Life in lockdown 2: experiences of living with MS during the coronavirus pandemic

Findings from the UK MS Register
‘Additional impacts of lockdown’
survey

August 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. In partnership with the UK MS Register we were able to move quickly to gather information on the experiences of people living with MS. The data we collected in May and June are presented in the first of this series of reports ‘Life in Lockdown: Experiences of living with MS during the coronavirus pandemic. The UK MS Register has continued to collect data on people with MS across the period of the pandemic. Here we report the data collected from people with MS during August 2020. As the some of the guidance and restrictions had moved on since the previous survey, such as lifting of the shielding guidance, some questions were removed and others were added. This allowed us to capture some information on how the needs and experiences of people with MS had changed across the course of the pandemic, but also delve into some of the issues that had arisen such as those around returning to the workplace or pressures on physical and mental health and the impact of the disruption or cancellation of rehabilitation support.

Some of the data captured in this round of the survey helped inform our Too Much To Lose campaign. Our report shows that missing out on vital rehabilitation support is having a devastating impact on the lives of people with MS. Too many are losing their mobility, confidence and independence. We’re asking local health decision-makers to sign our pledge. We want them to commit to doing all they can to make sure people with MS can get this vital support, during the pandemic and beyond. We're also calling for national governments across the UK to make sure rehabilitation services are given the funding and staff they need.

Thank you to everyone that took part in the survey.

2. Key Findings

- 64% of respondents said that they were coping in August.
- 40% of respondents said they were feeling calm, but 30% responded that they were feeling anxious.
- The proportion of people who said they felt lonely was significantly lower in August following an upward trend between May and June.

Employment and finances

- Those respondents who were employed prior to lockdown 71% were working at pre-lockdown levels but 20% were still seeing a negative impact on their pay or hours.
- Of those people who were employed prior to lockdown the proportion that have returned to pre-lockdown levels of employment has increased from 65% in June to 71% in August.
- Conversely, the proportion that report that their pay or hours have reduced has gone down from 30% in June to 18% in August
- 51% of respondents are working from home, 19% are working from their workplace and 10% are splitting their time between their workplace and working from home
- 29% of respondents feel safe to return to their workplace, but 19% will be or have been asked to return but are concerned about infection
- 30% of respondents said that the pandemic will have a negative impact on their household finances either in the short or long term

Access to healthcare services

- 34% of respondents said that they had appointments cancelled or delayed
- 7% had to wait a long time or were unable to speak to an MS specialist when they needed to
- Respondents who said that they had appointments by phone or video was up to 59% in August from 27% in May
- The most common appointment reported to have been cancelled or delayed was MS Nurse (46%), followed by physiotherapist (31%) and continence specialist (18%).
- 69% of respondents reported that they were unable to see a professional in at least one of the specialisms listed.
- 35% didn't receive enough support and information from video/telephone appointments

Impact on physical and mental health

- 50% of respondents are doing less physical activity or exercise than before lockdown
- 20% of respondents have attended group exercise classes online
- 34% of respondents said their MS or symptoms are worse than before lockdown
- When asked what specific symptoms respondents had seen deteriorate 76% said walking/balance, 41% said memory/concentration and 51% said they were struggling with low mood
- 51% of those who had seen a deterioration in their MS or symptoms said they thought the disruption to the services they normally receive had contributed to this greatly or to some extent.

3. About the survey

This survey was compiled by the MS Society. Feedback on the draft survey was gathered from 5 people with MS who are members of our Research Network co-production group.

The survey was hosted on the UK MS Register. The study was promoted via MS Society social media and direct mail, UK MS register direct mail and via professional contacts. Due to the time constraints and the rapidly changing environment, alternative completion methods (paper/verbal) or accessible versions of the survey were not produced.

The survey opened on 12 August 2020 and was continuously available to members of the UK MS Register until 26 August 2020 when the survey closed. The survey was completed by 1,674 people with MS who are members of the UK MS Register.
Demographic data on age, MS diagnosis, gender or nation 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.

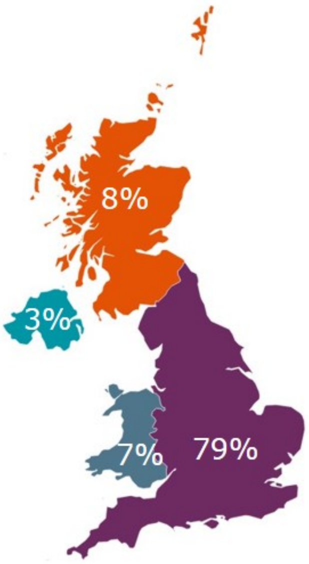
Trend analysis was carried out on questions that were asked across all three surveys. Respondents were only included if they had completed the same question in all three surveys. Trend analysis should be treated as indicative only, as some questions were removed or added in the August iteration, and so surveys are not directly comparable.

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.

Figure 1 Distribution of respondents UK



Unknown = 3%

Figure 2 Age of respondents

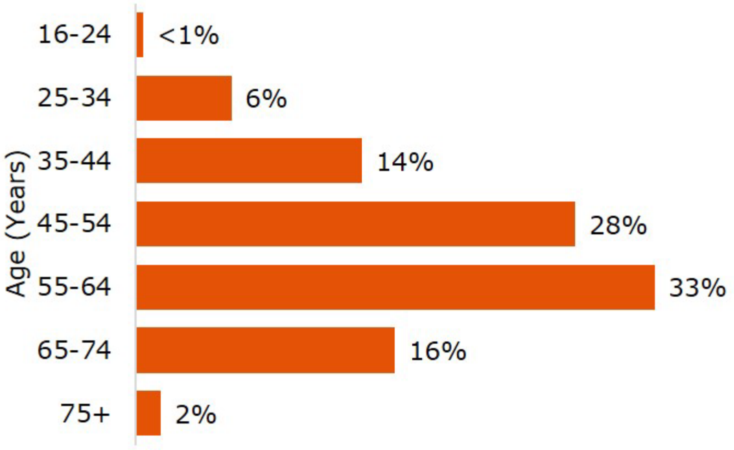


Figure 2 Self-reported MS diagnosis of respondents

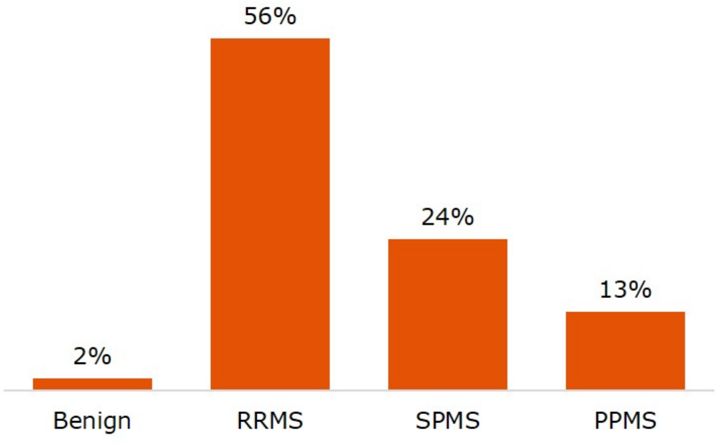
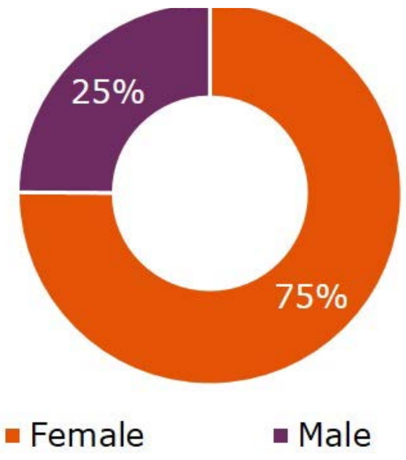


