My MS My Needs 2022

Survey findings for the UK

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April 2023

Let's stop MS **together**

Contents

1. Introduction

Thank you

We would like to start this report with a huge thank you to everyone who completed the 2022 My MS My Needs survey. Over 6,500 people from across the United Kingdom gave their time to help build a better understanding of the needs of people with MS, and we are grateful to them all.

The 2022 survey came three years after our previous My MS My Needs survey, and that time witnessed significant global and local challenges due to the covid pandemic and the associated effects of such a pandemic. This work helps us understand some of the impacts of this time on the MS Community.

How we use this data and its impact

The My MS My Needs (MMMN) survey started in 2013 and this, the most recent survey, was the fourth to be undertaken. The information we collect in these surveys has been valuable in so many ways, for example, in work with healthcare professionals, in campaigns and to shape new services. We also use the data to shape our goals and strategies. Your responses really do create awareness and provide evidence for change.

What you tell us via the survey also provides us with evidence to use in government consultations and inquiries. Some of the ways we used the 2019 survey includes:

- ‘Shaping Future Support: the health and disability green paper’; our consultation response used information around employment, including numbers of people working, and employment support people received to stay in work.

- The MS Society submission to the Work and Pensions Committee 2022 inquiry ‘Plan for jobs and employment support’. This included information about the impact of MS on working-age adults’ ability to stay in employment.

- The MS Society’s Breaking Point campaign, 2022, used survey data to show that people with MS are more likely to receive a DMT if they see a specialist to demonstrate how important it is to be able to access them.

- Data was provided to the Health & Social Care Committee 2022 inquiry ‘Integrated Care Systems: autonomy and accountability’ to illustrate the differences in access to Disease Modifying Treatments (DMTs) between different groups.

- The data is also used by teams based in each of the devolved nations, with My MS My Needs data being cited in most government consultations and in many meetings with politicians.

What the 2022 survey tells us about the needs and experiences of the MS Community

There have been changes to the numbers of people on a DMT. Between the survey conducted in 2016 and 2019, the numbers of people on a DMT increased but between 2019 and the 2022 survey, the numbers decreased. The most likely explanation for this decrease is the disruption to health services caused by the outbreak of the Covid pandemic.

There are around 4 in 10 (43%) people with relapsing forms of MS not currently taking a DMT. When we consider people with primary progressive MS, 85% are not currently on a DMT. New treatments for some types of progressive MS have become available since our last MMMN survey, such as Siponimod for active secondary progressive MS in 2020. However, the majority of available DMTs are for treating relapsing remitting MS.

Since the 2016 survey, we can see that unmet needs are increasing and this report gives detailed evidence of some of those needs.

We can see that there is a significant degree of financial hardship for some members of the MS Community. The effects of that hardship are felt across their lives and include a reduced ability to manage their MS effectively. Of those who reported that they were struggling financially:

- 23% of respondents are going without care and support
- 8% are going without medicines or health services
- 30% identified that their MS had become worse

This is obviously of deep concern to us and, we're sure, the whole MS Community. We will use this evidence to raise awareness, and campaign, to seek improvements in this situation.

Taking Action

Across the next three years, we will use the information provided by you to:

- Make in-roads to the unacceptable and rising levels of unmet need
- Work with the government and health services to tackle barriers to timely and effective care
- Fund research into treatments focussed on stopping the progression of MS
- Campaign and raise awareness of the needs of people with MS
- Tailor our own services to meet the range of needs identified here
- Raise awareness of both the levels of financial hardship and the effects of such hardship, specifically for the MS community

The survey is hugely important in our work for the MS community and we owe a debt of gratitude to everyone who took part in this piece of work. We look forward to continuing to work together to improve the lives of people with MS across the UK.

Nick Moberly
Chief Executive Officer

2. About the My MS My Needs Survey

There are an estimated 134,790 people living with MS in the UK and the MS Society is committed to understanding, and highlighting, the needs and experiences of the MS Community. As part of this commitment we undertake this large-scale survey every three years; these have taken place in 2013, 2016, 2019 and this, the most recent survey, was undertaken in 2022.

The survey is one of the largest collections of patient-reported data representing the MS Community. However, the survey is a snapshot of the respondents' lived experiences, at the time of surveying. Also, while a significant number of people responded, this is only a small proportion of the MS Community. However, the data from these surveys are hugely important in building our understanding of how people with MS feel about their treatment, care and support.

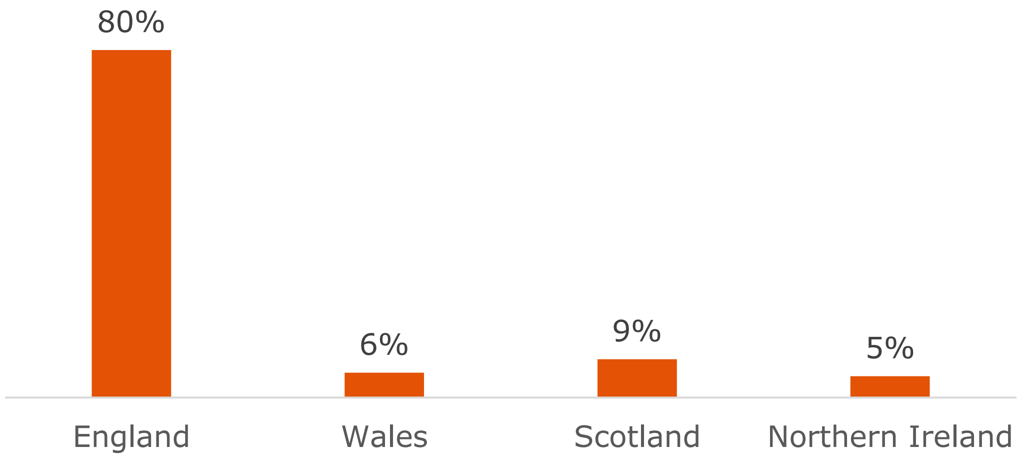
There follows a breakdown of some key information on who responded to the 2022 survey.

Number of respondents (UK)

A total of 6,697 people responded, and they were spread across the UK:

- England 5,347
- Wales 372
- Scotland 605
- Northern Ireland 352
- Other location *or* location not completed (21)

Figure 1: % of respondents across each nation of the UK



When considered as proportion of respondents, Figure 1 illustrates this across the UK nations[1]. This broadly mirrors the proportions responding in 2019.

The significant number of respondents results in rich and detailed data to inform policy, practice, and future research activities. However, the response rate to this

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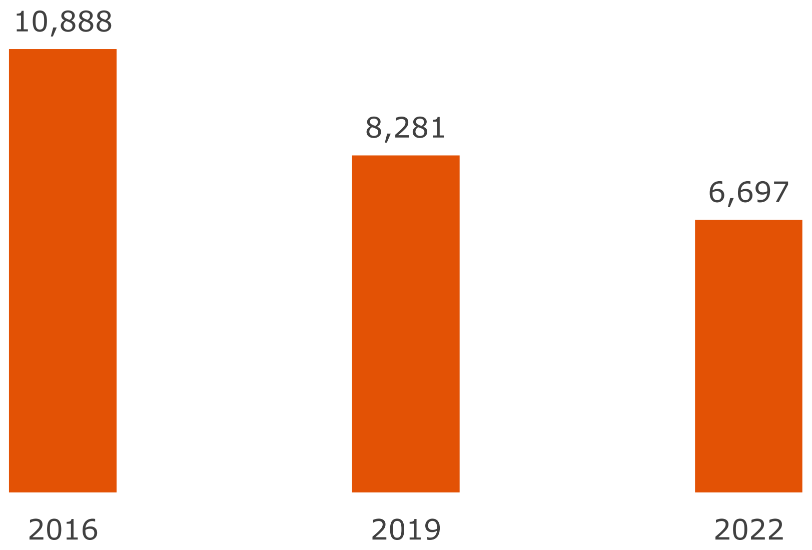
[1] There were also responses from the Isle of Man and the Channel Islands totalling less than 5% of 6686 responses (11 missing responses to this question).

survey does continue a pattern of reducing numbers of responses. Decreasing engagement is affecting most areas of social research and our experience here reflects that challenge. Figure 2 shows the pattern in response rates from 2016 to 2022 (we also estimate that 2013 was around 10,500).[2]

Figure 2: Number of respondents by year

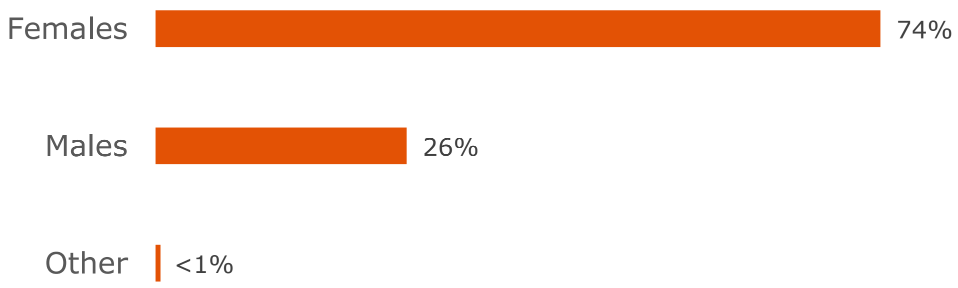


Gender of respondents (UK)

The gender profile of respondents has remained fairly static over the survey years, in the 2022 survey, 26% of respondents were male and 74% female. The third bar on the chart captures a range of other responses, as follows: 17 people who preferred not to say which gender they identify with; 10 people who identified as non-binary; and three respondents who preferred to use their own term.

