

A large, stylized graphic element consisting of a central orange triangle pointing to the right, surrounded by a white outline that forms a larger, irregular shape. The background of the entire page is white with orange geometric shapes and lines.

**My MS My Needs survey
2019: UK findings**

Thank you

Over 8,000 of you across the UK took part in the 2019 My MS My Needs survey. Thank you.

Since the survey closed, we've all been affected by the coronavirus pandemic. This report captures the experiences of the MS community as they were before the pandemic began.



While the context into which we release this report has altered dramatically, the needs of the MS community described here haven't disappeared. Indeed, as we gather insight into the impact of the pandemic on the MS community, we expect to find that some of these needs are more urgent than ever.

The 2013 and 2016 My MS My Needs survey findings had a diverse and invaluable impact on our work. They informed the development of our new services and strengthened our fundraising bids. They enabled engagement with healthcare professionals on the needs of people with MS, and made our national campaigns more successful. Being able to tell decision makers about the lived experience of people with MS and how it's changed over time remains a powerful tool for change. We'll be using these new findings to continue to fight for improvements in the lives of people with MS.

What does the 2019 survey tell us about the needs and experiences of the MS community in the UK before coronavirus?

My MS My Needs 3 shows a lot of continuity with the findings of the 2016 survey, but there have been some notable changes.

The proportion of people with relapsing MS on a DMT has increased 7% since the 2016 survey, to 60% in 2019. This is good news. Being on a treatment to slow the progression of MS provides the best chance of living well with the condition for longer.

Since 2016, new treatments have been made available on the NHS, including the first treatment for primary progressive MS, ocrelizumab. The first oral treatment for secondary progressive MS, siponimod, has been licensed in Europe and is currently being evaluated for use on the NHS. This is in no small part thanks to the MS community speaking out about the difference such treatments can make. Locally, in 2019 alone we successfully campaigned to save or create at least 12 new MS nurse posts, vital to supporting people with MS on treatments and to live well.

However, not everyone has the same access to treatment across the UK. This year's survey shows access to treatment varies by as much as 28% depending

on where you live. Whether or not you can access the support you need also depends on your income. The findings show that people on low incomes are less likely to be able to access the information, care and support, treatment and specialists they need.

What hasn't changed since 2016, is the lack of access to support and therapies that help people with MS to live well. The persistently high level of unmet need for emotional support is particularly striking (44% of respondents in 2019). And it's similarly not good enough for physiotherapy, continence support and help to remain physically active.

It's also the case that a significant minority continue to feel their care is poorly coordinated, and this is having an impact on their health and wellbeing. 16% said the professionals that plan their care don't work well together. This causes many to have to chase professionals for information/appointment, for some causing stress that exacerbated their MS symptoms.

Social care continues to be underfunded and in need of radical reform. 1 in 3 people that need support with essential activities like washing, dressing and getting out of the house, continue to go without any or enough support in 2019. And the benefits system continues to let people with MS down, failing to adequately protect them from financial hardship. For example, only 36% of PIP recipients said they were comfortable on their current household income.

Taking action

While we're currently focused on limiting the negative impact of coronavirus on the lives of people affected by MS, over the next four years we will continue to take action to improve the lives of people with MS more broadly. This will involve:

- Addressing the huge gap in access to emotional support for those that need it.
- Tackling the unacceptable inequality and unwarranted variation in access to services and support, so that getting the right treatment and support is not dependent on where you live or on your income.
- Funding research into new treatments to stop the progression of MS and making sure these treatments are available on the NHS more quickly.
- Working with professionals and people with MS to improve the coordination of care - so you have timely access to personalised support and are better supported to navigate the complexity of the health and care systems.
- Improving support for people to remain in employment as long as they wish.
- Continuing to campaign to make both care and support systems in each nation and the welfare system across the UK, work for people with MS.
- For the first time in this year's survey we asked what you thought of the MS Society's services and support. We'll use this insight to tailor our own

services and support to better meet the wide variety of needs of different people affected by MS.