Figure 4 Gender of respondents

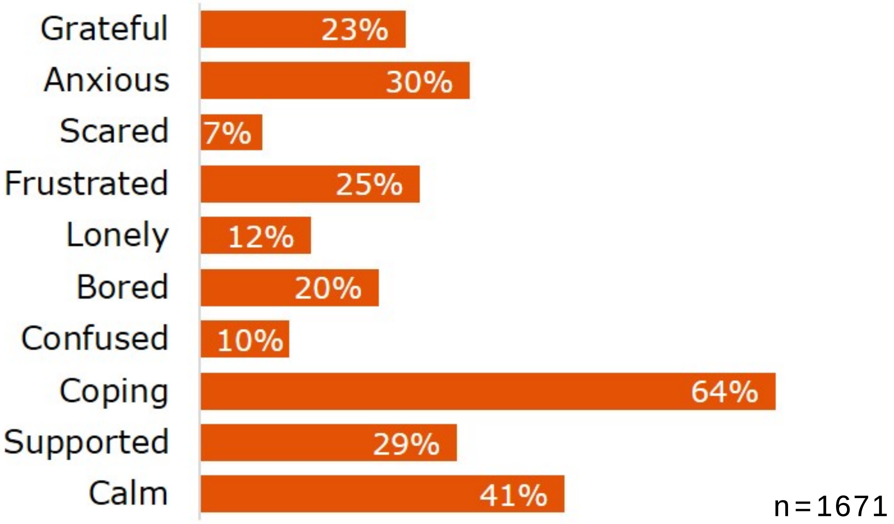


5. Survey findings

Emotional wellbeing

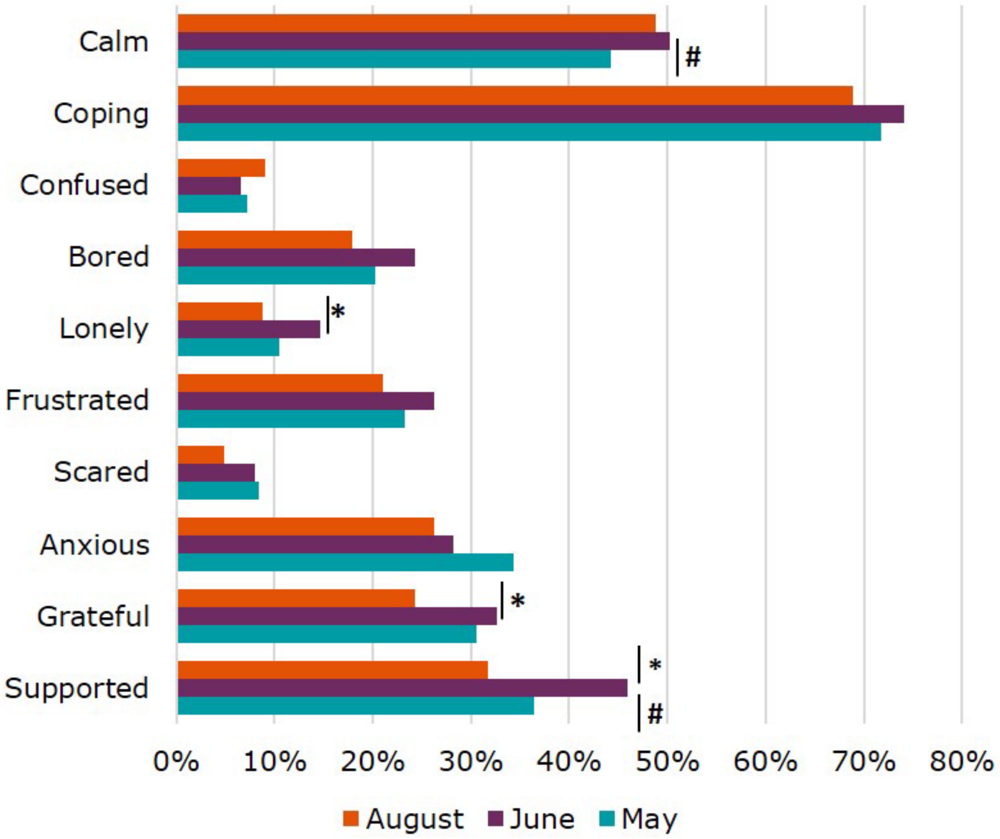
We asked respondents to identify how they were feeling right now from a list including calm, coping, anxious, supported and frustrated, among others. 40% of respondents said they were feeling calm, but 30% responded that they were feeling anxious. 64% of respondents said that they were coping in August (Figure 5). We had seen an increase in the proportions of people who responded that they were coping between May and June (68% of respondents in May said they were coping compared with 73% of respondents in June) (Figure 6). These results reflect the range of feelings and experiences of the MS community.

Figure 5. Which of these comes closest to how you are feeling right now?



Looking at those respondents that completed this question in May, June and August we see that there was a significant increase in those respondents saying they were feeling calm from May to June, and this persisted through to August. Although, there was a significant increase in those responding that they felt supported in June compared to May, this dipped down significantly in August along with those feeling grateful. In addition the proportion of people who said they felt lonely was significantly lower in August following an upward trend between May and June (Figure 6).

Figure 6. Which of these comes closest to how you are feeling right now?



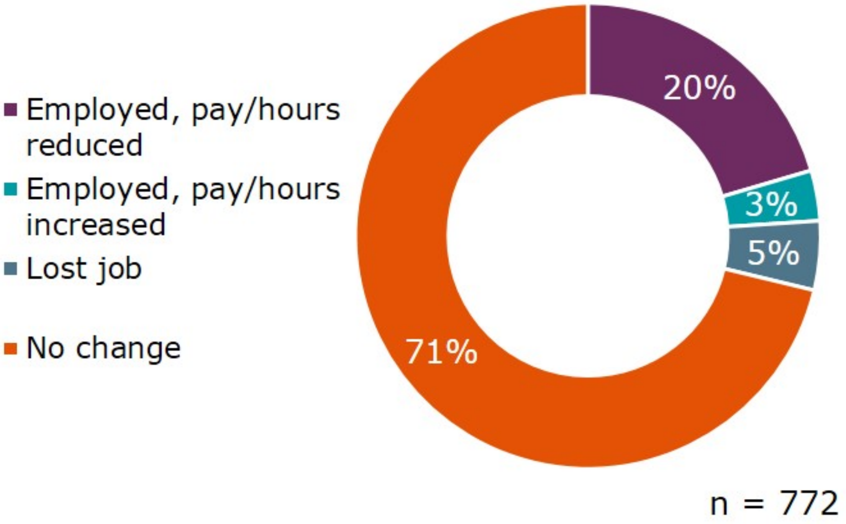
*= Significant difference between June and August, 95% confidence interval, #= Significant difference between May and June, 95% confidence interval, n=515

Employment, benefits and finances

We asked people about their current employment situation, where they are carrying out their job (e.g. working from home or office), and whether they have any concerns about returning to the workplace or about the support they are receiving to work from home.