The split between female and male largely mirrors MS Society estimated prevalence figures for 2022 (73% female, 27% male).

Figure 3: Gender of respondents



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[2] The exact figure for the 2013 work has not been retained but it exceeded 10,000 so have used an estimate.

Ethnicity

96% respondents identified as White, 3% as Black, Asian or mixed other ethnic groups and, 1% preferred not to say. This reflects the demographic profile of the 2019 survey respondents.

Sexuality

5% of respondents identified as LGBTQIA+, 92% straight/heterosexual, and 3% preferred not to say. In 2019, 93% identified as heterosexual, 5% LGBTQIA+ and 2% of respondents preferred not to say.

Age of survey respondents

The age of the survey respondents shows good representation across the age groups, in a pattern that could be reasonably expected given the profile of the MS community. However, the proportion of respondents in the younger age group has dropped between 2019 and 2022.

Figure 4: Age of respondents 2019 & 2022 surveys

Respondents by type of MS

The type of MS across respondents shows a good representation of prevalence of the different types of MS in the UK and also broadly echoes the 2019 survey response.[3]

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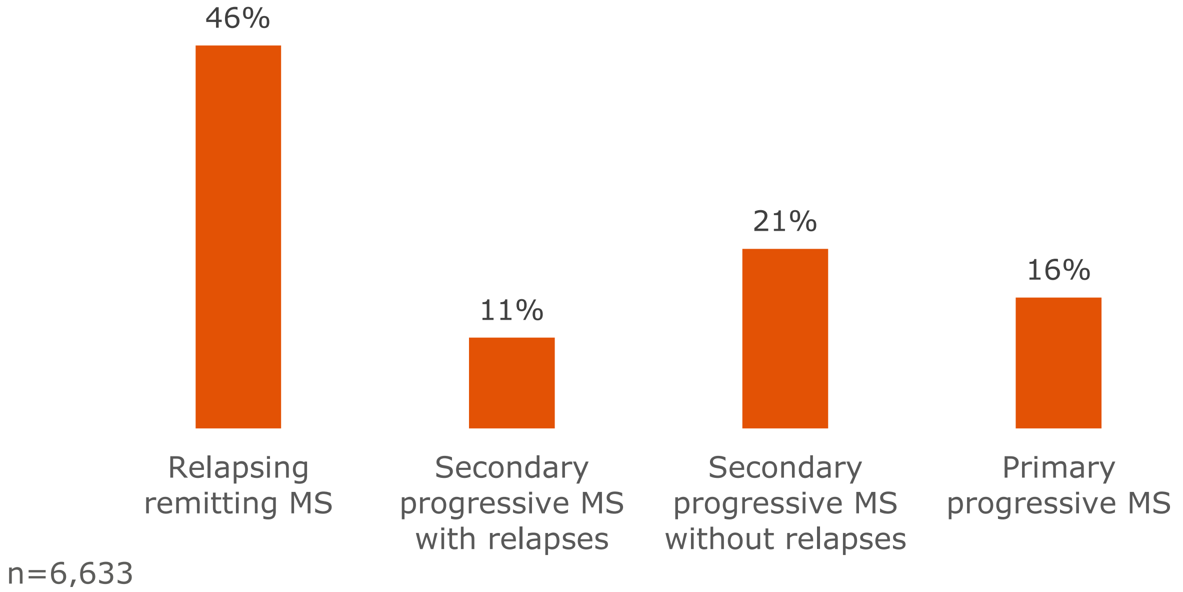
[3] Respondents by type of MS: responses of don't know, prefer not to say <10%

Figure 5: Respondents by type of MS



Just under half (45%) of all respondents described their MS as being at an advanced stage.[4]

Undertaking the survey

Survey Design

The 2022 survey design is led by our Evidence Team within the MS Society drawing in additional expertise from across our organisation. The team also worked with our Research Network, which is made up of volunteers from the MS community. The network aims to help and enhance public and patient involvement in our research and evidence activities, and the members reviewed the survey design and questions.

Dissemination

The dissemination, or distribution, approach for the 2022 survey differed from prior survey approaches. Previously, the surveys went out to our organisation's members and was provided on request to other interested parties. However, the 2022 survey was shared with our database of contacts which is made up of people who have agreed to be contacted for research purposes. This approach was successful in reaching people but there is some learning for us to take from it.

The survey was also promoted via our channels, professional contacts, and regional teams and network officers. It was also highlighted and shared by the UK MS Register[5] via its own portal, by emailing portal users and also alerted clinics, so they too could make people aware of the work being undertaken.

Responses

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[4] Question phrasing: 'By advanced, we mean, your MS greatly restricts how much you can move around and carry out daily tasks. You have multiple symptoms at the same time that don't go away, and are complicated to deal with'.

[5] The MS Register has been funded by the MS Society since its inception and it was launched in 2011 by Swansea University's Population Data Science Team. It captures real world data about living with MS.

The survey was available in both an online and paper format, to facilitate accessibility across the community. Responses were as follows:

- 60% of respondents online survey (2019, 45%)
- 40% of respondents postal survey (2019, 55%)

In total, in 2022, the number of respondents was 6,697 this compares to 8,281 respondents in 2019.

Analysis

When the survey responses are received a number of steps are taken to ensure the data is ready for analysis. Next, our Evidence Team undertakes a systematic analysis of the data. This work includes making sure that no individual can be identified in the data reporting. The team uses specialist software (SPSS) to support organising, managing and reporting the findings.

Outputs

The analysis produces lots of findings which the Evidence Team compile and review. These findings are then used in many different ways, for example, to inform, update and influence our activities in policy, practice, awareness-raising, campaigning and more. Some findings will be used in reports, like this one, as well as presentations. The data is also available to the whole organisation to support its work.

Notes on the data

Some of the figures used in the report show needs (and unmet needs). There are a number of ways of answering some of the ‘needs’ questions in the survey. Some people could indicate that that ‘yes, I have that need’ and that it is being met. Other people might respond to say ‘yes, I have that need’ but that the need is not being met. So, firstly we establish whether the respondent has that need, secondly, whether the need is being met, or not met.

It should also be noted that the N number – which indicates the total number of individuals answering – varies for each question. This because we designed the survey so that people would be asked the questions most relevant to them, so not everyone was asked every question.

Finally, some of the question responses in this will total more than 100% when combined. This is an effect of multiple choice questions in which more than one option can be selected as a response.

3. Key Findings

Introduction

In the following sections we explore key findings from the 2022 survey. This does not represent all of the data collected via the survey, however, as we describe above, the survey data supports and feeds into a wide range of activities to raise awareness of MS and the needs of people with MS.

Access to treatments and therapies

This section looks at the survey responses to questions about treatments and therapies. At the outset, it is worth noting that the proportion of people in the UK, responding to our survey, with relapsing MS on a DMT decreased by 3 percentage points between 2019 and 2022 (Figure 6).

