

MULTIPLE SCLEROSIS SPECIALIST NURSING IN THE UK 2021:

Plain language summary



This is a plain language summary of a report originally published on the MS Trust website www.mstrust.org.uk

People with multiple sclerosis (often shortened to MS) have concerns about access to specialist MS services and health professionals with a special interest and expertise in MS. To understand more about these concerns, 133 services and 176 MS health professionals took a survey with questions about them and their MS services.

If you would like to access the original nurse mapping report for 2021, this can be found on our website at www.mstrust.org.uk/health-professionals/resources/service-development/ms-nurse-mapping

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Plain language executive summary

- We found that there are 360 specialist MS nurses working across the UK. When we factor in the hours each individual works, this is equal to 298 nurses working full time - the **whole time equivalent (WTE)**.
- We asked MS nurses to tell us about how many people they are responsible for looking after, known as their caseload. We know that a typical MS nurse can provide safe, high-quality care with 315 people on their books, we call this the **sustainable caseload figure**.
- On average, an MS nurse's caseload is 472 people with MS, this is higher than in the 2018 survey and much higher than the sustainable caseload figure.
- Around 8 in 10 people with MS live in areas where caseloads are higher than the sustainable number. In 2018, this was around 7 in 10.
- For every MS nurse in the UK to have a sustainable caseload we would need an extra 149 MS nurses working full time.
- When MS nurses have unsustainable caseloads, it becomes harder to provide safe, high-quality care to people with MS. For example, we know that seeing people who have become suddenly unwell as soon as possible can help stop them needing to go into hospital, but when caseloads are high this becomes much more difficult. There may be no free appointments or there may be multiple unwell people who all need seeing but not enough time in the day to see them all. This puts MS nurses in an impossible position, makes it difficult to intervene early and makes it harder for people with MS to receive the best possible care.
- People with advanced MS can find it particularly difficult to access clinic appointments, and they often find it easier to be seen on the ward or at home. Unfortunately, 1 in 10 teams are unable to offer both ward visits and home visits and 1 in 3 teams can only offer one of these. This can exclude people with the most advanced forms of MS from accessing face to face care.
- Around 1 in 5 MS nurse teams have no administrative support. Providing this support can help MS nurses use their time more effectively to help people with MS.
- Only 4 in 10 MS specialist nurse teams have an up-to-date database that covers all their patients.
- Most MS nurse teams (96%) had returned to providing face to face outpatient appointments by August 2021. All teams were providing telephone appointments.
- Workforce planning is going to be an important issue facing MS nurse teams in the future as a third of MS specialist nurses are thinking about retiring in the next 5 years. This is an important consideration due to the training and experience MS nurses have, which is not easily replaced.
- The MS Trust is a leading provider of MS specialist education, helping to keep health professionals informed and up to date.
- We are the only MS charity working directly with NHS sites to help fund and recruit MS specialist nurses and advanced MS champions (see p5-6) in the areas that need them most.



Plain language summary - multiple sclerosis specialist nursing in the UK 2021: results from the MS Trust nurse mapping survey

What is the aim of the nurse mapping survey?

The MS Trust surveys multiple sclerosis (MS) nurses every two years to investigate MS specialist nurse services across the UK. When the first report was published in 2014, we knew that MS nurses were a vital part of the teams supporting people with MS but there was little evidence to back this up. The MS Trust wanted to change this and launched the Generating Evidence in MS Services (GEMSS) project to investigate the role of MS nurses, where they worked and what their caseloads looked like. This year's survey was due to take place in 2020 but was delayed due to Covid-19.

Key messages

- 8 in 10 people with MS live in areas with unsustainable caseloads.
- MS nurse caseloads are growing faster than the number of MS nurses. Most MS nurses in the UK are working with unsustainable caseloads. This makes it harder to provide safe, high-quality care to people with MS.
- People with the most advanced forms of MS may be the least likely to receive specialist MS care. They can be excluded from face-to-face care when teams are unable to provide ward or home visits and they are the first group to be lost from unsustainable caseloads.
- For every MS nurse in the UK to have a sustainable caseload we would need 1.5 times the current MS nurse workforce, equivalent to an extra 149 MS nurses working full time.

What did we do?

