A large, stylized graphic element consisting of a central orange triangle pointing to the right, surrounded by a network of thin orange lines that form a complex, interconnected shape. The background is white with a subtle pattern of orange and yellow geometric shapes.

**Life in lockdown:  
experiences of living  
with MS during the  
coronavirus  
pandemic**

Findings from the UK MS Register  
'Additional impacts of lockdown'  
survey

20 July 2020

**Let's stop MS together**

## 1. Living with MS during lockdown

In March 2020 the UK went into lockdown to slow the spread of the novel coronavirus Covid-19. The restrictions imposed had a significant impact on everyone in the country. For those living with long-term conditions, including the estimated 130,000 people living with MS in the UK, it heralded the beginning of a period of instability and uncertainty for them and their loved ones. A new and therefore little understood virus, brought uncertainty about the risks to people with MS and the additional risks associated with treatments that modulate the immune system. Some people with MS were identified as 'extremely clinically vulnerable' to Covid-19 and advised by the Government to limit time outside and contact from others in order to 'shield' themselves from potential infection. The shielding guidance brought new challenges to safely accessing essentials such as food and medications, and employment. Some healthcare appointments and social care were delayed or cancelled, or moved to telephone and video platforms where appropriate. It also meant that many people were left with little or no ability to interact socially with family, friends or support systems, and were less able to exercise. There were concerns about deteriorating physical and mental wellbeing as a result of the restrictions.

The UK MS Register moved quickly at the beginning of lockdown to capture as much information as we could from people with MS on its impact. This included clinical data on the number of people infected by the Covid-19 virus and their experiences post infection. We also recognised that understanding the indirect impact of lockdown on wellbeing, employment, access to health and care, was going to be crucial to ensuring that we were doing everything we could to support you during this critical time. So, at the end of April we launched the 'Additional impacts of lockdown' survey on the MS Register. This report outlines some of the findings from that survey and a follow up survey in June. They have already enabled us to successfully campaign and influence UK governments to improve support for people with MS during lockdown, making a real difference to the whole MS community. Thank you to everyone that took part in the survey.

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## 2. Key Findings

### Emotional wellbeing and connectedness

- Significantly higher proportions of respondents said they were coping and feeling supported in June than in May
- 16% of respondents don't live with another adult, and 36% of them said they felt lonely, which is significantly higher than amongst those that live with one or more adults (12%).

### Employment and finances

- Of those that were in employment before lockdown, 29% had pay/hours employment reduced
- 12% of respondents think there will be a long lasting negative impact on their household finances while 20% said short term impact.

### Access to healthcare services and self-management

- 32% had their appointments cancelled or delayed by their healthcare professional, but 7% had cancelled or delayed appointments themselves due to concerns about infection
- In June, 45% of respondents had accessed appointments by phone or video conference (up from 30% in May)
- 29% of respondents said they were struggling to stay physically active, consistent in both May and June
- When asked what support would be most useful right now, 19% of respondents wanted exercise tips or classes they could do from home.

### Care and support

- In June 8% of people told us that care had been reduced by their provider and 7% reduced it themselves because of fear of infection (down from 12% in May).
- 24% were receiving help from volunteers, but 14% also told us that they needed help but weren't getting any
- 9% of respondents said they needed help with delivering shopping in June. This is significantly less than the 16% of people that told us they needed this support in May.

### Experiences of shielding

- 23% of respondents had received a letter or message from the NHS advising them to shield
  - Of the 77% of total respondents that didn't receive a shielding letter or message, 30% told us they do not leave the house at all
  - People who were shielding were significantly more likely to say that they were struggling to stay physically active than those who were not shielding (38% vs 25%)
  - People who were shielding were significantly more likely to say they had appointments with the healthcare professionals that help to manage their care delayed or cancelled than those people who were not shielding (40% vs 28%).
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### 3. About the survey

This survey was compiled by the MS Society. Feedback on the draft survey was gathered from over 100 people with MS who are members of our Research Network co-production group.

The survey was hosted on the UK MS Register. Due to the time constraints and the rapidly changing environment during the early phase of lockdown, alternative completion methods (paper/verbal) or accessible versions of the survey were not produced.

The survey opened on 24 April 2020. The first round of the survey was continuously available to members of the UK MS Register until 11 May 2020 when the survey closed. The survey was completed by 2,387 people with MS who are members of the UK MS Register.