Figure 6: Proportion of people with relapsing MS on a DMT across the UK (2019 & 2022 surveys)

However, the same people will not necessarily have responded to the survey in 2019 and again in 2022, which means we are not looking at the same people, but at two different points in time. Instead, the data is capturing different samples (although some people may have responded in both years) at two different points in time. The numbers of respondents, in relation to the chart above (for the whole UK) are as follows:

In 2019, 2,850 people from a sample of 4,732 were taking a DMT (60%)
In 2022, 2,149 people from a sample of 3,742 were taking a DMT (57%)

Looking in more detail at treatment and therapy responses shows us:

- The variation in terms of proportion of people with relapsing MS on a DMT between nations of the UK is 17% (Figure 6)[6]
- 4 in 10 (43%) of people with relapsing MS are **not** currently taking a DMT
- 83% of people with secondary progressive MS are **not** currently taking a DMT, although unfortunately for many there are still no DMTs they are eligible for
- 89% of people with primary progressive MS are **not** currently taking a DMT, although unfortunately for many there are still no DMTs they are eligible for
- Among those who haven't seen a MS specialist in the past 12 months, 12% are on a DMT, compared to 44% who had seen a specialist
- Of all respondents on a DMT, 94% had seen an MS specialist in the past 12 months
- Of those currently taking a DMT, 74% started treatment within 12 weeks of decision being made, 15% did not start within 12 weeks (8% unsure)
- 3% (128 out of 4,424) respondents have been prescribed Sativex in the past 12 months to ease symptoms of their MS. The majority of those (95%) were prescribed Sativex through the NHS. However, these numbers, and those in the point below, will somewhat reflect that only a small proportion of respondents would have been eligible for these.
- In the past 12 months, 1% (74 out of 6,476) of respondents have been prescribed medicinal cannabis to ease symptoms of their MS. The majority of those accessing medicinal cannabis do so privately (47 people out of 74 currently accessing).
- 35% of people report not having received enough information from healthcare professionals about drugs available to support the treatment of their MS - this is an increase of 7% from 2019

Summary on Access to Treatments and Therapies

The trend on accessing DMTs is a downward one between 2019 and 2022. The most likely explanation for this decrease is the disruption to health services caused by the outbreak of the covid pandemic. This disruption continues to affect health services across the UK, with long waiting lists for hospital treatment being a significant ongoing challenge for the NHS.

However, 94% of those on DMTs had seen an MS specialist in the past 12 months (at the point of survey).

There is a notable difference in the proportion of people with relapsing MS on DMTs compared to those with progressive MS. While new treatments for some types of

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[6] It should be noted that due to the small sample sizes in the devolved nations, changes in percentages should be treated with some caution.

progressive MS have become available since our last MMMN survey, such as siponimod for active secondary progressive MS in 2020, overall there are fewer licenced DMTs for progressive types of MS compared to relapsing. Also, people with progressive types of MS can be less likely to access these treatments for a range of reasons, including a tendency to ‘fall between the gaps’ of health services due to the complexity of the condition and the limited number of treatment options available.

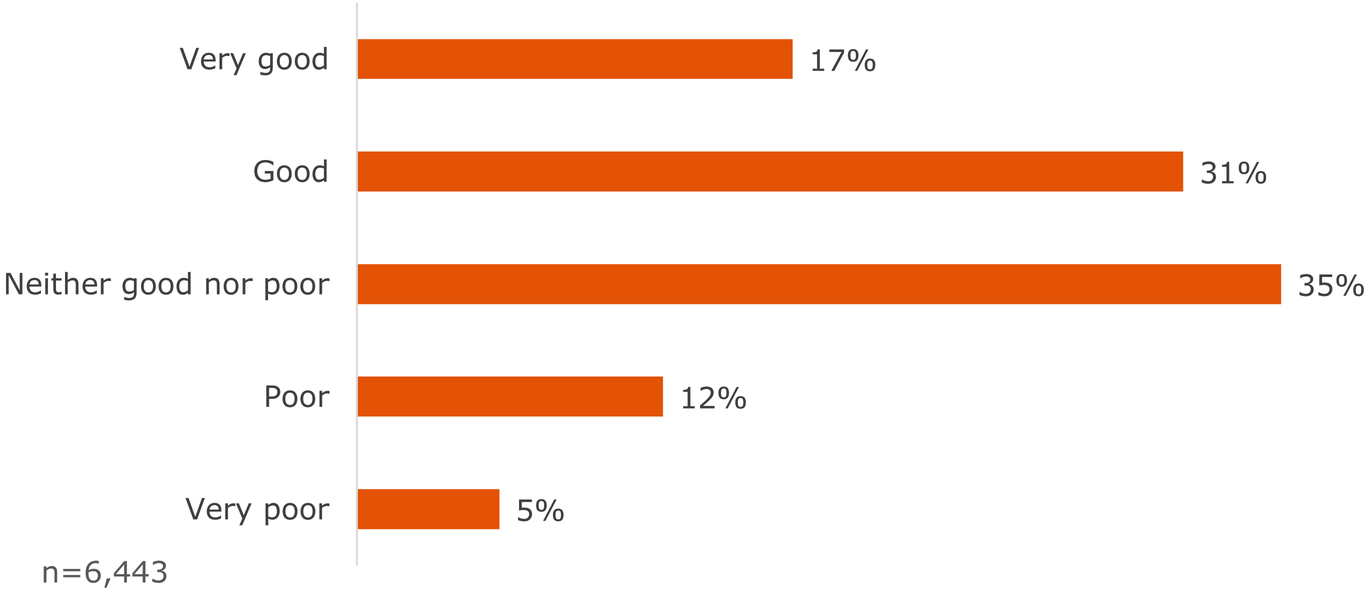
The low numbers of people accessing Sativex is partly driven by its prescribing eligibility criteria – Sativex is not suitable for everyone with MS. However, there is also a postcode lottery in access to the treatment. Many eligible people with MS cannot access Sativex because their local health bodies aren't prescribing it. We have been campaigning to improve access to Sativex since 2021, with our most recent phase of the campaign running in early 2023.

The data also shows that 35% of respondents reported that they had not received sufficient information about medications to treat MS; this could affect both the awareness of potential drug treatments and levels of knowledge about treatment they are being offered or receiving.

Access to MS specialist healthcare

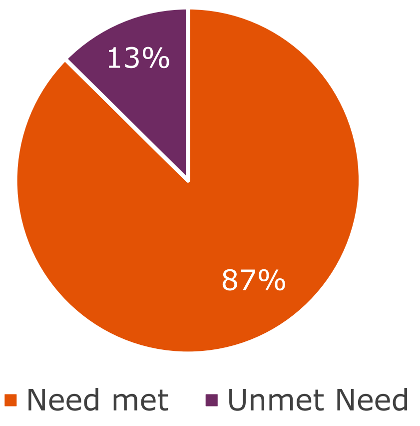
Almost everyone (96%) responding to our survey had received healthcare for their MS in the last 12 months. Just under half of them (48%) rated the quality of that healthcare as either good or very good (Figure 7).

Figure 7: Quality of healthcare received over the past 12 months



Across the UK, 87% of respondents had needed and had been able to access an MS nurse in the last 12 months. This is a small drop from the 2019 survey, when the figure was 89%. A further 13% had wanted to access an MS nurse but had not been able to.

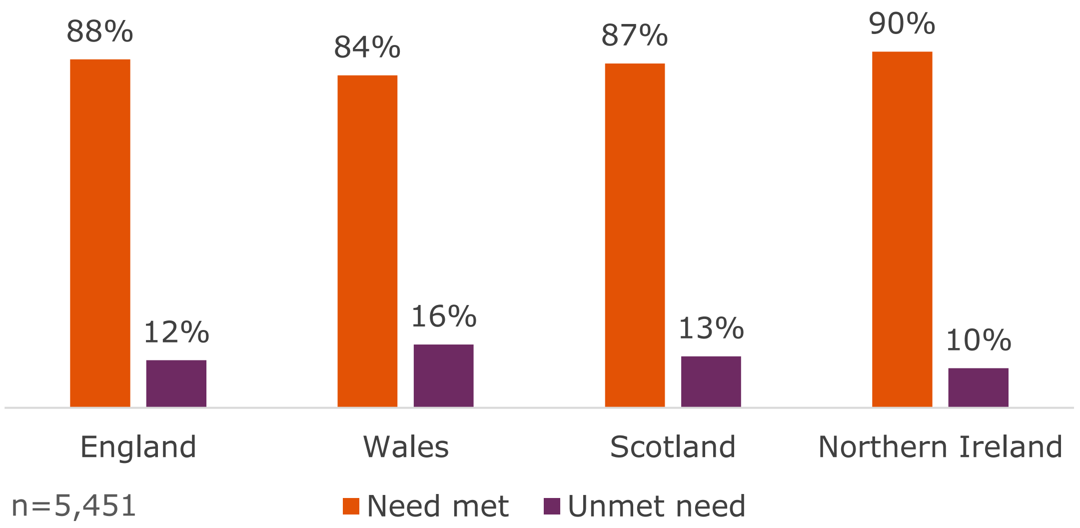
Figure 8: Access to MS nurse (UK)



n=5,459

This level of access is fairly consistent across UK nations (Figure 9). In 2019 the variance between nations was 18 percentage points ranging from 93% (Wales) to 75% (Northern Ireland). However, because we have only a relatively small number of respondents from each of these countries, we need to treat these percentages with some caution.