Thank you again for taking part. I look forward to continuing to work together to improve the lives of people with MS in the UK.

Nick Moberly

CEO

About the My MS My Needs survey

We conducted a survey of 8,281 people across the UK with MS between March and May 2019, making this one of the largest collection of patient-reported data from the UK MS community. There are an estimated 131,000 people living with MS in the UK.

The initial survey was run in 2013 and again in 2016. Together, the results of the My MS My Needs surveys provide an opportunity to understand in detail how people with MS feel about their treatment, care and support.

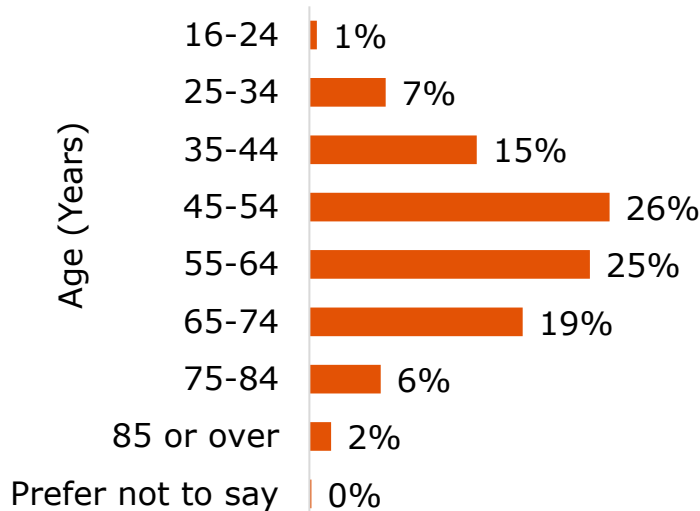
82% of respondents were from England, three quarters were women and most were aged between 45 and 64 years old.

Number of respondents in each nation of the UK

NB: location unknown for 83 respondents



Age of survey respondents (UK)



3/4 of respondents were women

Methodology

In 2019, 55% of respondents completed a paper-based survey, sent out to MS Society members and upon request. 45% of respondents completed the survey through an email link, promoted via the MS Register, MS Society channels, professional contacts and through our regional influencing teams and local network officers. Due to age and gender bias in our sample, the data has been weighted to be representative of the UK MS population. However, in the 2019 survey some questions were changed, removed or added, meaning that comparisons to 2016 or 2013 cannot always be made. Please see the accompanying methodology report for further information.

Note on definitions used

Many of the figures cited in this report are the proportion of people with a given need who said that this need was met. This is the number of people who answered 'Yes' to a specific question, divided by the number of people who answered either 'Yes' or 'No, but I needed to'.

Many of the figures cited in this report are the proportion of people that accessed a particular service or type of support. This is proportion of respondents that had a **need** for said service or support, and were able to access it.