In August, 15% of respondents were unemployed prior to the pandemic and continued to be unemployed, and 38% were retired. We saw that of those respondents who were employed prior to lockdown 71% were working at pre-lockdown levels but 20% were still seeing a negative impact on their pay or hours (Figure 7).

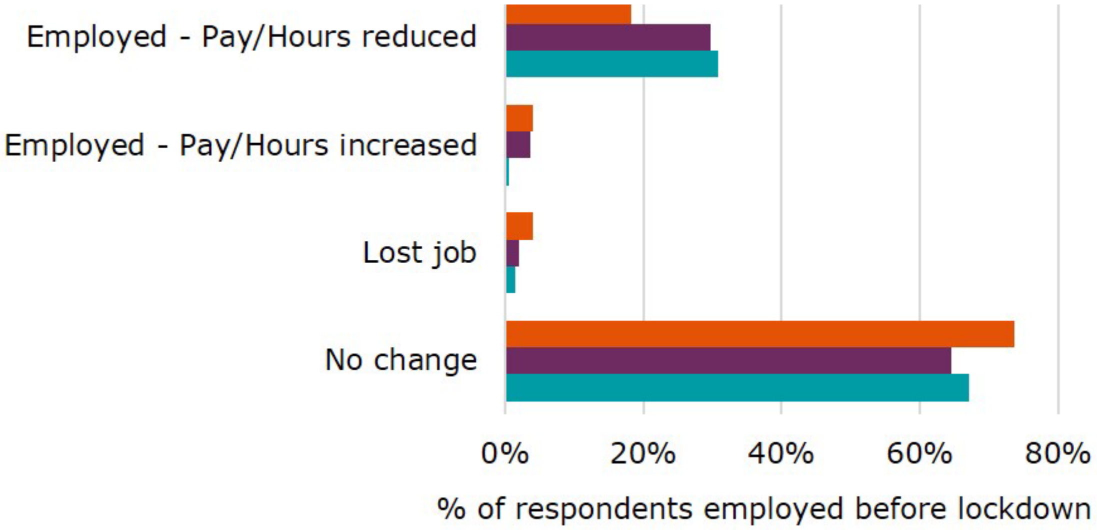
Figure 7. Has the coronavirus outbreak changed your employment situation?



Note: Pay/hours reduced includes furlough, employed includes self-employed

Looking at the group of people who responded to this question in May, June and July we can see that of those people who were employed prior to lockdown the proportion that have returned to pre-lockdown levels of employment has increased from 65% in June to 71% in August. Conversely, the proportion that report that their pay or hours have reduced has gone down from 30% in June to 18% in August (Figure 8).

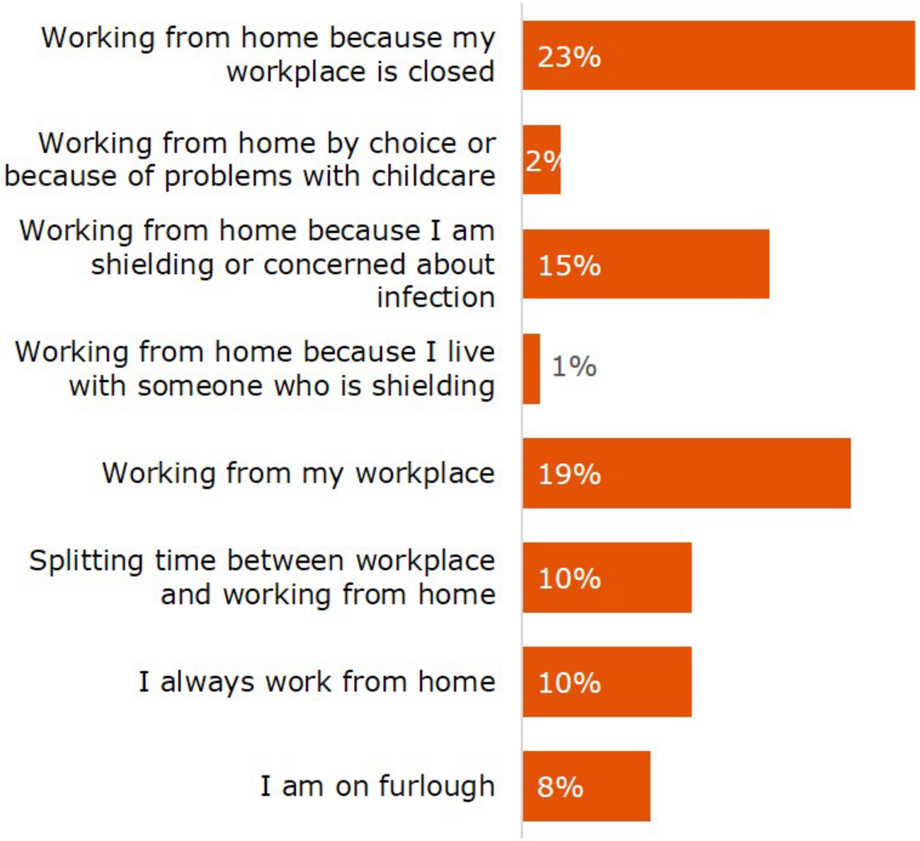
Figure 8. Has the coronavirus outbreak changed your employment situation?