A follow-up survey with the same questions was sent to those people who completed the first survey to assess any changes in responses or overall proportions. This survey was available to be completed between 8 and 22 June 2020. The follow-up survey was completed by 1,137 people with MS who are members of the UK MS Register.

Unless otherwise stated the data in this report refers to the sample from the follow-up survey in June 2020. Unless otherwise stated any comparisons to the figures from the May data are direct comparisons to the sample cohort that completed the original survey and the follow-up survey.

Demographic data on age, MS diagnosis, gender or EDSS score are taken from additional surveys hosted by the UK MS Register and linked by a unique user ID. Data on EDSS was included if respondents had updated their response within the previous 6 months.

Shielding status is similarly linked from the UK MS Register Covid-19 clinical survey. Shielding status in this data is the last known shielding status for respondents. When the clinical survey first opened the question around shielding asked if people were self-isolating. In the follow-up questionnaire the questions changed to include asking if people had received a shielding letter and a question on different behaviours for social distancing including not leaving the house at all, going to shops, talking with people at a distance or travelling to work. The shielding status used in this data refers to the last entry from each respondent and combines the original data collection and follow-up questionnaire. The survey opened on 17 March 2020 and respondents have been asked to review their responses every two weeks in order to capture any changes. This data captures responses up to 28 May 2020.

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## 4. Demographics of respondents

Due to the rapid nature of the survey construction and data collection, the survey sample was not designed to be directly representative of the general UK population or the population of people living with MS in the UK.

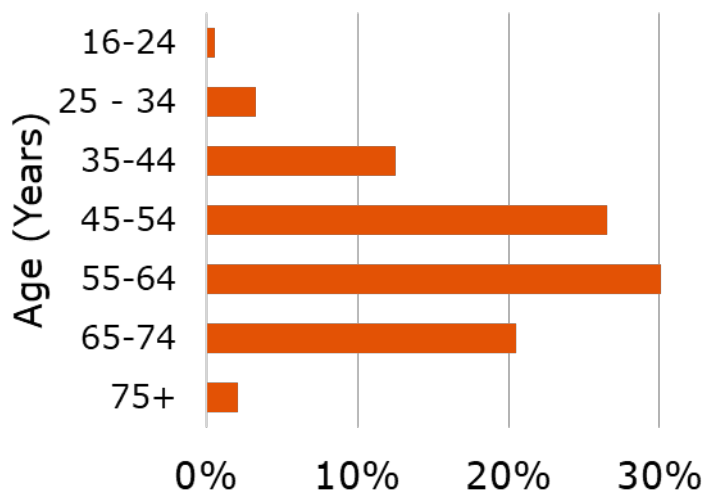
68% of respondents were from England. 61% of respondents were female, the majority of respondents were aged between 45 and 64, and 44% reported a diagnosis of relapsing remitting MS.