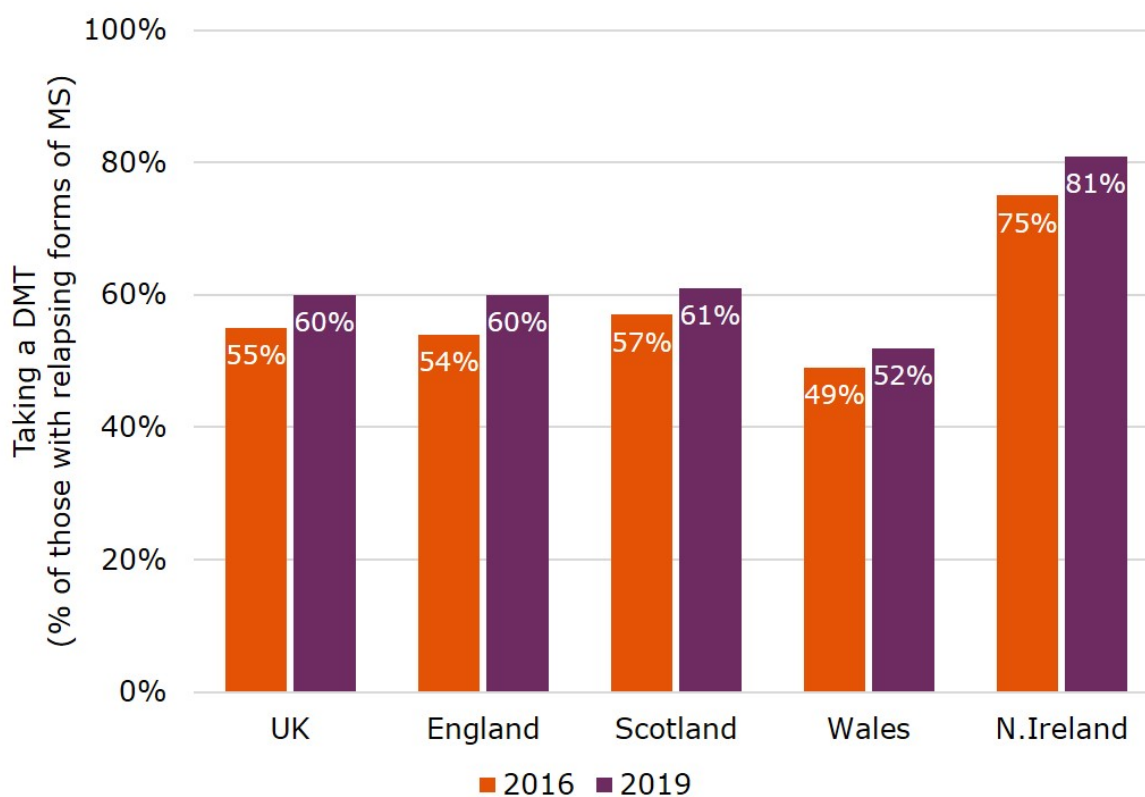
At the time of the survey, there were no disease modifying treatments (DMTs) available on the NHS for people with primary progressive MS and very limited options for people with secondary progressive MS. Therefore, in this report when we refer to people that could 'potentially benefit from a DMT', this only includes respondents with relapsing forms of MS (both secondary progressive MS with relapses and relapsing remitting MS). We acknowledge that this will include some people that are not eligible for a DMT and exclude some people with progressive forms of MS that are.

Key findings

Access to treatments and therapies

- The proportion of people with relapsing MS on a DMT has increased by 5 percentage points between 2016 and 2019. 60% were on a DMT in 2019 (figure 1)
- 2 in 5 people who could benefit from taking a DMT aren't currently taking one.
- Among those people who haven't seen an MS nurse or neurologist in the past 12 months, just over 1 in 6 (17%) are on a DMT compared to 65% who had seen a specialist.
- Since 1 November 2018, of those who wanted to have a conversation with a healthcare professional about accessing cannabis for medicinal use, 78% had not and 21% had.

Figure 1: Proportion of people taking a DMT who could benefit in the UK and the four nations of the UK in 2016 and 2019



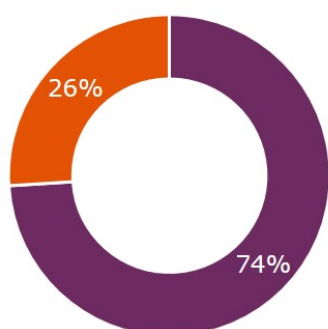
Access to services

- There is high unmet need for access to specialist services from physiotherapy to continence support, help to remain physically active and emotional support (figure 2).
- Among these services, unmet for emotional support is highest, with 44% of people not getting the emotional support they need.