Figure 9: Access to MS nurse (Nations)



n=5,451

Analysing the survey responses on neurologist access shows the following (Figure 10 & 11):

Figure 10. Have accessed a neurologist when needed to over the past 12 months (MS type)

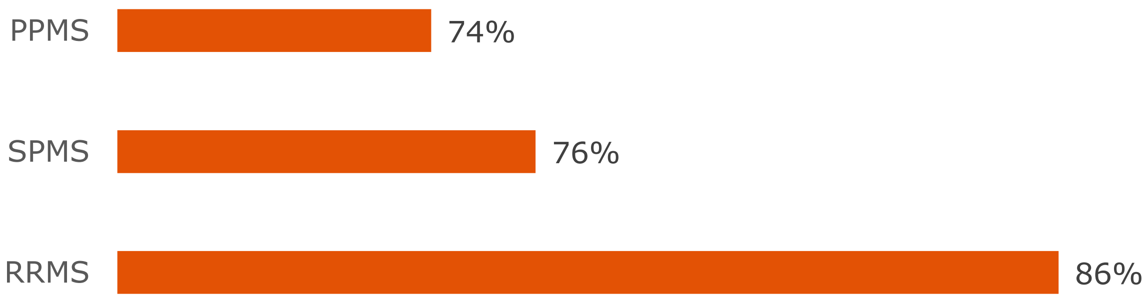
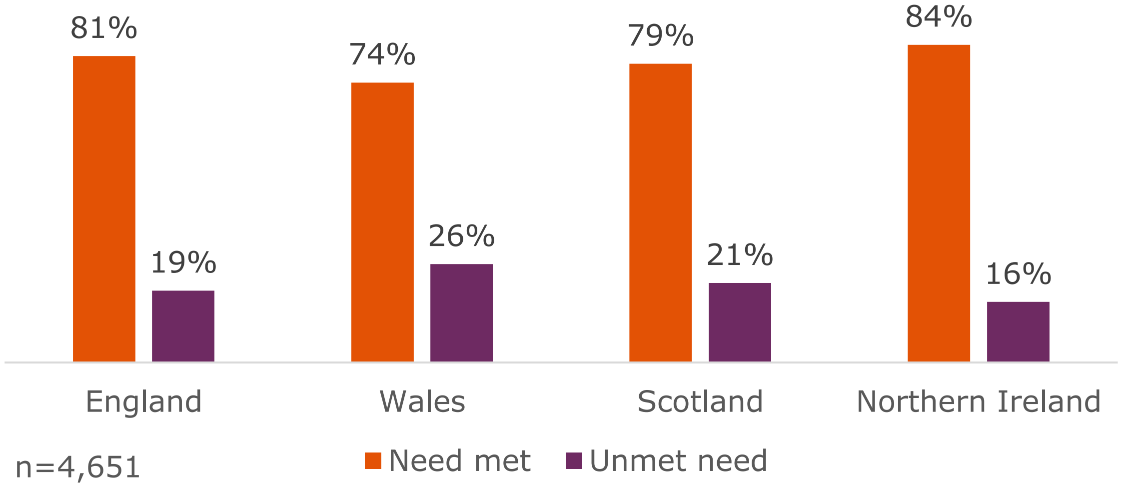


Figure 11: Access to neurologist (Nations)



Reviewing the data on appointments shows:

- Over the past 12 months the majority of appointments with MS nurses have occurred on the telephone (62%) or in a hospital setting (41%) (Only 9% of appointments occurred within the home)
- 80% of respondents who needed to see a neurologist had an appointment in the past 12 months
- Over the past 12 months the majority of appointments with neurologists have occurred in a hospital setting (58%) or on the telephone (45%)

Summary on Access to Specialist MS Healthcare

The data in this section shows that while almost half (48%) of people are positive about the healthcare that they have received, the rest of our respondents were ambivalent or negative about the quality of their care.

The proportion of respondents able to access an MS nurse when they wished to has dropped since 2019. The majority of those appointments were delivered via telephone. This is likely to be as a result of the pandemic, which significantly shifted healthcare practices to remote consultations, carried out online or over the phone.

One in five (20%) respondents who needed to have an appointment with a neurologist, did not get one in the past 12 months. The UK neurology workforce is under stretched and under resourced, with the UK ranking 44 out of 45 European nations for the number of neurologists for each person with a neurological condition.[7]

When unmet need in terms of access to a neurologist is considered, the data shows a significantly different picture for those with progressive forms of MS compared to those with relapsing forms of MS. Overall, the data suggests that those with progressive forms of MS are less likely to have accessed a neurologist when they needed to.

People with progressive types of MS can require more support and care due to level of disability and the deterioration of health over time. They can also be more likely to disengage with services due to the complexity of their care and lack of treatment options available as compared to relapsing MS. The pressure on the neurology workforce may also be driving low access rates to the small number of treatments available for progressive MS.

Access to other specialist services

When the survey data concerning access to services is examined, it shows significant unmet need for access to specialist services.

In this section, the questions ask ‘In the past 12 months, have you received support for…’, if the respondent answers ‘yes’ then the need is recorded as ‘met’. If the respondents answer ‘No, but I needed it’, then this is recorded as ‘unmet need’. The unmet needs span a wide range of provision and are shown in the figures below (the number of people answering each question are shown next to the ‘n’ under the figures).

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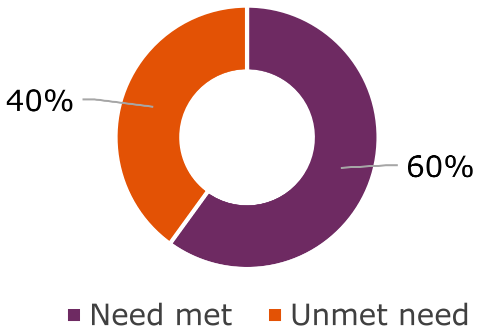
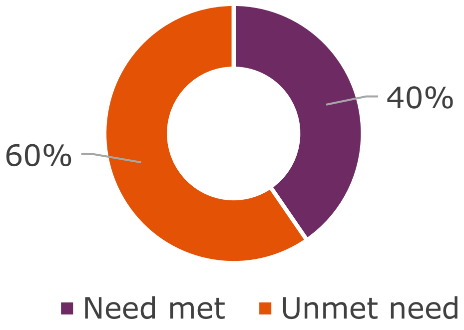
[7] Association of British Neurologists, *2020. Neurology Workforce Survey conducted by the Association of British Neurologists.* https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf

Figure 12: Specialist continence support



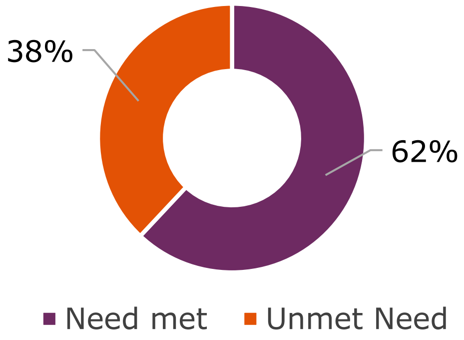
n=2,880

Figure 13: Mood and emotional support



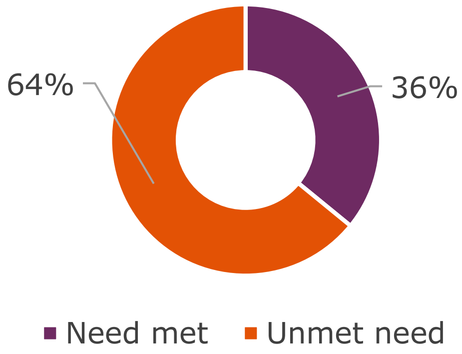
n=2,224

Figure 14: Physiotherapy



n=3,380

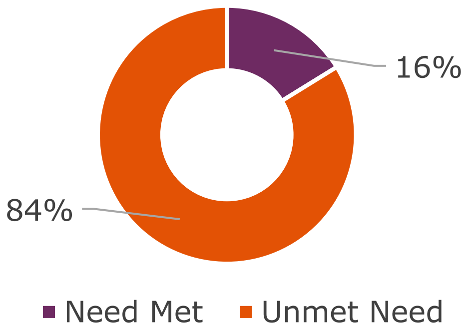
Figure 15: Support keeping physically active



n=3,014

In the 2022 survey we asked about cognitive support for the first time and 84% of people told us they specifically have an unmet cognitive need (this might be their only unmet need or it could be one of several).