Note: Pay/hours reduced includes furlough, employed includes self-employed

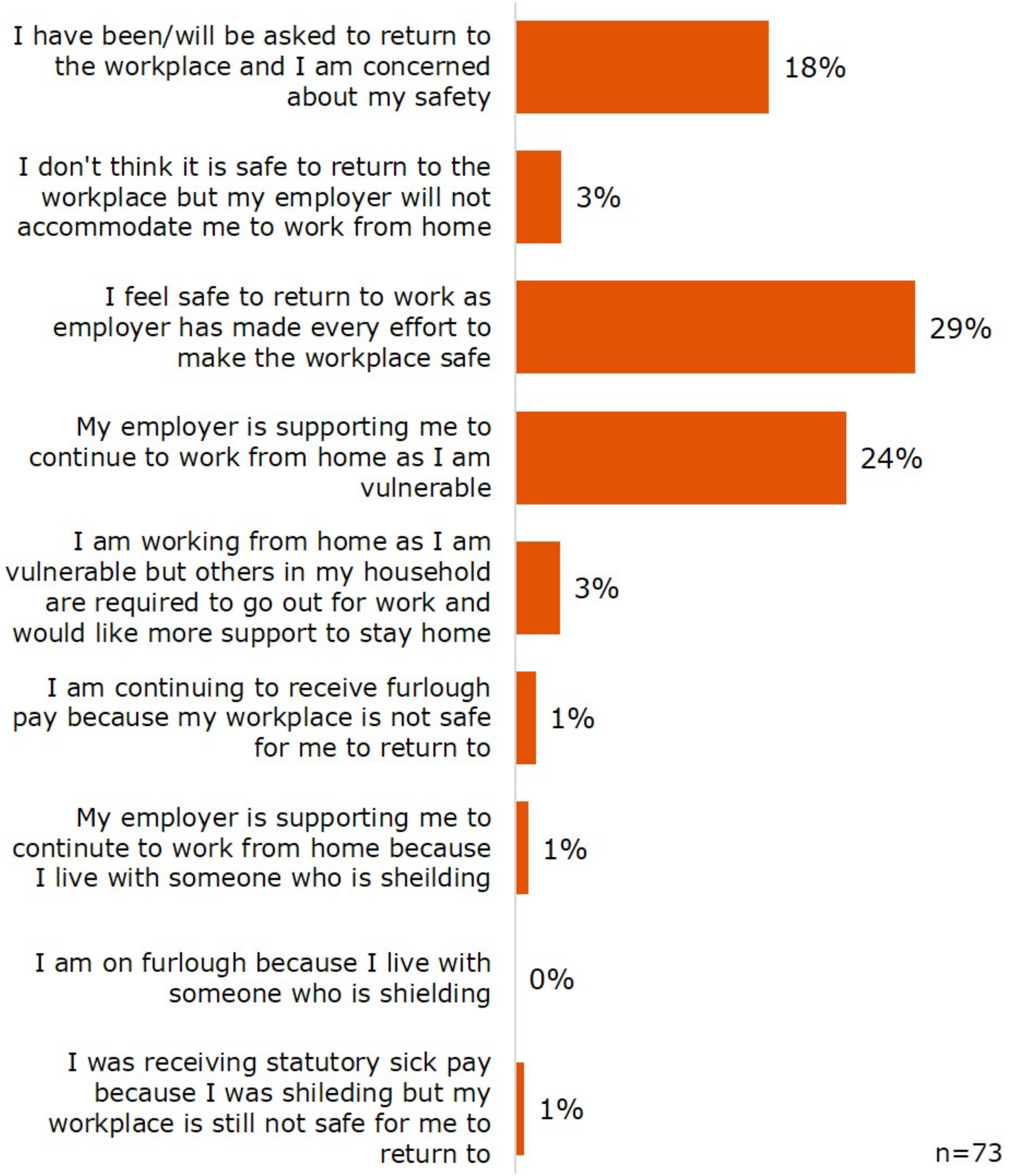
n=201

Figure 9. Where are you currently carrying out your job?



Other=7%, None of the above=5%, n=738

Figure 10. Do any of the following apply to you?



We asked people to think about whether this period of lockdown will have an ongoing impact on their household finances. 30% of respondents said that the pandemic will have a negative impact on their household finances either in the short or long term. However, 53% of respondents think that it won't really have any really impact (Figure 11). In the people that respondents to all three surveys we can see a steadily increasing trend of people say that there is unlikely to be any real impact on their finances (Figure 12).

Figure 11. Do you think the coronavirus outbreak will have an impact on your household finances?

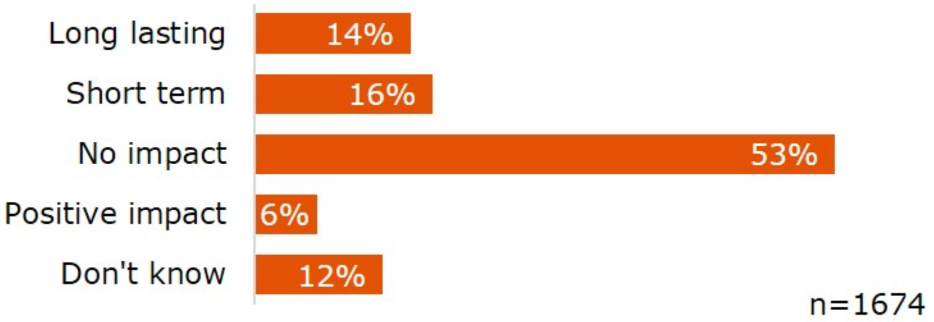
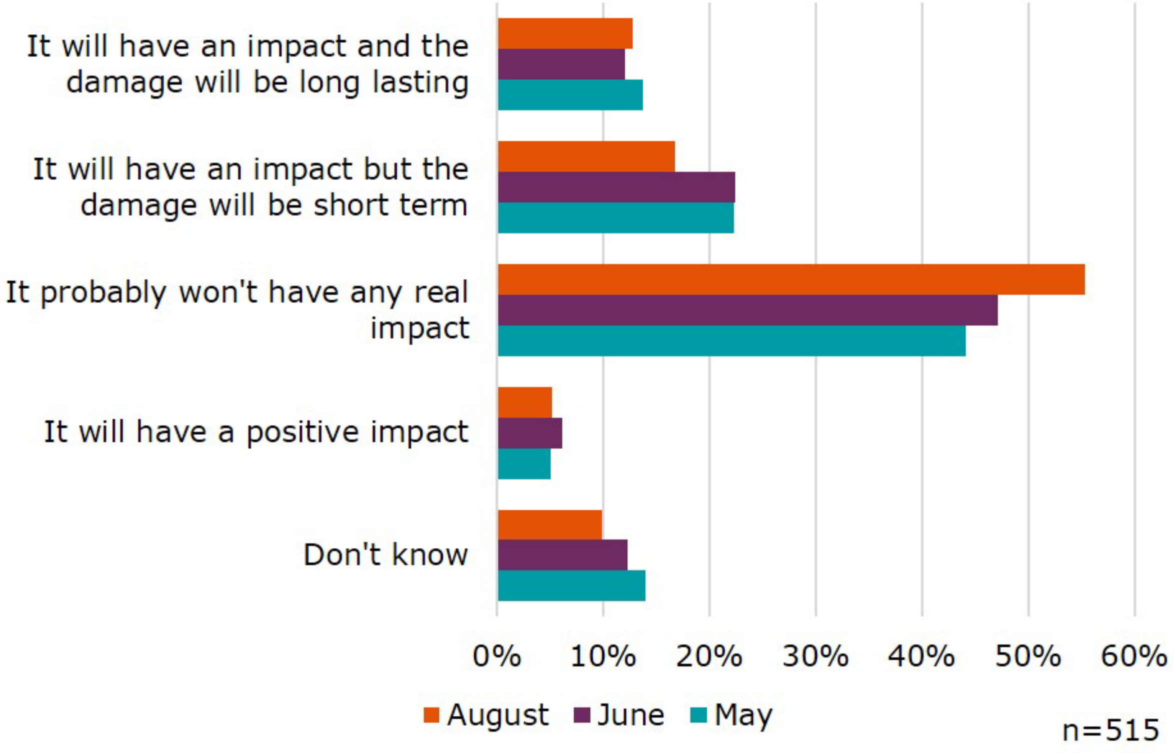


Figure 12. Do you think the coronavirus pandemic will have an effect on your household finances?

