensive information across the website
- The enquiry team answer queries directly from people living with MS, either by telephone or email, and have continued to do so throughout the pandemic, at a time when MS services were struggling to maintain staffing levels
- The map 'MS services near me' (MS Trust, 2021) is available for health professionals and people living with MS alike to find their local MS teams and to understand how they can access care provided by those teams. The map is updated whenever new information is forwarded by MS teams, and all data within the map is reviewed and updated every 2 years as part of the MS nurse mapping survey.



Conclusions

This report summarises the data collated from the MS specialist nurse mapping surveys, giving a snapshot of MS specialist nurse provision across the UK as of August 2021.

While there has been an increase in numbers of MS specialist nurses employed since we last undertook the mapping exercise in 2018, the caseload per WTE MS specialist nurse has also increased significantly, meaning that 4 out of every 5 people with MS must access care from an MS specialist nurse with an unsustainable caseload. While this, in part, reflects the change in survey methodology since 2018, the current caseload values are more likely to accurately reflect MS specialist nurse workload.

Given the increase in workload identified, it is evident that MS specialist nurses are having to work harder than ever to try and meet the needs of pwMS. Inevitably, many MS specialist nurse teams will be unable to meet the needs of everyone with MS on their caseloads, and an urgent review of MS specialist nurse capacity and resource within each MS specialist nurse team is required, with a view to engaging Directorate Managers and Commissioners to increase MS specialist nurse resource.

We estimate that 149 additional WTE MS specialist nurse posts are required across the country to ensure that pwMS get the care and support they need at every stage of their condition, thereby improving their quality of life and long term outcomes.



Recommendations

1. MS nurse teams continue to be significantly under-resourced across the country. MS specialist nurse team leads, Commissioners, Directorate Managers, etc, should review local MS specialist nurse provision and upscale services appropriately. Costs of increasing MS specialist nurse posts will be offset by the reduction in use of unscheduled care and emergency services by pwMS gained from effective and efficient MS specialist nurse working
2. For every full-time MS specialist nurse role recruited, there should also be provision for 0.6 WTE administrative support for that post holder to ensure efficient use of resource
3. As MS specialist nurses retire, recruitment must be prompt and effective to minimise lack of provision for pwMS. It is recommended that the incoming MS specialist nurse be recruited before the retiring MS specialist nurse leaves, to ensure a transition accompanied by effective training and handover for the new MS specialist nurse
4. Given the extensive backlog now being faced by MS specialist nurse services, it is strongly recommended that MS specialist nurses are not redeployed away from MS care in future
5. It is essential that MS specialist nurse teams are able to deliver home visits and are able to see pwMS admitted onto hospital wards
6. MS specialist nurse competencies should be revised and updated to inform training provision and recruitment for MS specialist nurses. We are working with the UKMSSNA on these and expect them to be completed by spring 2022
7. There needs to be a UK-wide agreement on core datasets to be collated by each MS service, which would help greatly in facilitating commissioning of MS services to meet the needs of everyone with MS
8. Further work to accurately map availability and capacity of other essential services across health and social care is required, particularly to build our understanding of the availability and capacity of allied health professionals across the UK
9. Further work to determine the impact of the lack of MS neurologists across the UK is urgently needed as this affects neurologists but also the rest of the MS team and of course, pwMS themselves
10. Availability of respite care for pwMS across the UK is inadequate and needs to be reviewed as a matter of urgency.



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Resources

- The MS Trust have produced the **Guide to writing a strong business case**, which can help when constructing a business case locally. In addition, there is a tool that can be worked through to help MS specialist nurse teams calculate their capacity and better understand the resources they need to deliver the care required. The **Capacity planning tool** can be used to understand how many appointments can be offered given current capacity and to model what could be delivered if capacity changes. [Capacity planning and writing a business case | MS Trust](#)
- Reports from the MS Trust **GEMSS¹⁷ project** ([Generating Evidence in MS Services reports | MS Trust](#)). These reports date from 2015, but are still relevant and provide useful evidence and benchmarks around the role of the MS specialist nurse
- The reports written as a result of the work around MS Forward View in 2016 contain specific recommendations as to how MS services can improve the care they deliver in these areas: [MS Forward View | MS Trust](#). These include **Improving services for people with Advanced MS and Improving the efficiency of disease modifying drug provision**
- Information about the **Specialist Nurse Programme**, which is funded and supported by the MS Trust ([Specialist Nurse Programme | MS Trust](#)). If you would like more information about how the MS Trust can support your team or service to develop, please email us (hpteam@mstrust.org.uk)
- Information about the **Advanced MS champions pilot** and ongoing funding and support for sites wishing to establish their own AMSC lead is also available: [Advanced MS Champions programme | MS Trust](#)
- Information about the **MS Trust Foundation in MS Care** (Development Module) is located within the Health Professionals Section of the website: [Foundation training \(Development Module\) | MS Trust](#). This is regularly updated with information about funding and how to book
- All you need to know about the **MS Trust Annual Conference** can be found at these links: [MS Trust Conference | MS Trust](#). You can download the programme, book your place, see if you are eligible for funding towards a place, find out about how to submit a poster and review past Conferences
- Information about upcoming **MS Trust Study Days** can be found here: [Study days | MS Trust](#)
- Make sure you are signed up to receive the **MS Trust monthly email newsletter for Health Professionals**. This will let you know well in advance of any forthcoming events or publications. You can sign up using this [form](#)
- **MS Trust Publications** can be viewed and downloaded from the shop, free of charge. Health professionals can create an account, which enables you to order multiple copies to give to pwMS should you wish to: shop.mstrust.org.uk/
- **MS Trust website** provides a resource covering every aspect of MS: mstrust.org.uk/about-ms and mstrust.org.uk/a-z
- **MS Map of Services** is available on the website for health professionals and pwMS alike. It is possible to search for MS specialists by locality and provides referral criteria and contact details for local teams: mstrust.org.uk/map
- **The Enquiry Service** can be contacted by email, phone, through social media or even by post, and will provide evidence-based information for pwMS and health and social care professionals: mstrust.org.uk/infoteam

¹⁷ Generating Evidence in MS Services (GEMSS).