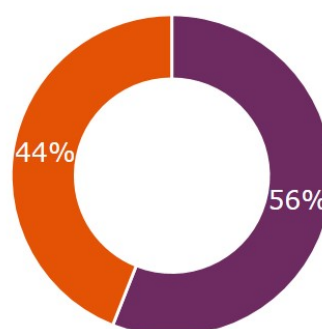
Figure 2: Access to specialist services to manage MS symptoms when needed

Specialist continence support



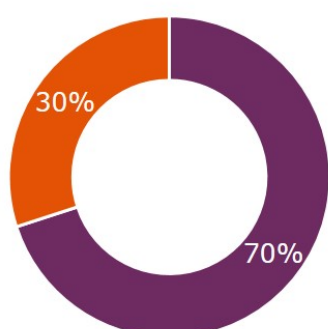
■ Need met ■ Unmet need
N = 3,862

Emotional support



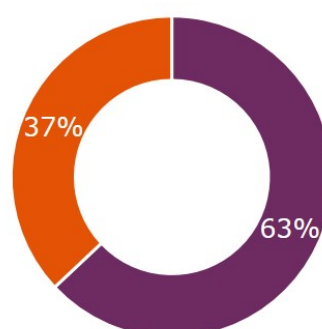
■ Need met ■ Unmet need
N = 3,565

Physiotherapy



■ Need met ■ Unmet need
N = 5,109

Support to stay physically active



■ Need met ■ Unmet need
N = 5,376

Variation in access to treatment and support

- 89% had needed, and been able to, access an MS nurse in the last 12 months. However, this varies across UK nations by 18 percentage points, from 93% to 75% (figure 3 and figure 4)

Figure 3: Access to MS nurse when needed in the preceding 12 months - UK average

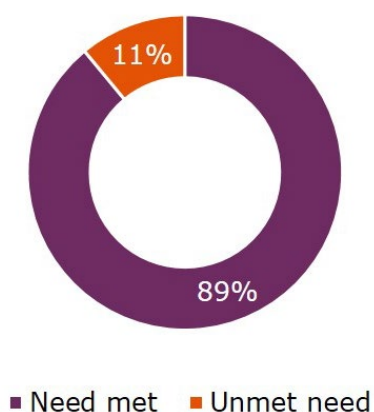
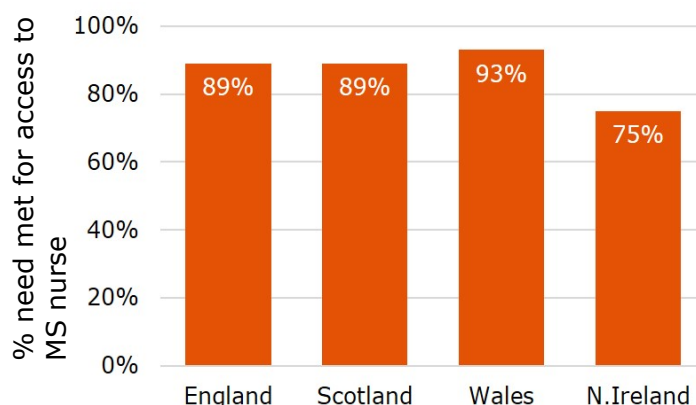


Figure 4: Access to MS nurse when needed in the preceding 12 months



- The variation in terms of proportion of people on a DMT is even greater, with a 28% gap between nations of the UK with the best access and the worst (see figure 1)
- People with progressive forms of MS were less likely to be able to access MS specialists (MS nurses and neurologists) when they need to than people with relapsing forms of MS (40% need met vs 65%)
- People with progressive forms of MS were less to have received the emotional support they needed than people with relapsing forms of MS (58% with unmet need v 44%)

Care coordination and information

28%



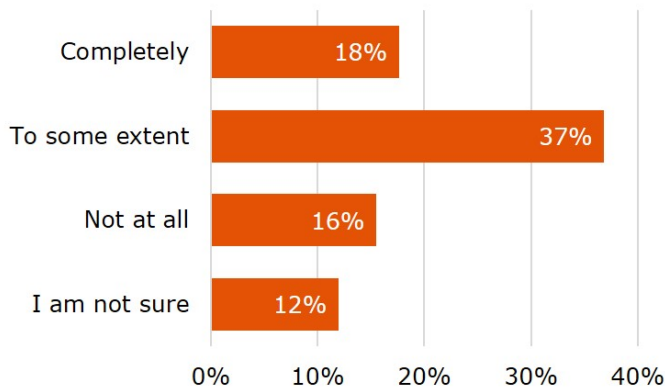
of you haven't received enough information about treatments from health professionals