Figure 16: Cognitive support



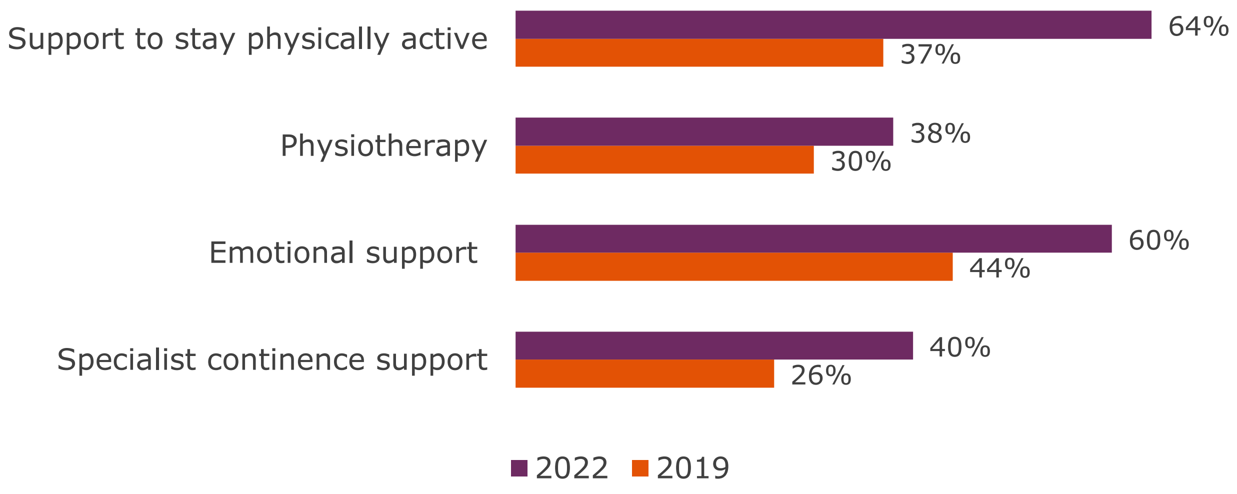
n=2,104

For those who have received specialist support, it is provided as follows:

- Support and advice for continence problems was largely provided by Continence or MS specialist nurses (82%)
- The NHS contributed a large proportion of cognitive support (79%), physiotherapy (73%), and support for mood and emotional issues (72%)
- Support to become physically active was largely provided by the voluntary & charity sector or private organisations 55% (34% provided by the NHS)

When the unmet need findings from this survey are compared to the 2019 survey the changes are clear (Figure 17).

Figure 17: Unmet need for specialist services (2019 & 2022)



Summary on Access to Specialist Services

The most significant areas of unmet need, as reported by the survey respondents who required support but are not receiving it, are:

- Cognitive Support: 84% unmet
- Support keeping physically active: 64% unmet
- Mood & Emotional: 60% unmet

This raises a number of concerns regarding support across both mental and physical wellbeing. Furthermore, when the levels of unmet needs reported by our survey respondents in 2019 and 2022 are compared, a significant increase in unmet needs is shown.

Some of the drivers of this increase in unmet needs may stem from lingering impacts of the covid pandemic. The cumulative impact of lockdowns across the UK, immense pressure on health services and workforce, and ongoing vulnerability of some people with MS has led to worsening health or deconditioning for many people. This is happening in parallel with ongoing recovery of health services, and the loss or closure of other key community support services such as leisure centres.

Health and care workforce pressures also remain high across the UK, with significant vacancy rates in the NHS and social care workforce. This can be compounded by an inadequate skill mix across support settings, which can cause people with MS to fall through the gaps due to a lack of understanding or confidence around supporting someone with MS or other neurological conditions.

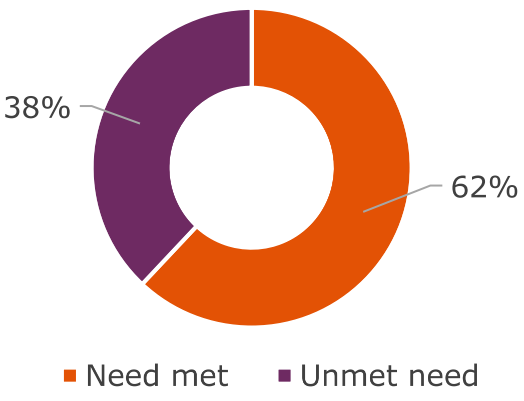
Unmet specialist support needs have significant consequences for the economy, health services and society as a whole. Previous research has shown that the leading cause of emergency hospital admissions for people with MS are bladder and bowel issues, such as urinary tract infections. Emergency admissions for bladder and bowel related issues for people with MS in England cost the NHS £10.4m in 2015/16. Many of these admissions can be prevented with timely specialist support.[8]

Care and support

The data shared in this section shows a range of care needs and that there are risks associated in those needs not being met.

Those who needed care and support (almost half of all of those surveyed), almost 4 in 10 (38%) had not received adequate provision to assist with daily living in the preceding 12 months (Figure 18). This is an increase of 6% from the 2019 survey.

Figure 18: Proportion of respondents reporting needs concerning care and support required to assist with daily living



n=3,289

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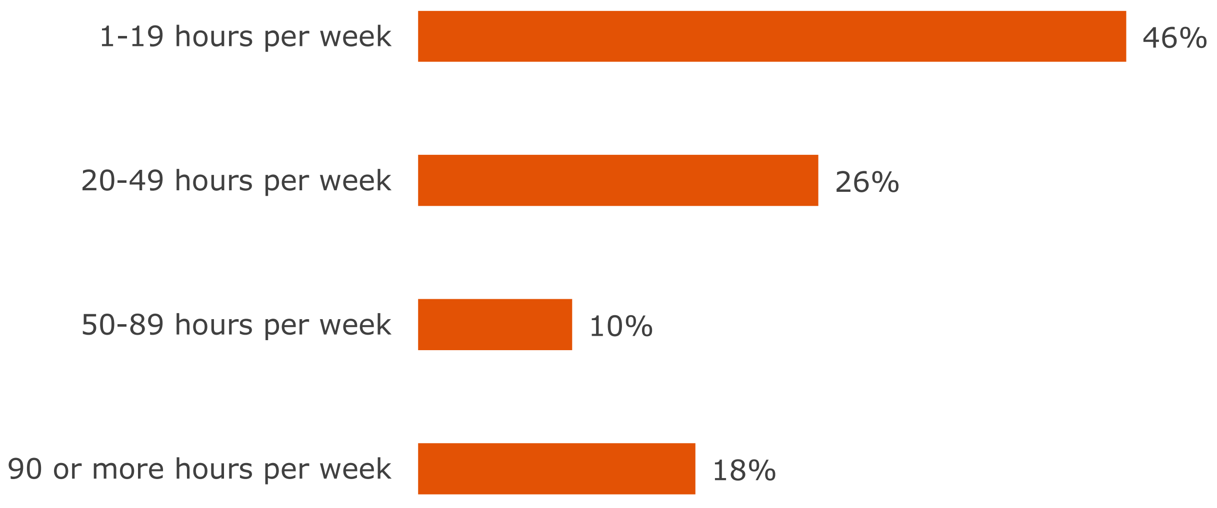
[8] Wilmington Healthcare and MS Trust, 2017. *Multiple Sclerosis Emergency Admissions in 2015/16.* https://wilmingtonhealthcare.com/wp-content/uploads/2017/04/MS-Infographic-2017.pdf

Large proportions of the 38% of respondents with unmet care and support needs had also experienced deteriorating health (64%), or felt lonely/isolated (59%) and a significant minority (20%) had been unable to work.