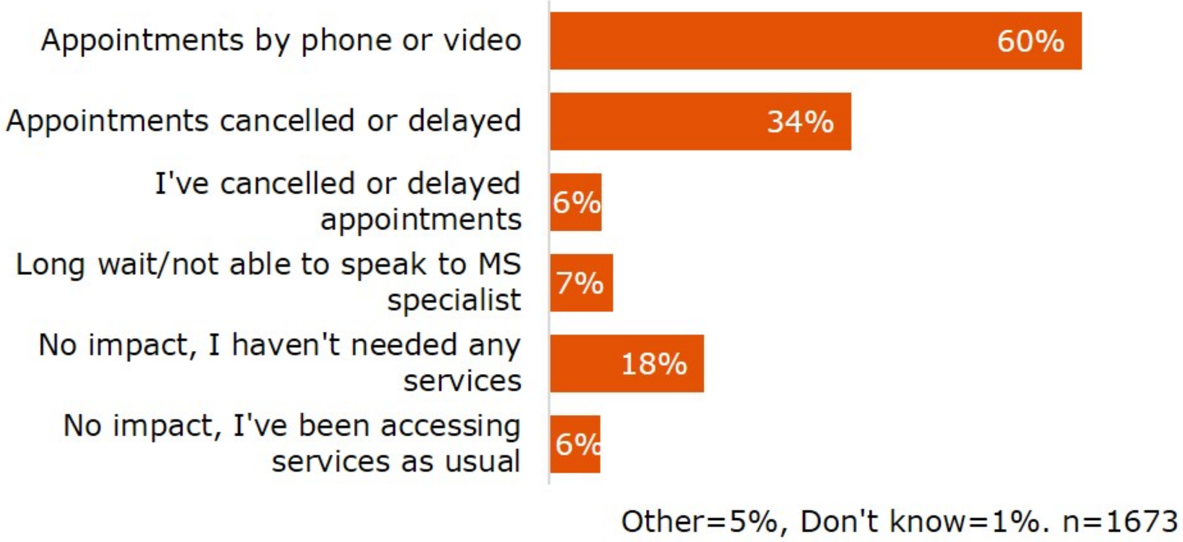


Access to healthcare services

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. Appointments cancelled, delayed or limited have included symptom management, rehabilitation, mental wellbeing and diagnostic procedures. Although in August services for people with MS had begun to reopen there was still pressures such as a backlog of patients that were affecting access.

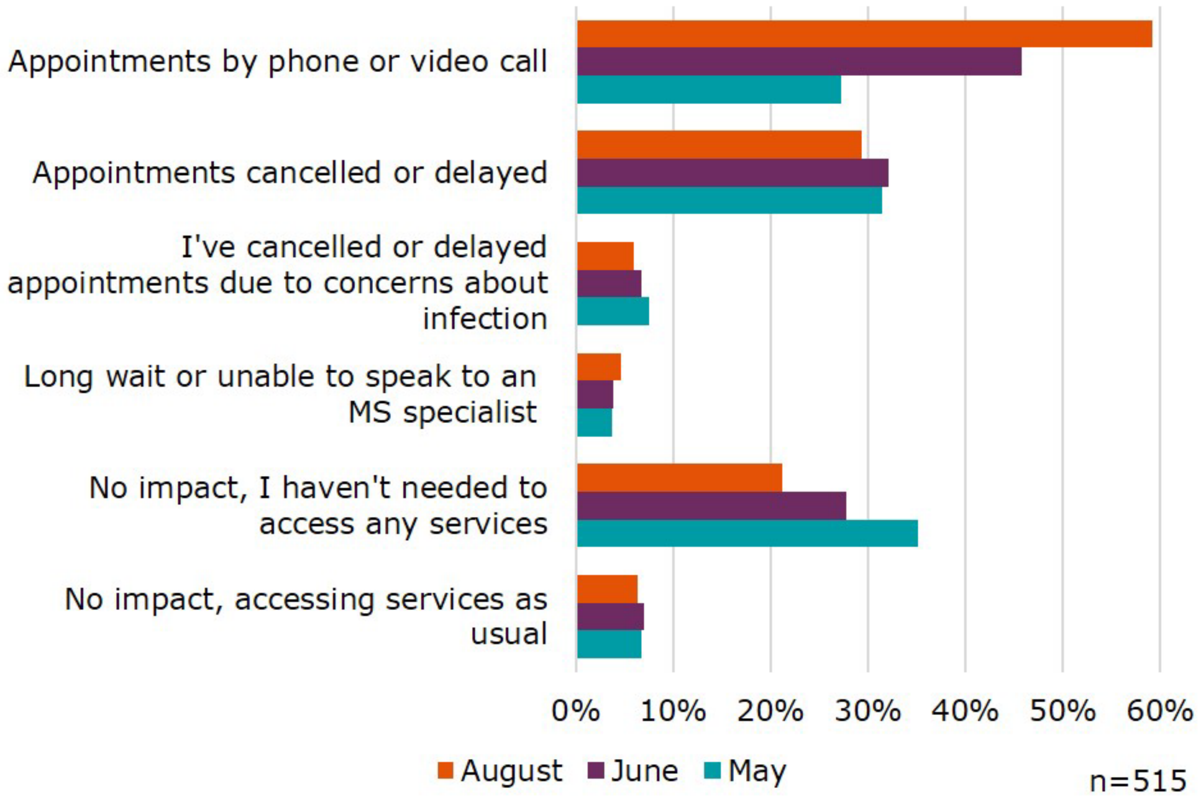
In August, 34% of respondents said that they had appointments cancelled or delayed and 7% had to wait a long time or were unable to speak to an MS specialist when they needed to (Figure 13). When comparing the results from people who had completed all three surveys these proportions had not significantly changed over the period of the surveys. We did see a consistent increase in the proportion of respondents who said that they had appointments by phone or video up to 59% in August from 27% in May (Figure 14).

Figure 13. How has the coronavirus outbreak impacted on your access to services?



> ***"I have not been able to have massage therapy during lockdown and this has impacted quite significantly on my pain and my ability to cope with my symptoms."***

Figure 14. How has the coronavirus outbreak impacted on your access to services?



The most common appointment reported to have been cancelled or delayed was MS Nurse, followed by physiotherapist and continence specialist (Figure 15). Although a proportion of respondents had been able to have appointments either in person or by telephone or video, large proportions of people said that where not able to see a professional despite their need to. This was consistent across all of the specialisms listed. 69% of respondents reported that they were unable to see a professional in at least one of the specialisms listed (Figure 16).

Figure 15. What appointments did you see cancelled or delayed?