**Proportion of respondents in each nation of the UK**

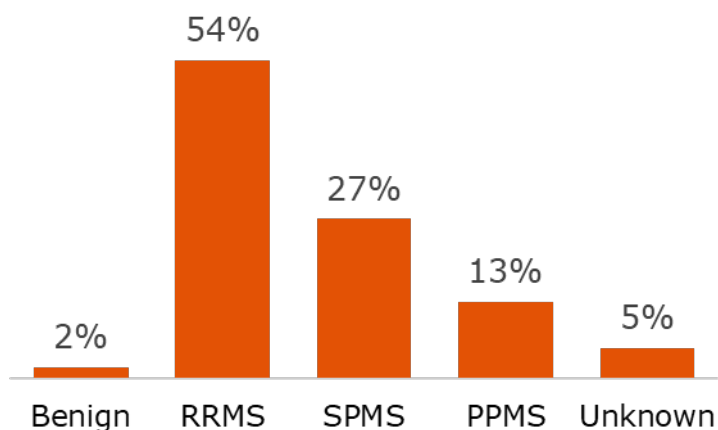


Unknown = 3%

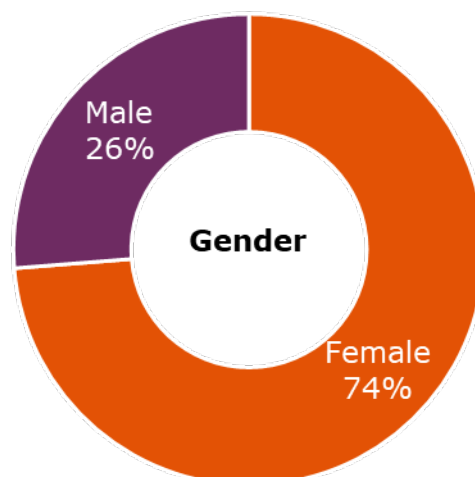
**Age of survey respondents (UK)**



**Reported MS diagnosis of respondents**



**Gender of respondents**

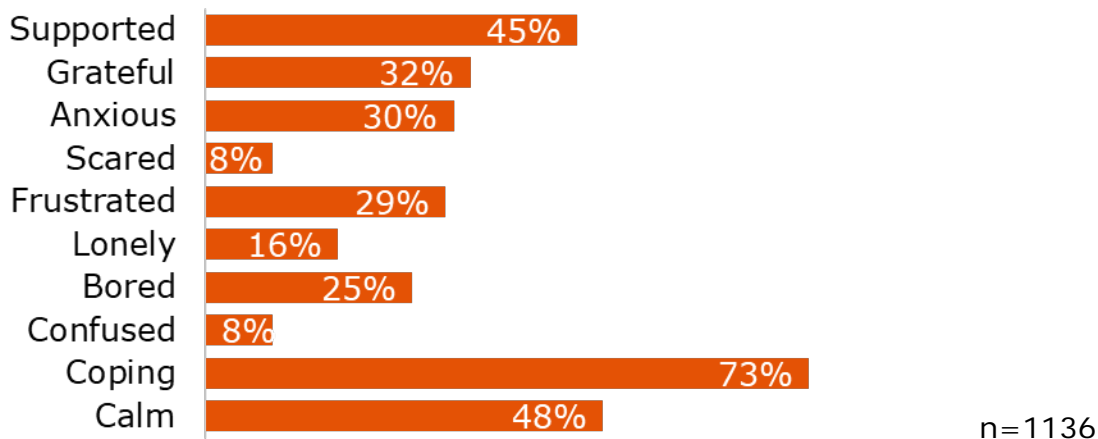


## 5. Survey findings

### Emotional wellbeing and connectedness

We began by asking respondents to identify how they were feeling right now from a list including calm, coping, anxious, supported and frustrated, among others. During the period from May to June we saw some positive changes in the proportions of people who responded that they were coping (68% of respondents in May said they were coping compared with 73% of respondents in June). When we looked at the same people who responded in May and June a significantly higher proportion reported that they were feeling supported in June. Similar proportions of people were feeling anxious, grateful, frustrated and bored (between 25% and 32%). These results reflect the range of feelings and experiences of the MS community.

#### Which of these comes closest to how you are feeling right now?



Although large proportions of people are feeling calm, supported and grateful we know that some people have struggled at different points in different ways. Small proportions of people go days without speaking to anyone (7%), have had to do without essential items (4%) and haven't been able to get medications (2%).

*"I've been able to do a lot more around the house as my energy is now focused on that... I am managing to help neighbours in a small way by getting their shopping added to my delivery."*

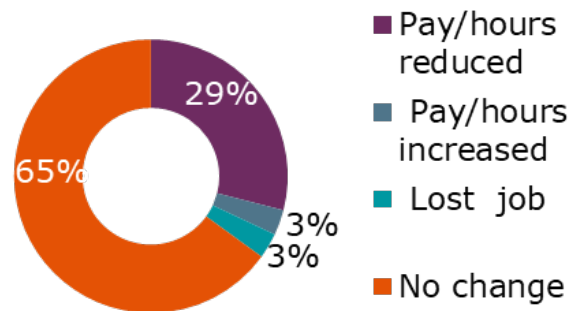
24% of people told us that they felt more connected to their neighbours and community. However, 16% of respondents don't live with another adult, and 36% of them said they felt lonely, which is significantly higher than amongst those that live with one or more adults (12%).

## Employment, benefits and finances

The nationwide lockdown has had an unprecedented impact on the way we work and will inevitably have affected many people's employment status and household finances.

Overall the majority of respondents were either not in work or had seen no change to their employment situation. But, of those that were in employment before lockdown, 29% had pay/hours employment reduced.