Concerning care, the data collected also shows:

- 61% of respondents (n=6,270) received one or more hours of unpaid care from family and friends (Figure 19)
- The most common areas of support needed included; shopping, cleaning, and laundry (70%), cooking meals (59%), housework and gardening (59%), getting out the house (50%) and washing and bathing (35%)
- 46% of those receiving care paid for it through their own income (including benefits received)
- 13% of people with MS provide unpaid care and support to others including friends or relatives

Figure 19: Estimated hours of unpaid care received from family and friends



n=3,830

Summary on Care and Support

This data evidences significant unmet need in terms of care and support as well as giving some indications of the detrimental effect the unmet needs can result in.

What the respondents told us also provides a clear picture of a range of care and support being provided by family and friends. Over half of respondents were receiving 20 hours or more of unpaid care by family or friends a week (this is an area that will be explored further in Friends and Family report, 2023).

As discussed in other sections of this report, workforce shortages and health and care pressures are likely to be contributing factors in the levels of unmet need for care and support.

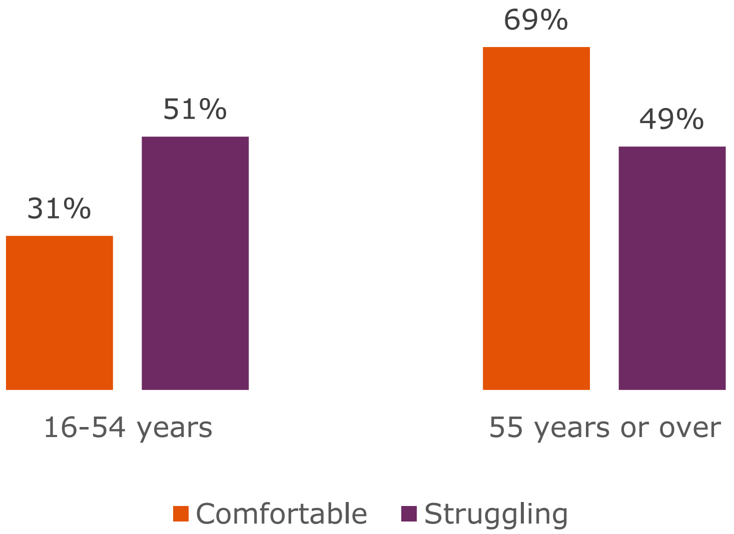
Unmet care and support needs have clear cost implications for the economy, health services, and society as a whole. One in five respondents with unmet care and support needs were unable to work. The majority of care received by respondents (53%) was unpaid support provided by family and friends.

Financial security

In the 2022 survey we were keen to understand respondents' financial situations. We also wanted to learn more about whether financial status could potentially affect their ability to live, and to manage their MS, in the way they would wish to.

As part of our analysis we included splitting the financial responses into two large age groups (Figure 20). This was an important way to consider the data as many respondents to this survey fall into the older age group (see Figure 4, earlier in the report).

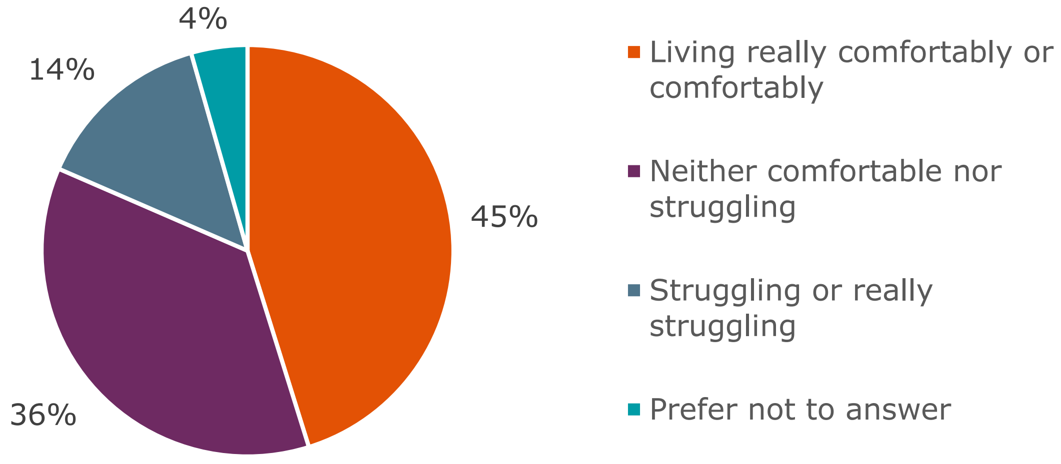
Figure 20: Proportion of people comfortable or struggling financially, by age group



Income

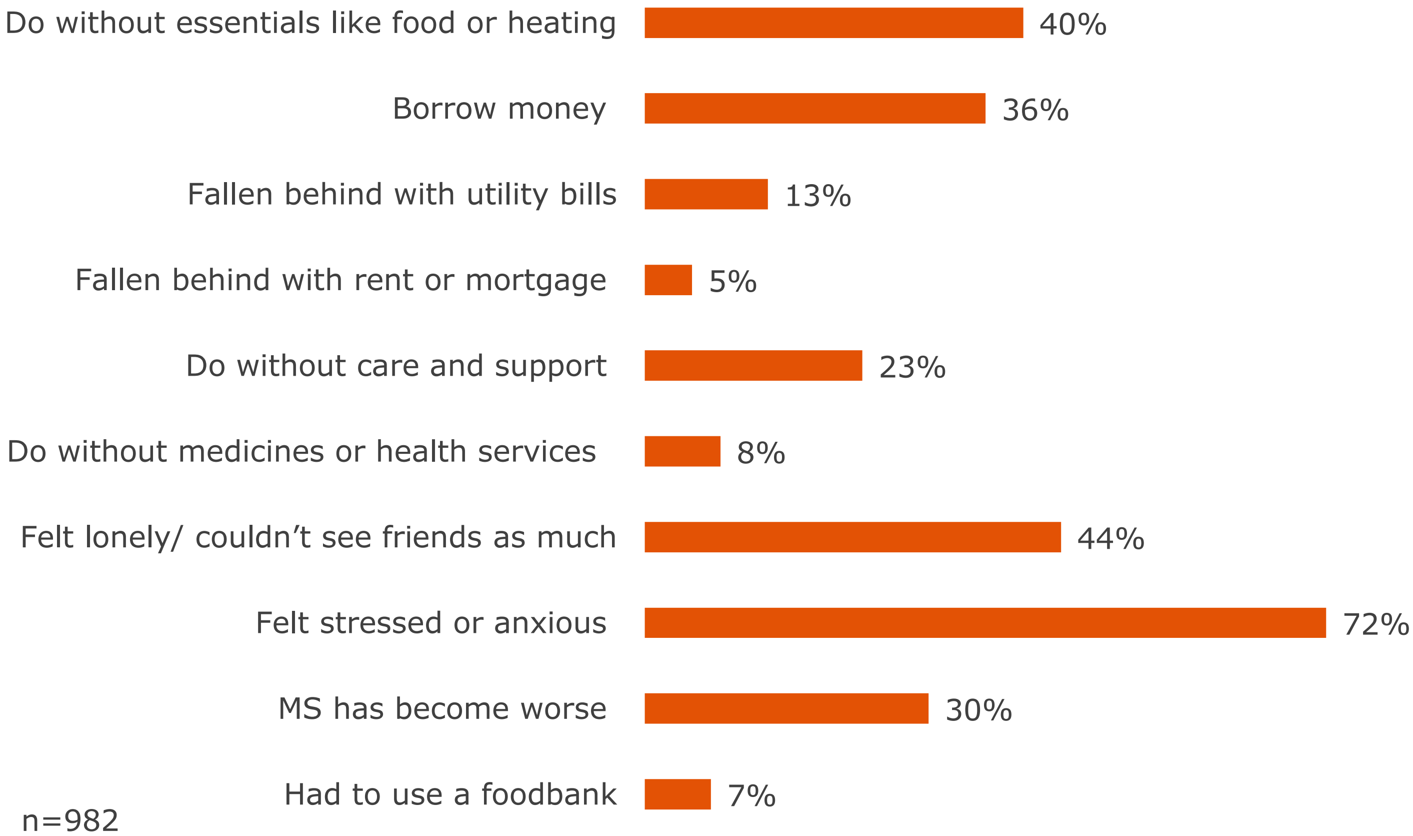
When the data concerning household income is analysed, we can see that 14% of respondents are ‘struggling or really struggling’ (we refer to this as ‘struggling’ or ‘hardship’ in the text of the report) on their current income (Figure 21).