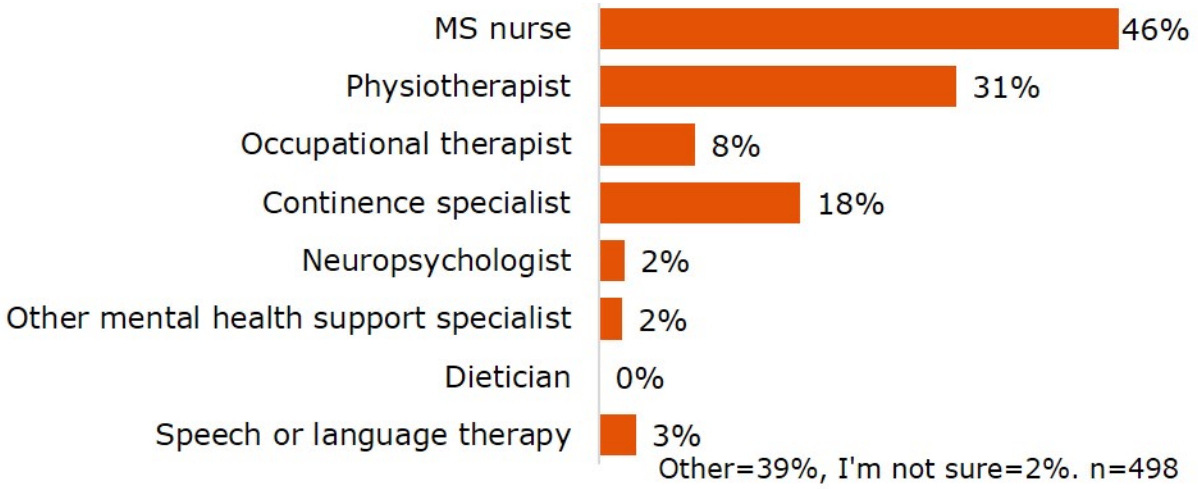
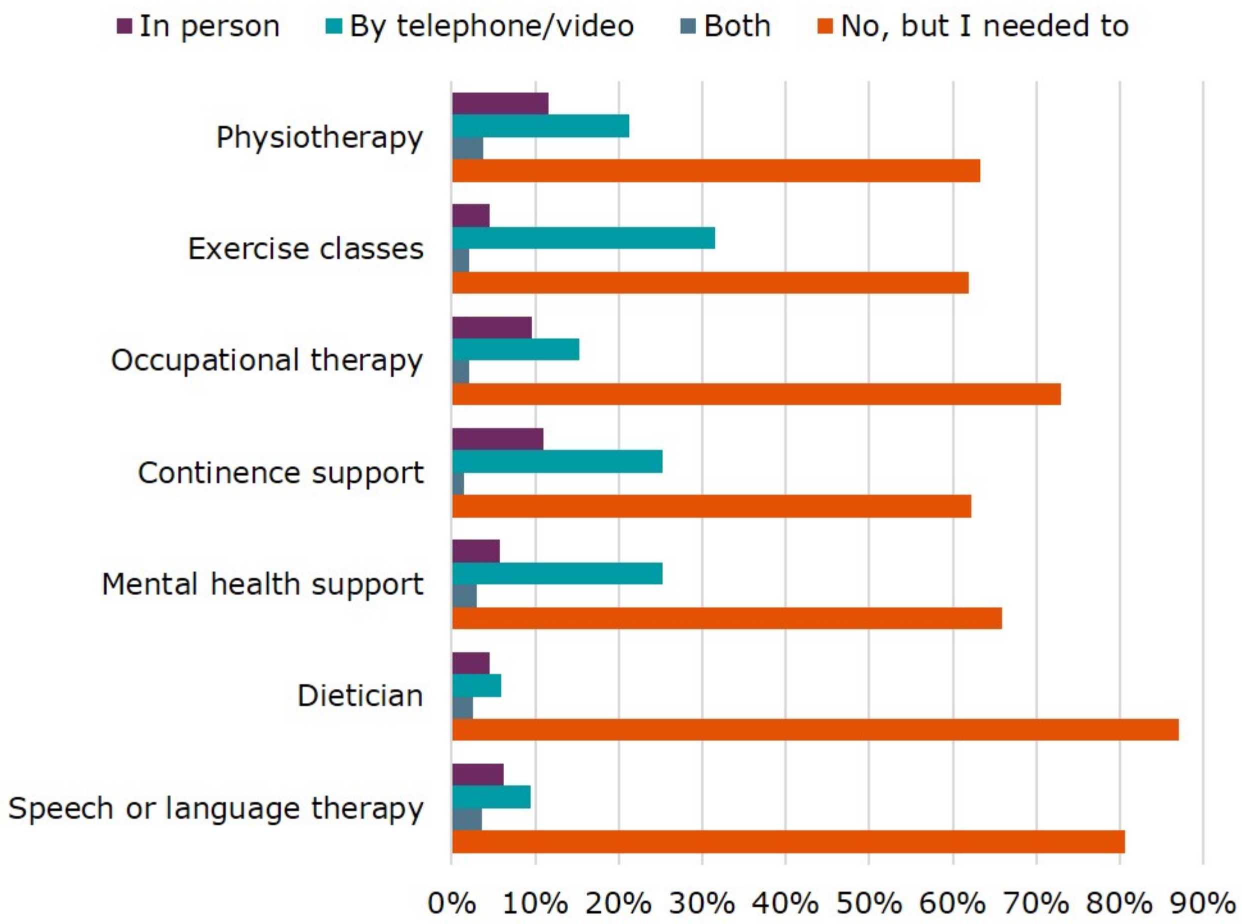


Figure 16. Since March this year, have you attended any of the following appointments by telephone / video or in person?



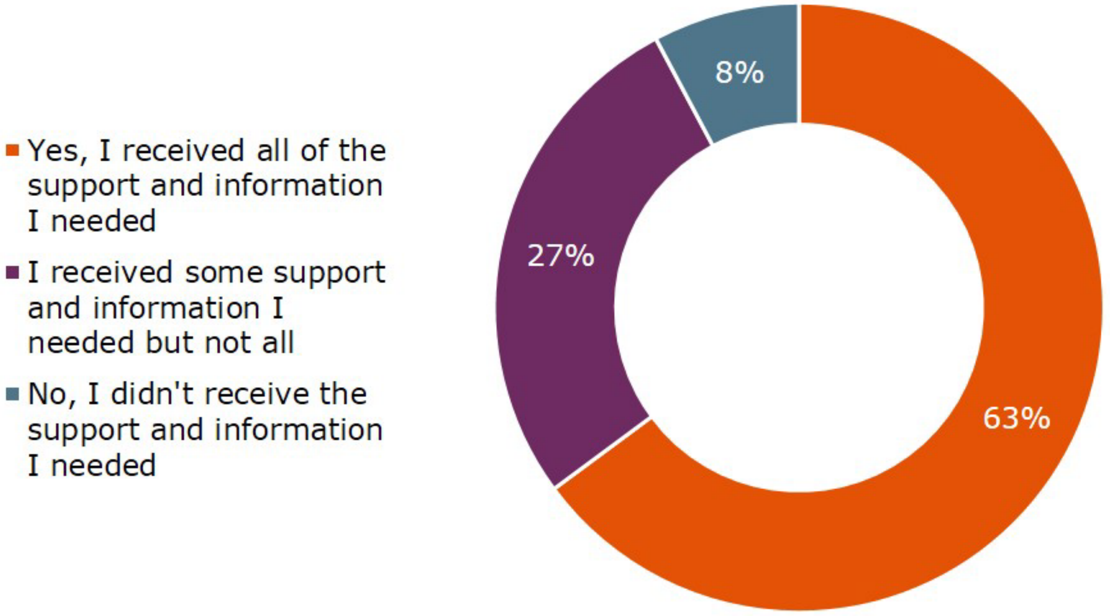
Proportions of those who needed an appointment for a specific specialist. Physiotherapy, n=619. Exercise classes, n=627. Occupational therapy, n=333. Continence support, n=391. Mental health support, n=293. Dietician, n=201. Speech and language therapy, n=191. Of the overal sample of n=1675, 56% had not needed an appointment for the support listed, 3%=other, 4%=Don't know.