- 3 in 10 (28%) don't feel they have received enough information about available treatments from healthcare professionals

- MS Specialist nurses are the key professional most people with MS (53%) identify as their key contact about their health and care

- Only 16% had a care plan and 23% would like one but hadn't got one
- 55% said the professionals involved in their care worked well together completely or to some extent. But 16% said they didn't work well together at all (figure 5)

Figure 5: How well respondents feel the professionals who plan their care work together

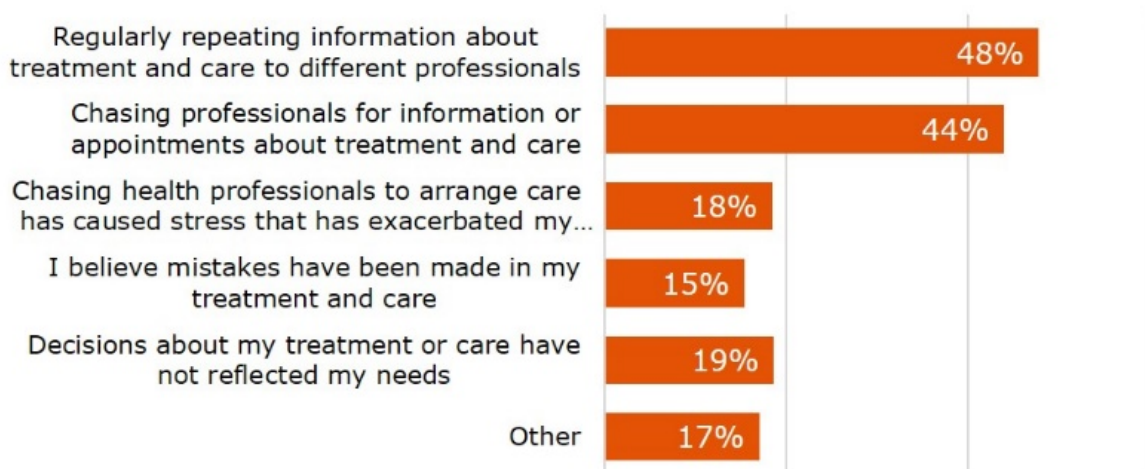


n = 8,203

Note: those who responded Not Applicable are not included in this graph.

- As a result of not believing the professionals who help plan their care work well together, 48% of them had to repeat information regularly. 44% had to chase professionals for information or an appointment. 18% said chasing professionals caused stress that has exacerbated their MS symptoms. And 15% believe mistakes have been made in their treatment and care (figure 6)

Figure 6: Impact of professionals who plan care not working well together

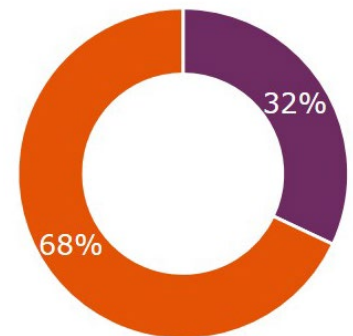
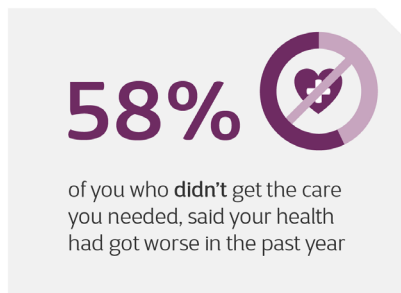


n = 4,154

Care and support

- In the past 12 months, 1 in 3 people who needed care and support (32%) hadn't received the care and support they need to assist with daily living (figure 7)
- 4 in 10 respondents with a need for care and support relied on some degree of unpaid care from their family and friends.
- Among those with unmet care needs, large proportions had also experienced deteriorating health (58%) or felt lonely/isolated (65%) over the same time period and a significant minority (21%) had been unable to work