Figure 21: How do you feel about your current household income



n=6,611

Figure 22: Impact of struggling or really struggling financially

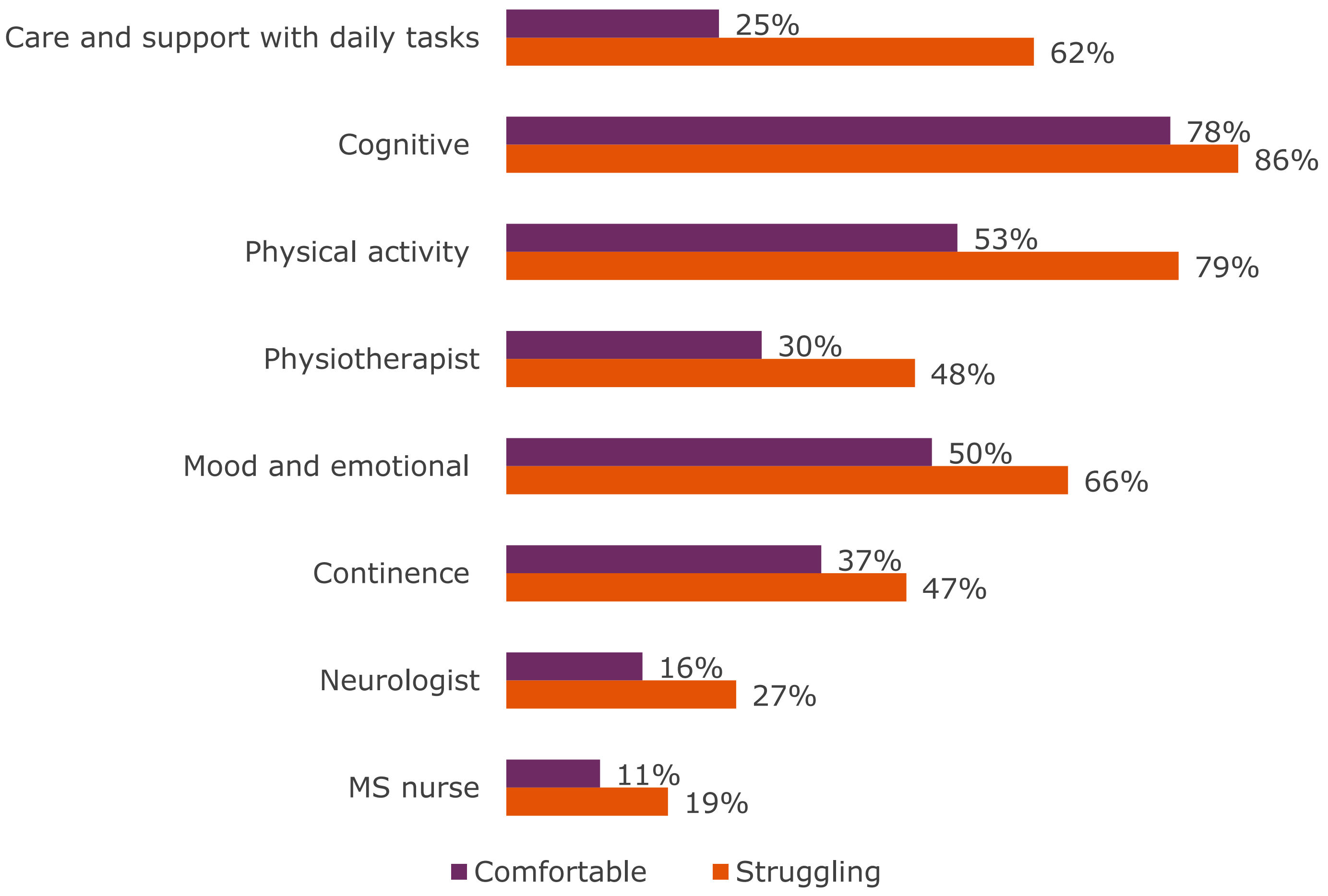


n=982

Some of the most significant impacts for those struggling with their household income can be seen to be around mental wellbeing; just under three-quarters feel stressed and anxious (72%) and over one-third feel lonely (44%).

People who are in financial hardship are also more likely to have unmet care and support needs and are less likely to access specialists than those who are not struggling. We examine this data in more detail below (Figure 23).

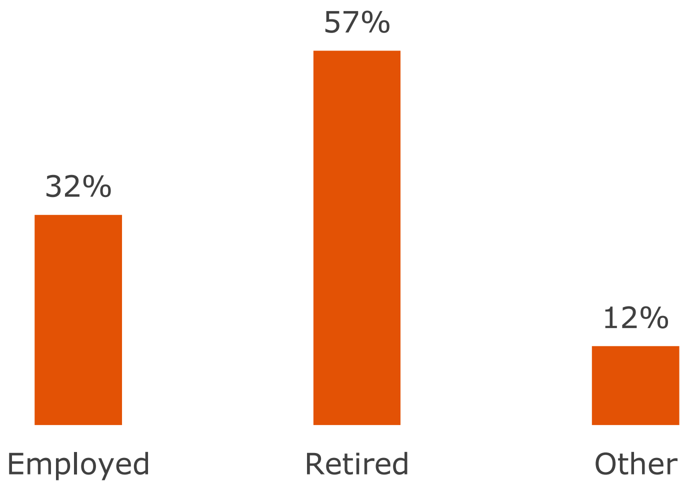
Figure 23: Proportion of unmet needs among those who are financially 'struggling' and those who are financially 'comfortable'



Employment

When employment status is considered, the following picture emerges (Figure 24).

Figure 24: Employment status of respondents



n=6,576

[9]

Overall 19% of respondents (of a sample of 6,474) told us that being in employment had made their MS symptoms worse.

Of the retirees (3,748 respondents) completing the survey, 46% had retired or left work early due to ill health. Of those people, around one-third of them (32%, or 534 respondents), reported that they did not get enough support from their employer to leave at the right time for them.

Benefits

The data shows that 60% (3,999) of respondents were in receipt of benefits at the time of being surveyed; this could be a number of benefits, both means and non means tested.

People who are receiving benefits are more likely to report that they are experiencing financial hardship than people who are not in receipt of any benefits (Figure 25).

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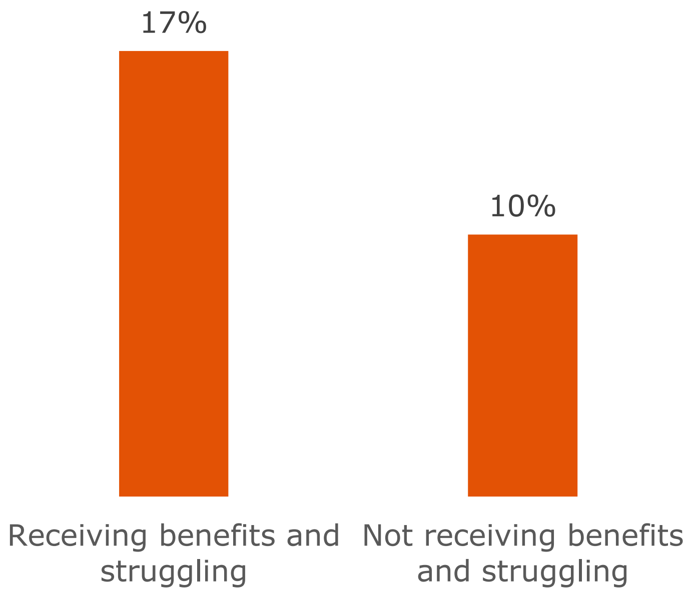
[9] Other = seeking employment, not seeking employment, student

Figure 25: Respondents reporting that they are struggling financially and benefit status



n=936

Of those in receipt of benefits (3,999), the respondent data shows:

- Over one-third of people (34%) are not assessed on an annual basis
- 29% have been assessed for disability benefits in the past 12 months
- 43% of people receiving Employment Support Allowance, and have been assessed for Universal Credit over the past 12 months, are receiving less than before or nothing at all
- Just over a third (35%) of those receiving PIP feel comfortable on their current household income
- Of those receiving Disability Living Allowance 47% feel comfortable on their current household income
- 48% of people receiving Universal Credit said that they were struggling on their current household income
- The Motability Scheme has been accessed by 27% of all respondents
- 7 in 10 of all survey respondents (71%) have unmet need with regards to receiving support to better understand the benefits system

Summary on financial security

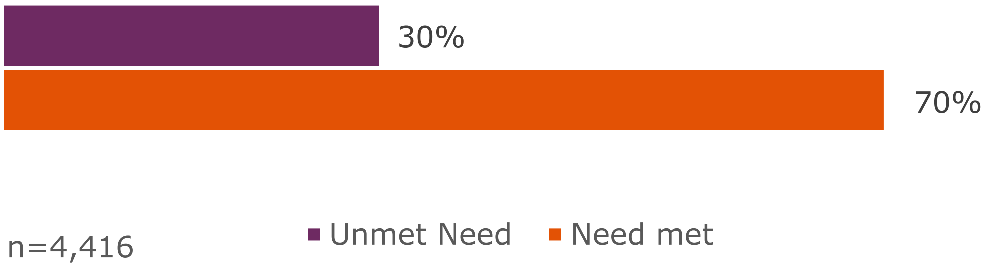
Household income has a significant impact across an individual's life and wellbeing. The evidence here shows that, for people struggling financially, the impacts include practical ones as well as detrimental effects on mental wellbeing.