### Changes to employment situation for those employed at the start of lockdown



Note: Pay/hours reduced includes furloughed employees  
'Employed' includes self-employed

n = 446

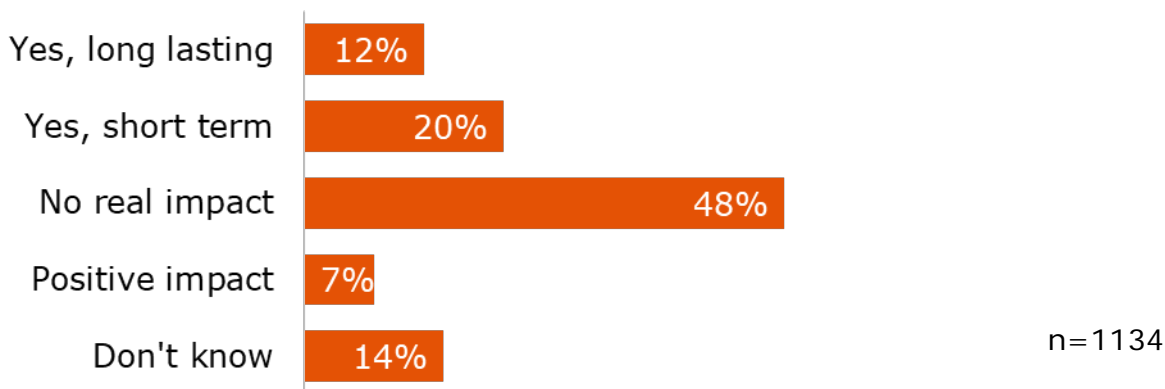
5% of respondents had newly applied for benefits. The most common benefit applied for was Universal Credit (40% of those who had applied for benefits) with a smaller number applying for Employment Support Allowance (ESA), Personal Independence Payment (PIP), Carers Allowance, Job Seeker's Allowance (JSA) and Housing benefit.

Of those that had received or applied for any benefits pre-pandemic, the pandemic did not cause any delays for the vast majority (91%) of respondents. A small number of respondents had experienced delays to assessments, tribunal hearings or mandatory reconsiderations.



We asked people to think about whether this period of lockdown will have an ongoing impact on their household finances. 12% of respondents think there will be a long lasting negative impact on their household finances while 20% said short term impact.

### Do you think the coronavirus outbreak will have an impact on your household finances?



### Access to healthcare services and self-management

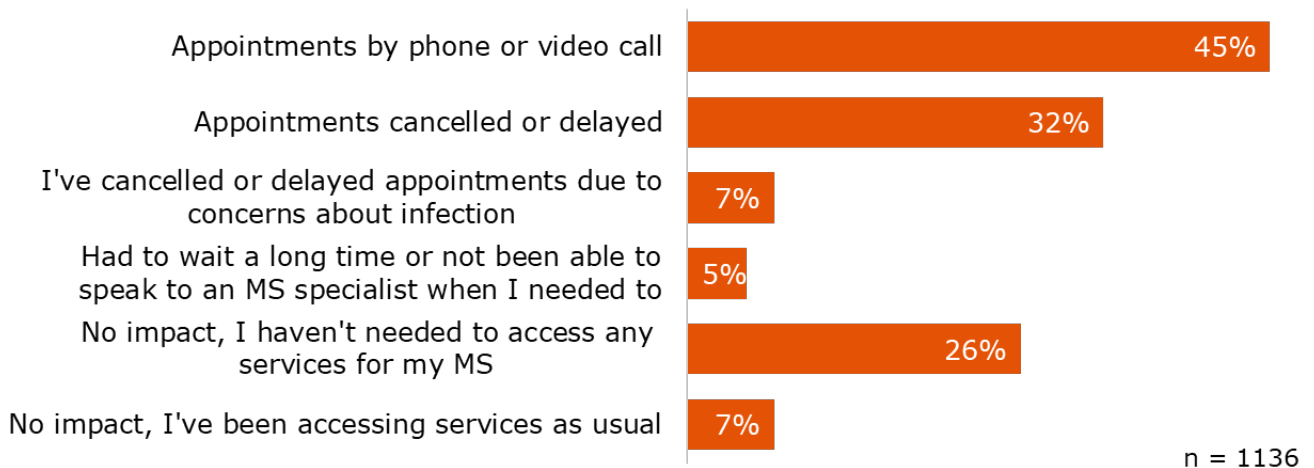
Non-essential face to face appointments with healthcare professionals were suspended at the end of March in accordance with the lockdown rules across the UK. This had a direct impact on the way people with MS were able to access services to manage their condition. Certain disease modifying therapies were not started during the peak of the pandemic in accordance with Association of British Neurologist (ABN) guidance, because they can increase the risk of catching an infection generally. Appointments cancelled, delayed or limited have included symptom management, rehabilitation, mental wellbeing and diagnostic procedures.