Surveys were emailed to health professionals on the MS Trust database and included in our health professionals' newsletter, containing questions about the number of people with MS on their caseload, what appointments they were able to offer, and what administrative support they had available. We also included a separate questionnaire for individual nurses about their training and if they had any plans to retire. We had responses from 133 MS nurse teams and 176 individual responses to the second questionnaire. The data was collected and analysed to produce the nurse mapping report.



What did we find?

We found that there are 360 specialist MS nurses working across the UK. When we factor in the hours each individual works, this is equal to 298 nurses working full time - the **whole time equivalent (WTE)**. This is more than in 2018 when there were 250 WTE MS nurses.

However, there has also been a large increase in the number of people MS nurses have on their books – their caseload. We know that a typical MS nurse can provide safe, high-quality care with 315 people on their books (we call this the **sustainable caseload figure**) but on average, an MS nurse's caseload is 472 people with MS. This is even higher than the 2018 average caseload of 391.

Each MS specialist nurse team provided their team caseload and the number of MS nurses working within the team. As part of our analysis, we calculated the number of WTE MS nurses per team and the average caseload per WTE nurse for each team. We then allocated a traffic light rating of red, amber, or green for the team (**RAG**):

RED: Average caseload per WTE is more than twice the sustainable caseload (ie >630 per WTE)

AMBER: Average caseload per WTE is > than 315 and less than or equal to 630

GREEN: Average caseload per WTE is 315 or less

Using the RAG rating we can see that 8 in 10 people in the UK live in red or amber areas where nurses' caseloads are higher than the sustainable caseload figure, which has increased from 7 in 10 in 2018. This varies throughout the UK: All people with MS in Northern Ireland live in areas where caseloads exceed the sustainable figure, with more than 8 in 10 people living in a red area. While people in England are the most likely to live in a green area, this is still only the case for less than 1 in 4 people.

Despite having more MS nurses, caseloads are growing faster than the number of nurses, causing increasingly unsustainable workloads. Where this is the case MS nurses will be unable to meet the needs of everyone on their caseloads. Where caseloads are significantly higher than 315, nurses may be unable to provide any care to some of the people on their caseloads – this is most likely to affect people with advanced MS.

The recommended, sustainable caseload figure is **315** people with MS per WTE MS nurse.

This figure assumes that an MS nurse's workload:

- Covers a mixture of urban and rural areas.
- Supports people with MS from diagnosis to the end of their life.
- Has administrative support of 0.6 WTE per nurse (ie. equivalent to 3 days admin support per full-time MS nurse).

When this is not the case, the sustainable caseload figure should be reduced as this usually makes a caseload more complex.



For every MS nurse in the UK to have a sustainable caseload we would need 1.5 times the current MS nurse workforce, equivalent to an extra 149 MS nurses working full time.

Other findings

Administrative support

For things like letters and referrals to be typed up and sent out promptly, MS nurses require administrative support. This support can also help with managing appointments and other phone calls that come into the team. The recommended amount of support is 0.6 WTE per WTE MS nurse, however less than 1 in 5 teams has this level of support available. This means that MS nurses have less time available to see people with MS while they manage these administrative tasks.

Types of appointments

During the pandemic many teams moved towards providing telephone or virtual appointments instead of face-to-face outpatient appointments. By August 2021, more than 9 in 10 teams had returned to offering outpatient appointments and all teams were offering telephone appointments.

We also asked about other types of appointments such as ward visits or home visits, as these are particularly important for people with advanced MS who can find it difficult to access clinic appointments. Unfortunately, 1 in 10 teams are unable to offer both ward visits and home visits and 1 in 3 teams can only offer either ward visits or home visits. This can exclude people with the most advanced forms of MS from accessing face to face care.

Availability of other services

MS nurses reported that speech and language services and continence services were the most likely to have good availability in the area they were working in, and this is similar to what we found in 2016. Other services had a more mixed picture with good availability in some areas and patchy or poor availability in others. Access to psychological services and respite services were particularly poor with only 2 in 10 nurses reporting good access to psychology and less than 1 in 10 for good access to respite care.