Figure 7: Proportion of respondents who were receiving all of the care and support needed to assist with daily living



■ Need met ■ Unmet need
n = 4,505

Financial security

Income

- A significant minority (15%) of people are struggling on their current household income (figure 8)

Figure 8: Feelings about annual household income

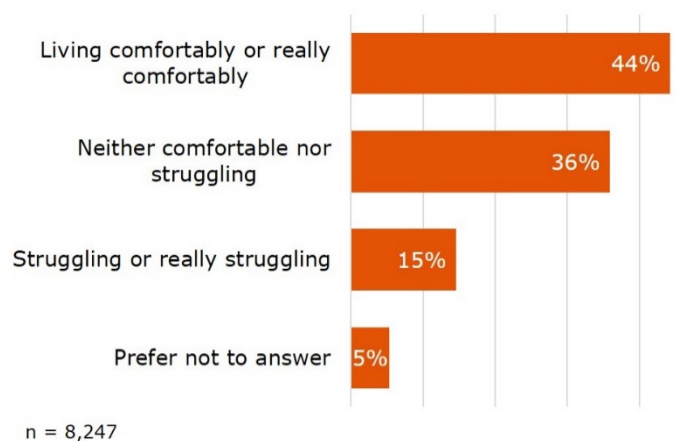
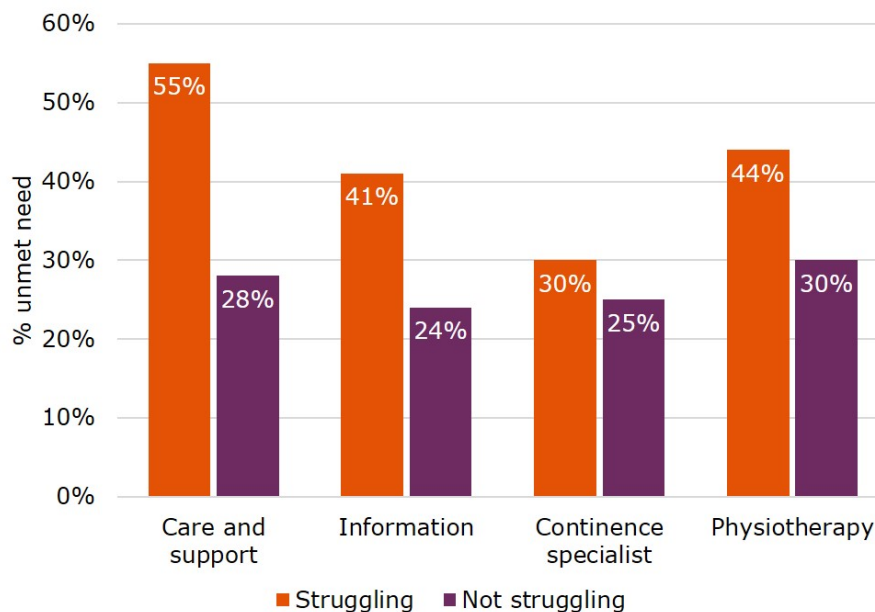


Figure 9: Impacts of struggling or really struggling on household income



- People struggling financially are more likely to have unmet needs from care and support, information, and access to specialists, than those who are not struggling (figure 10)

Figure 10: Proportion with unmet needs among those that are struggling and not struggling