> ***"Our physiotherapist for MS Group has been using WhatsApp and does a daily 5 min workout. Absolutely fantastic and keeps me focused."***

When we asked respondents who had attended appointments by telephone or video to think about whether they had received enough support and information in these appointments, 63% said that they had whereas 35% didn't receive enough support and information (Figure 17).

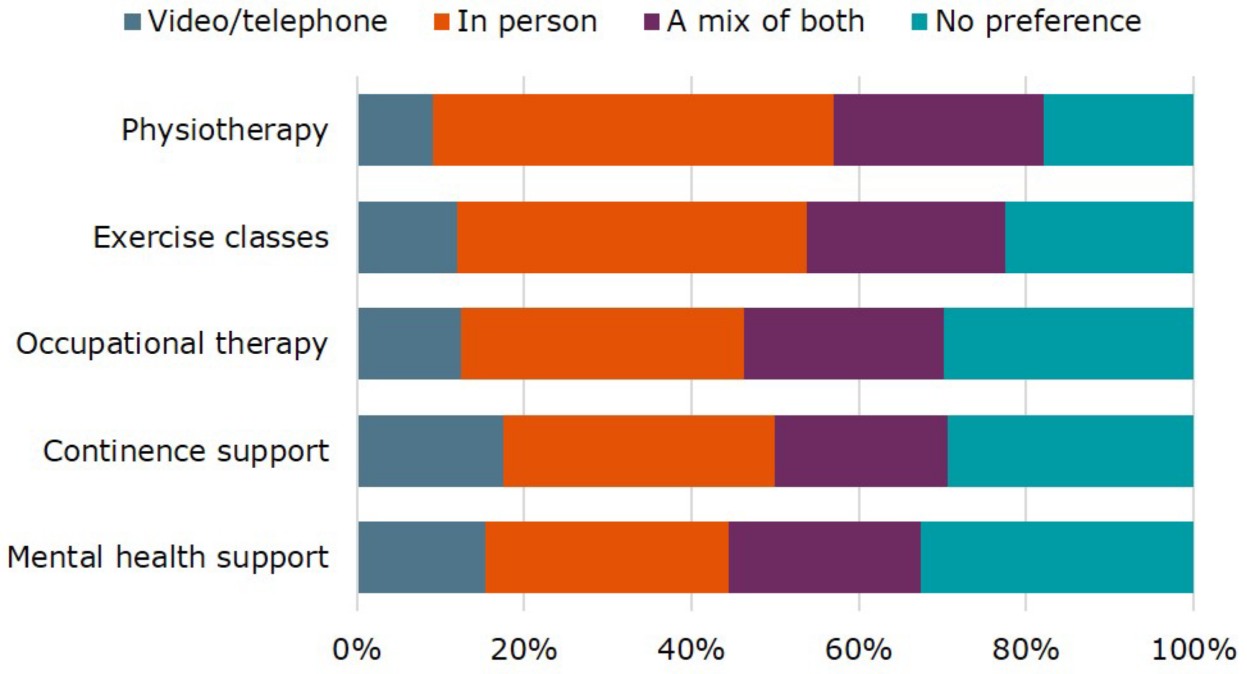
The majority of respondents who had a preference for future appointments said that they would prefer in person appointments in the future for physiotherapy, occupational therapy, exercise classes, continence support and mental health support (Figure 18).

Figure 17. Thinking about those appointments you have had by video or telephone, do you feel you got enough support?



Other=3%, n=436

Figure 18. In the future what would be your preference for attending appointments?



Respondent numbers vary as this was not a required question. Physiotherapy, n=1200. Exercise classes, n=1122. Occupational therapy, n=976. Continence support, n=979. Mental health support n=875.

Impact on physical and mental health

The disruption to lifestyles and access to the services that help people with MS to live well has had an effect on the physical and mental health of some people. In May and June a large proportion of respondents told us that they would like support to stay physically active and many commented that the disruption to access to services outside of neurologists and MS nurses was concerning them. In the following questions we aim to understand the extent of this disruption, the barriers to access and the impact this is having on the physical and mental health of respondents.

Figure 19. Compared to before lockdown do you think you are:

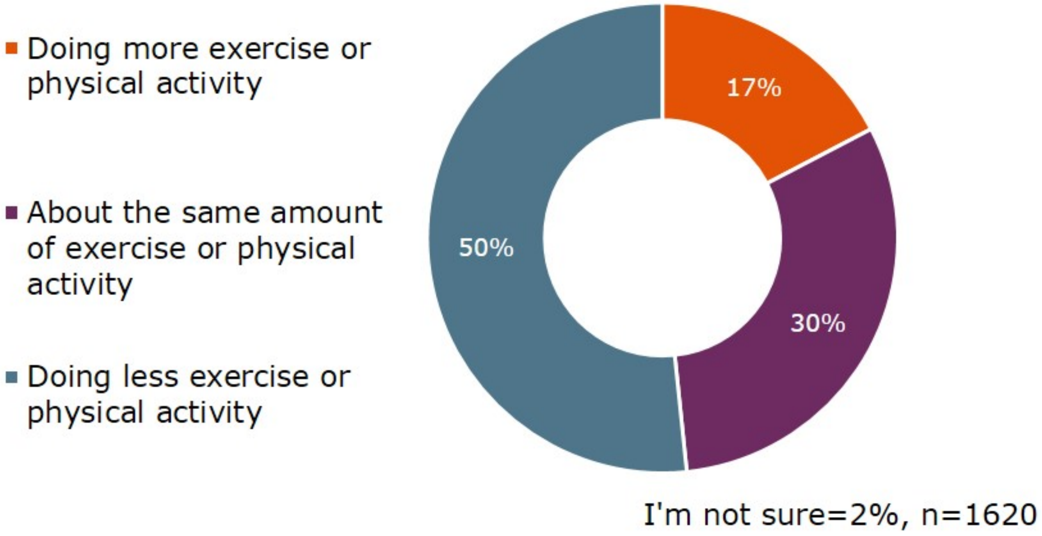
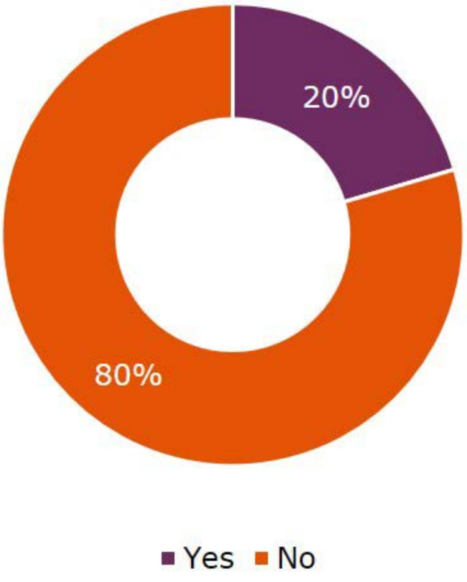


Figure 20. During lockdown, have you attended group exercise classes online?