Key findings from the individual survey

- Around 1 in 4 MS nurses are qualified as (or in training to become) non-medical prescribers. This means that they can prescribe medicines such as high-dose steroids to manage relapses. Less than half of non-medical prescribers prescribe disease modifying drugs (DMDs).
- Around 4 in 10 MS nurses were redeployed during the pandemic. On average they were away from MS services for 11 weeks. This made accessing MS services more difficult for people with MS. Due to the backlog in MS services it has been strongly recommended that MS nurses are not redeployed in the future.
- High numbers of nurses are considering leaving MS services in the next 5 years. 1 in 3 MS nurses are planning to retire in the next 5 years and 1 in 5 MS nurses are either considering or actively seeking roles outside of MS. This means workforce planning will be an important consideration due to the training and experience MS nurses have, which is not easily replaced.

What is the MS Trust doing?

As we can see from this report, there is a lot that needs to be done to make sure that everyone with MS is able to access the high-quality care they need and deserve. The MS Trust is working hard to ensure that no one has to manage MS alone. These are some of the things we are doing to support health professionals and people with MS:

Specialist nurse programme

The MS Trust Specialist Nurse Programme funds MS nurse posts, provides training and supports MS teams in improving their services. To date, we have funded eight nurse posts, with two more expected to start before July 2022. This programme uses information from the survey to target sites with the greatest need, ie those with the highest caseloads per whole time equivalent MS specialist nurse.

The MS Trust is the only MS charity working directly with NHS sites to help fund and recruit MS specialist nurses and advanced MS champions in the areas that need them most.

Advanced MS champions pilot

We know that people with advanced MS can often find it difficult to access the support they need, and their needs may be different from other people with MS. The MS Trust established a pilot programme to fund six advanced MS champion roles across the UK which were filled by MS nurses and therapists.



We are publishing a report on this in 2022, but early findings suggest that the advanced MS champion roles not only improve outcomes and quality of life for people with advanced MS and their families, but they also help the NHS save money by preventing unscheduled or emergency admissions to hospital.

Business case support

The MS Trust is always keen to support MS teams in developing their services and writing business cases. We have a list of online resources that we have developed to help MS teams with this.

MS specialist nurse competencies

The MS Trust works with the UK MS Specialist Nurse Association (UKMSSNA) to write and publish a set of MS specialist nurse competencies – these are the essential skills and knowledge needed to work as an MS specialist nurse. 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.

MS Trust annual conference

Training, networking, and keeping up to date 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 and funding is made available to most 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, most recently: Mental health and Palliative care in MS.

What is an Advanced MS Champion?

An Advanced MS Champion is an MS professional (a specialist nurse or therapist) who focuses on caring for people with advanced MS. They aim to support people with MS to live as independently as possible and to help improve their quality of life.

Some of the ways they provide this support include:

- Co-ordinating their care across different services and specialities.
- Working across boundaries within the NHS and social care to provide joined up care.
- Providing proactive, specialist and individualised care for people with advanced MS, helping them understand their condition, manage symptoms, and identify problems.



Foundation module

The MS Trust Foundation in MS Care module is 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 module is highly regarded, and we are always oversubscribed.

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' 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.



Getting in contact

The MS Trust believes nobody should have to manage multiple sclerosis alone. We are here to support you. We can answer your questions about multiple sclerosis and life with the condition. We are also keen to work with health professionals to improve their services and better support people with MS.

Our free enquiry service:

If you have a question about MS, call our free Enquiry Service on **0800 032 38 39**.

Our Enquiry Service is for everyone, from people with MS to health professionals. We are available from **Monday to Friday** (except UK bank holidays) from **9am to 5pm**. Outside these hours you can leave us a message and we will get back to you as soon as we can.

You can also email at ask@mstrust.org.uk

Speak to the team

General Enquiries

Call us: 01462 476700

Email us: hello@mstrust.org.uk

Write to us:

MS Trust,
Spirella Building,
Bridge Road,
Letchworth Garden City,
Hertfordshire, SG6 4ET

Health Professionals

Email us: hpteam@mstrust.org.uk

Queries about the plain language summary

If you have queries about this summary, please contact:
aurora.sharrock-haynes@mstrust.org.uk or hpteam@mstrust.org.uk

Accessing the original nurse mapping report

If you would like to access the original nurse mapping report for 2021, this can be found on our website at: www.mstrust.org.uk/health-professionals/resources/service-development/ms-nurse-mapping