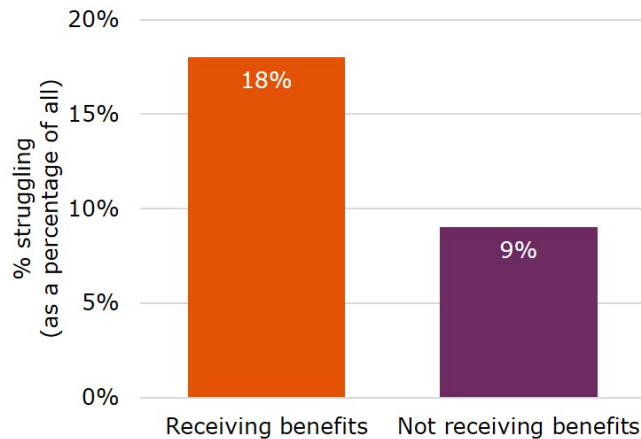


- People with an annual household income less than £25,000 – which is less than the median UK average - were less likely to have seen a neurologist, to be on treatment or get the physiotherapy they need than those with higher incomes.

Benefits

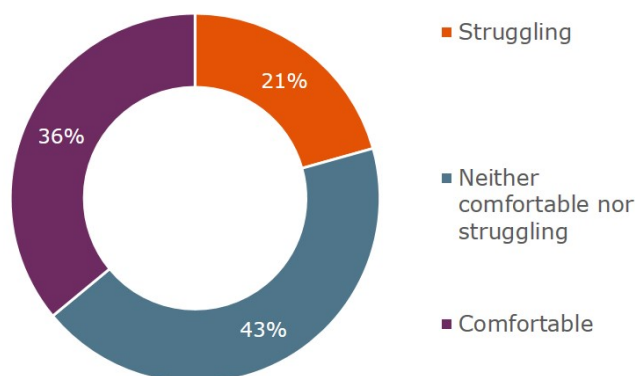
- People receiving benefits are twice as likely to be struggling on their current household income than people with MS who are not in receipt of any benefits (figure 11)

Figure 11: Proportion struggling on current household income among those receiving benefits



- Of respondents that had been on DLA and had been assessed for PIP, 17% received less money than before.
- Just over a third (36%) of those receiving PIP said they felt comfortable on their household income.

Figure 12: Feeling about current household income among respondents receiving PIP



Employment

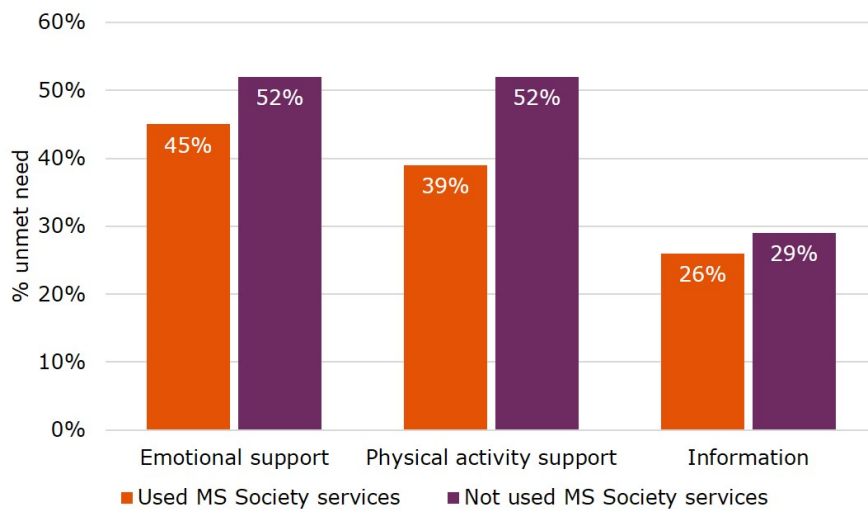
- 22% of respondents that retired early or left work entirely as a result of their MS said they wanted to stay in work, but their employer didn't support them.



MS Society services and support

- 75% of people had used one or more of our services in the past 12 months.
- People that used our services in the last 12 months had lower unmet needs for emotional support physical activity support (39% vs 52%) and information to manage their MS (26% vs 30%%), than those that had not used our services.

Figure 13: Proportion of unmet needs for services and information



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**