32% had their appointments cancelled or delayed by their healthcare professional, but 7% had cancelled or delayed appointments themselves due to concerns about infection. However, some appointments were taking place instead by phone or video conference instead of face to face. 45% (up from 30% in May) of respondents had accessed such appointments.

*“Due to not being able to have my first proper consultation face to face with a neurologist specialising in MS I have decided not to start treatment due to fears of not being able to access services should I need them if the treatment started affecting me negatively.”*



## How has the coronavirus outbreak impacted on your access to services?



While some respondents pointed out that they are exercising more, a large proportion of people have been struggling to stay physically active during the lockdown period. When asked how coronavirus had impacted their daily lives 29% of respondents said they were struggling to stay physically active, consistent in both May and June. When asked what support would be most useful right now, 19% of respondents wanted exercise tips or classes they could do from home. The proportion of people wanting support with physical activity at home was significantly higher for people with reported higher levels of disability as recorded by their EDSS score.

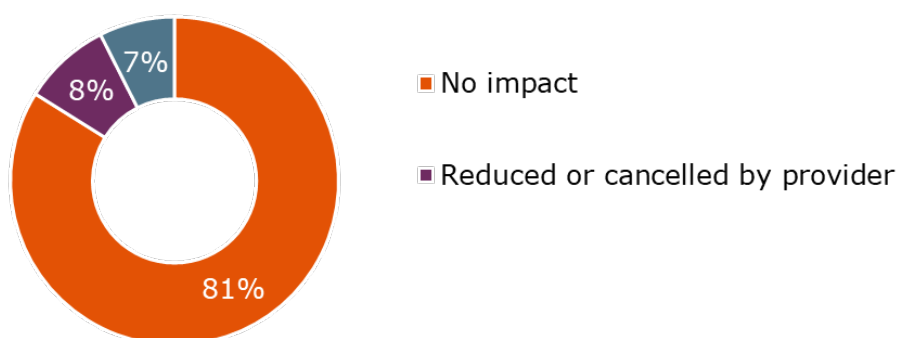
*"I am feeling a lot worse without the treatments which would normally keep me on an even keel. My walking has deteriorated. The [MS] Centre is also a wonderfully social place and I miss it."*

## Care and support

Many people with MS rely on support from either paid carers or informally from friends and family. We know that many people felt unsure about how to best manage care and support coming into their home with the uncertainty about the risks to their own health from Covid-19.

Of those that needed care and support most people had seen no changes to the care they received during the period of May and June. However, in June 8% of people told us that care had been reduced by their provider and 7% reduced it themselves because of fear of infection (down from 12% in May).

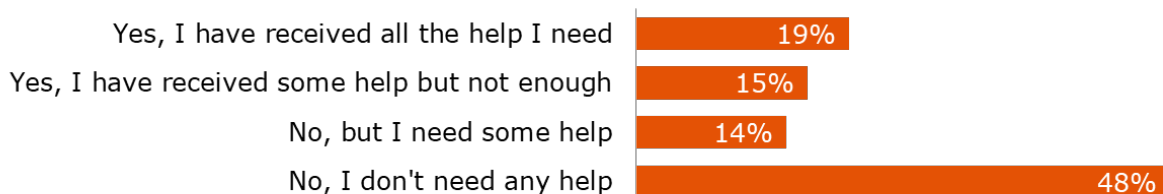
### Has the coronavirus outbreak had an impact on the support you get?



Note: Not included in this graph is 9% of respondents who selected other or don't know n = 422  
Question asked only of those respondents that had identified that they required care and support assist with daily living.

In response to the expected increase in need for support during lockdown, hundreds of thousands of volunteers were recruited nationally. In addition there was a massive mobilisation of localised community volunteer networks. Volunteers have delivered food and medicines, and offered social interaction to those isolating due to having Covid-19 or to being at increased risk of infection. 24% of respondents to this survey were receiving help from volunteers, but 14% of people also told us that they needed help but weren't getting any.