Those people experiencing financial hardship are also more likely to have unmet care needs and are less likely to be accessing specialist health care. The effects of financial hardship can be understood as systemic but, also, having negative impacts which are quite specific to our respondents – people with MS.

Information about MS and access to support

Over the past 12 months, 70% of people who identified they wanted information and support, had their needs met (Figure 26).

Figure 26: Proportion of respondents in receipt of enough information about their MS

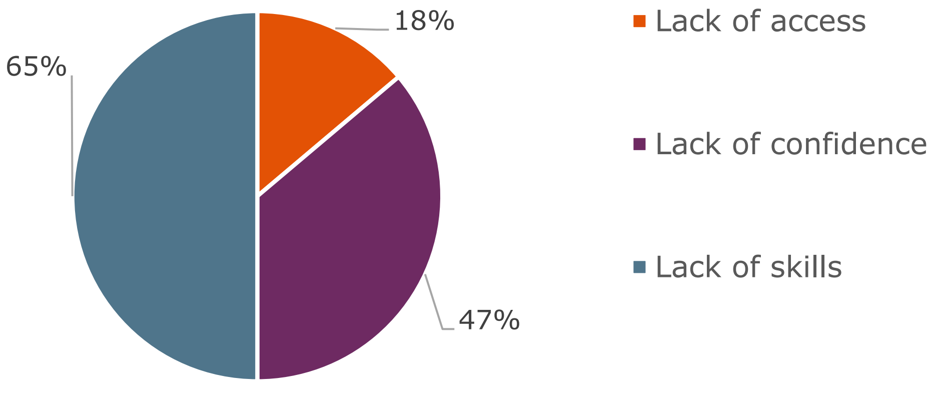


- Over half of respondents in this group (57%) report unmet need with regards to receiving regular support and guidance on how to self-manage (n=4,026)
- MS nurses (73%) and neurologists (39%) are the most common source of self-management support
- 43% of respondents (n=1361) had unmet need with regards to accessing an advocacy service when they needed to
- 77% of all respondents (n=6566) had not used, or required an advocacy service to speak on their behalf or in support of their views.
- The most common areas of support for those using advocacy services were employment (6%) and healthcare (6%) (n=6,566)

Digital technology

When looking at access to technology, the survey shows that 2 in 10 people completing the survey (22%) have problems accessing or using digital technology. Lacking appropriate skills was the barrier identified by 65% of that group of respondents (Figure 27).

Figure 27: Barriers to using digital technology



Analysing this data further shows:

- 27% of people who have problems accessing or using digital technology said they had not received enough information about their MS
- 68% of people who have problems accessing or using digital technology said this had made accessing support for their MS moderately or very difficult

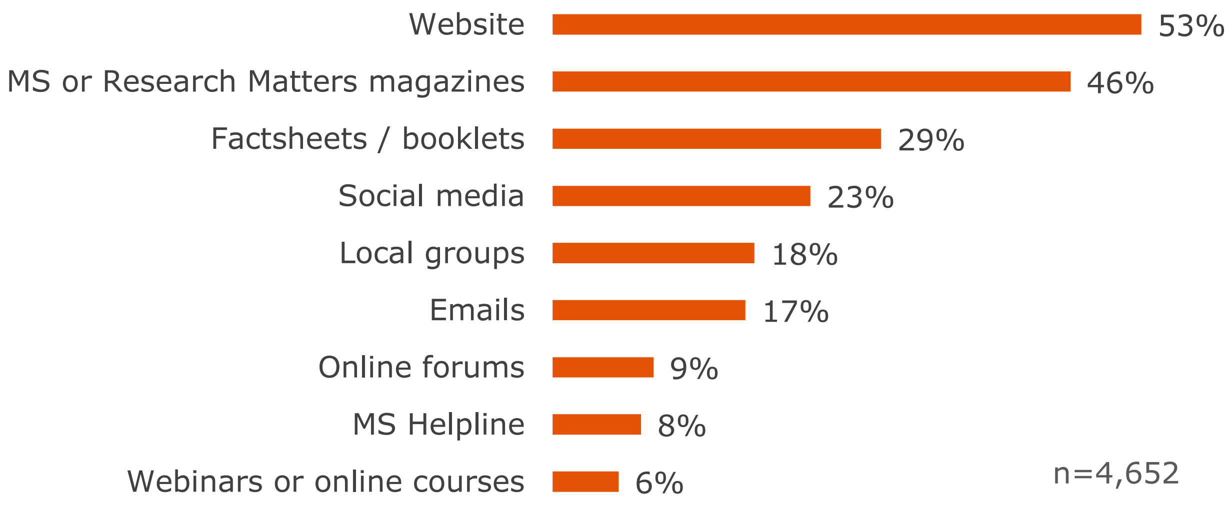
MS Society services and support

The MS Society aims to provide a wide range of support to people with MS. These services are driven and shaped by evidence and this survey helps us continue to build understanding about the needs the services must respond to.

The data shows that 71% of respondents had used one or more MS Society services in the 12 months leading up to survey completion. People were most likely to have found out about MS society services and support through the website or social media (69%) or via healthcare professionals (19%).

Of those services, the most accessed were:

Figure 28: MS Society services accessed over the past 12 months



Of those respondents who had accessed our services, 8% had contacted the helpline. The most common reason for calling was health and symptom management information (including speaking to an MS nurse).

Of those who had accessed the MS Society's services and support, 79% said they are likely or very likely to recommend the services and support to other people affected by MS.

Summary on information needs, digital technology and MS Services and Support

When considering the unmet need for information about MS, it is worth noting the number of respondents who report barriers in using digital technology. A significant proportion of that same group also reports that these barriers made accessing support more difficult for them.

Previous research indicates there are several barriers that can make it difficult for people with MS to use digital tools. These include difficulties due to visual impairments; issues with motor skills, affecting peoples' ability to use a mouse, keyboard or smartphone; memory problems which can make remembering passwords hard and difficulties with particular websites or apps that use a small font size or flashing images.

4. Summary and closing remarks

Summary of key findings from 2022 survey

There are some notable and worrying changes across some key areas when the data in 2019 is considered against the 2022 findings. While there are differences in the way the surveys were conducted, and the number of respondents, the data shows, at times, probable impacts of the covid pandemic. The information we have here is very important and useful; it will help us raise awareness and campaign for improvement for the MS community. Some of the most concerning findings are:

- ➔ The increase in unmet needs
- ➔ The clear systemic impact of financial hardship
- ➔ Challenges in accessing care and healthcare professionals
- ➔ Through this survey, 30% of people tell us that their MS has become worse
- ➔ The drop in number of people accessing DMTs

The potential impact and application of the survey data

Beyond the creation of this report, and other linked written outputs and presentations, the data collected through this survey is used in a range of other ways. This includes creating data assets which allows for all the anonymised data to be utilised as much as possible in a range of our projects and activities. These may include, for example:

- Informing and shaping other evidence collection activities
- Supporting awareness raising and influencing activities and campaigns
- Forming an evidence-base for policy-making recommendations
- Supporting fundraising activities to support clinical research into MS
- Informing the development of our services, to best meet the needs of our community

This report has highlighted just a small selection of findings which the MS Society know is of interest to their staff, stakeholders and our wider MS Community. We hope you have also found it interesting.

The importance of this survey and the data it produces should not be under-estimated; it is vitally important. Of course, none of this could be achieved without the time and effort of the people who took time to complete the survey. We also hope that this report is also one way of assuring those people that what they have shared with us is valued and appreciated; we thank you all for your time.

We're the MS Society.
Our community is here for you
through the highs, lows and
everything in between.
We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk

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▶ Let's stop MS together