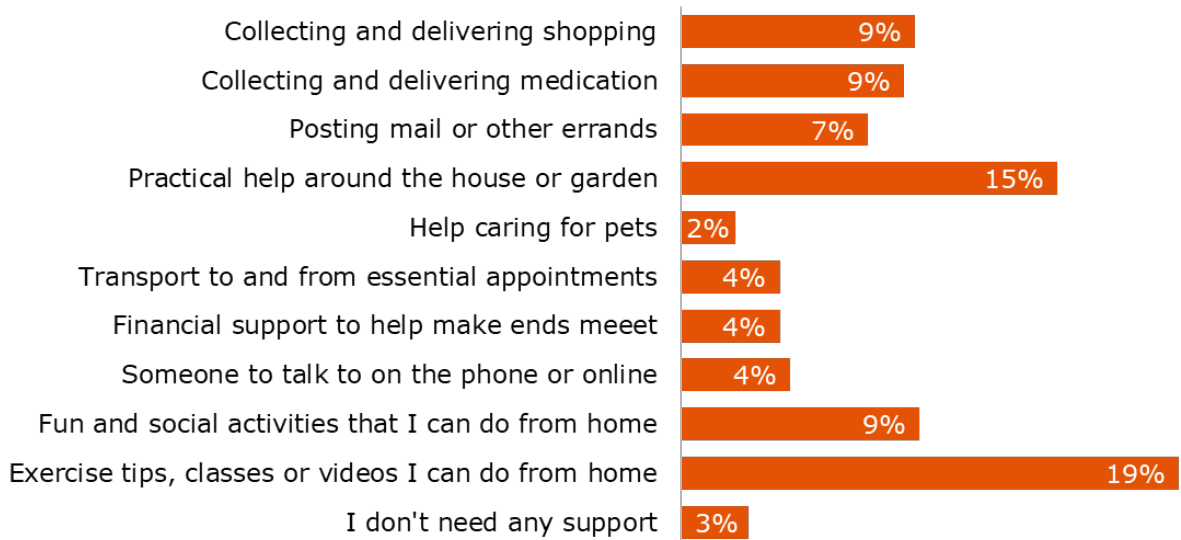
### Are you getting help from any volunteers?



Note: Respondents who selected 'I don't know' are not included in this graph n=52

When asked what kind of support would be most helpful right now 9% of respondents said help with delivering shopping. This is significantly less than the 16% of people that told us they needed this support in May. As mentioned earlier, a large proportion of people mentioned support to stay physically active at home (19%). 9% of people also mentioned that they would like fun, social activities they could do from home.

### What kind of support would be helpful to you at the moment?



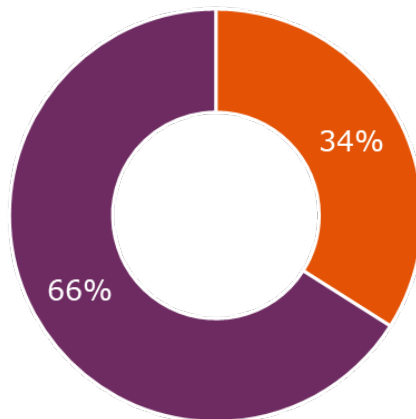
n=1119

## Experiences of 'shielding'

Data collected up to 28<sup>th</sup> May 2020 showed us that 34% of total respondents said they don't leave the house at all. 23% of respondents had received a letter or message from the NHS advising them to shield. However of the 77% of total respondents that didn't receive a shielding letter or message, 30% told us they do not leave the house at all.

Some people did receive advice to shield via phone calls in addition to by post or messages, so some of these people could have been advised to shield by some other means. However NHS guidance has emphasised that people should receive a letter or message for reference, so we suspect this is the minority. These findings therefore indicate that many people with MS have been shielding regardless of official advice to do so.

Proportion of respondents 'shielding'  
Not leaving the house for any reason



■ Shielding ■ Not shielding

n=729 shielding,  
2402 not shielding

Those shielding were significantly less likely to report feeling 'calm' or that they were 'coping' compared to those that were not shielding.

People who were shielding were significantly more likely to say that they were struggling to stay physically active than those who were not shielding (38% vs 25%). When asked what support would be helpful right now people who were shielding were significantly more likely to say that they needed support with delivering shopping, medication and essentials than those who were not shielding.

People who were shielding were significantly more likely to say they had appointments with the healthcare professionals that help to manage their care delayed or cancelled than those people who were not shielding (40% vs 28%).

### Those who were shielding



- more likely to say
- they were struggling to stay physically active
- Appointments had been cancelled or delayed
- They needed help with delivering shopping or medications



- less likely to say
- they were calm or coping

than those who were not shielding



### **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](http://mssociety.org.uk)

### **Contact us**

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