> ***"I attend group physio sessions on Zoom. I was doing them in person before lockdown. It's meant I can keep it up; if anything, it's easier to do it because I don't leave home."***

Figure 21. Do you think you will continue to attend online classes in the future?

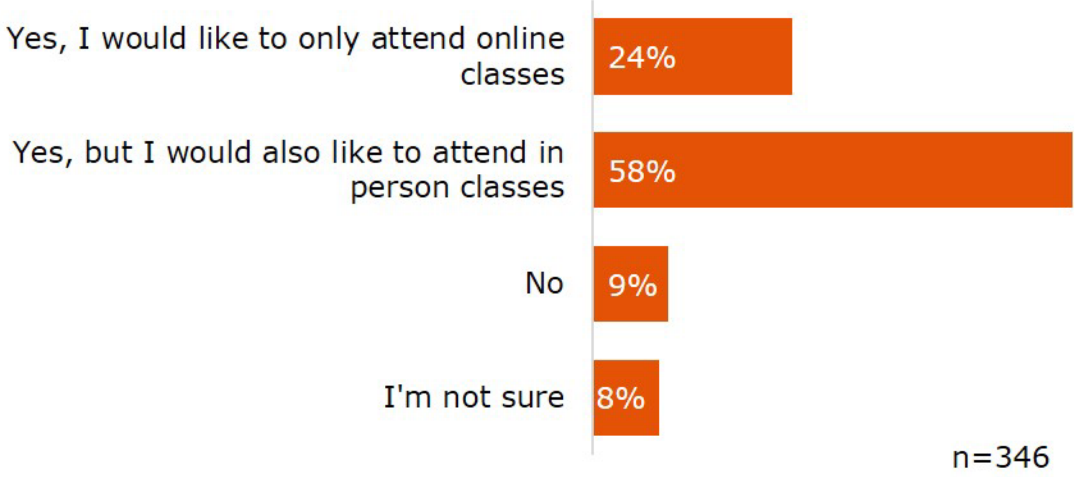
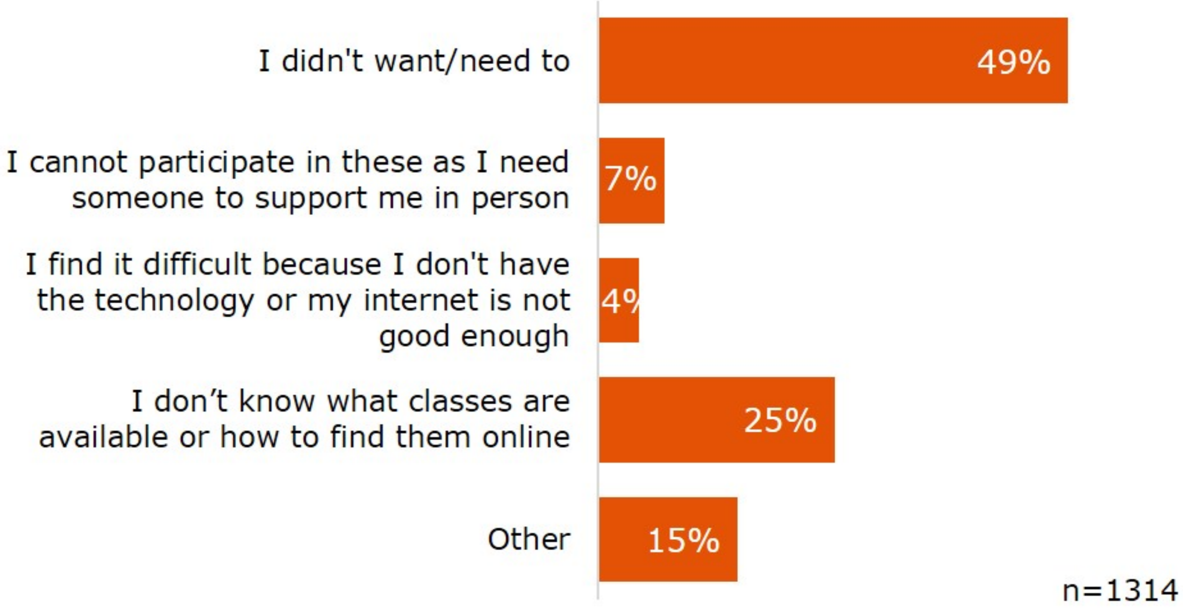


Figure 22. What was your reason for not attending online classes?



> ***"The online classes available, whilst good, do not have the same benefit (I feel) as face to face classes with people you have built up a relationship with."***

Figure 24. Do you feel your MS and symptoms have changed since the beginning of lockdown?

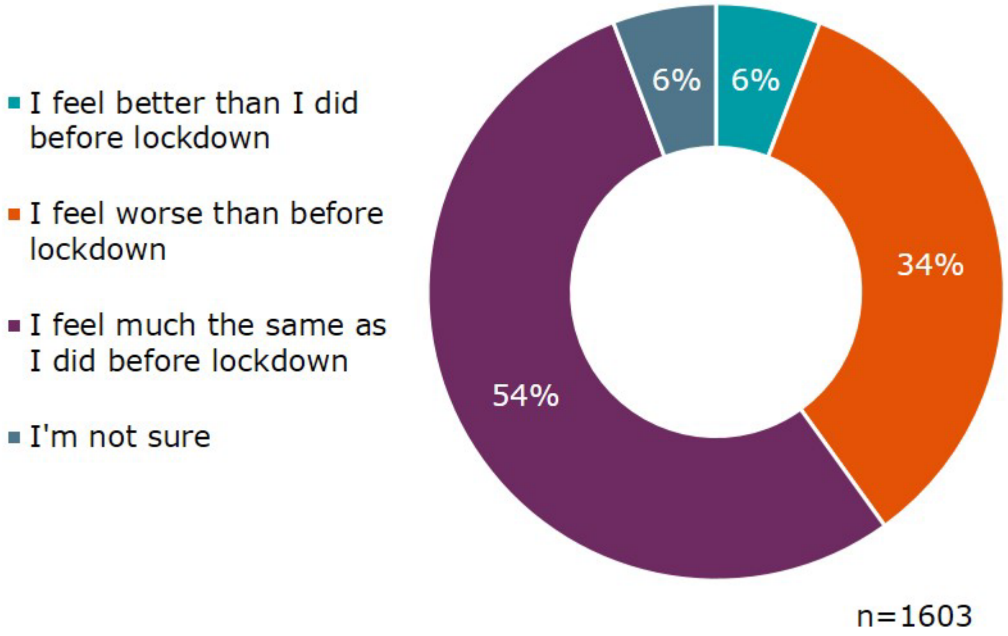
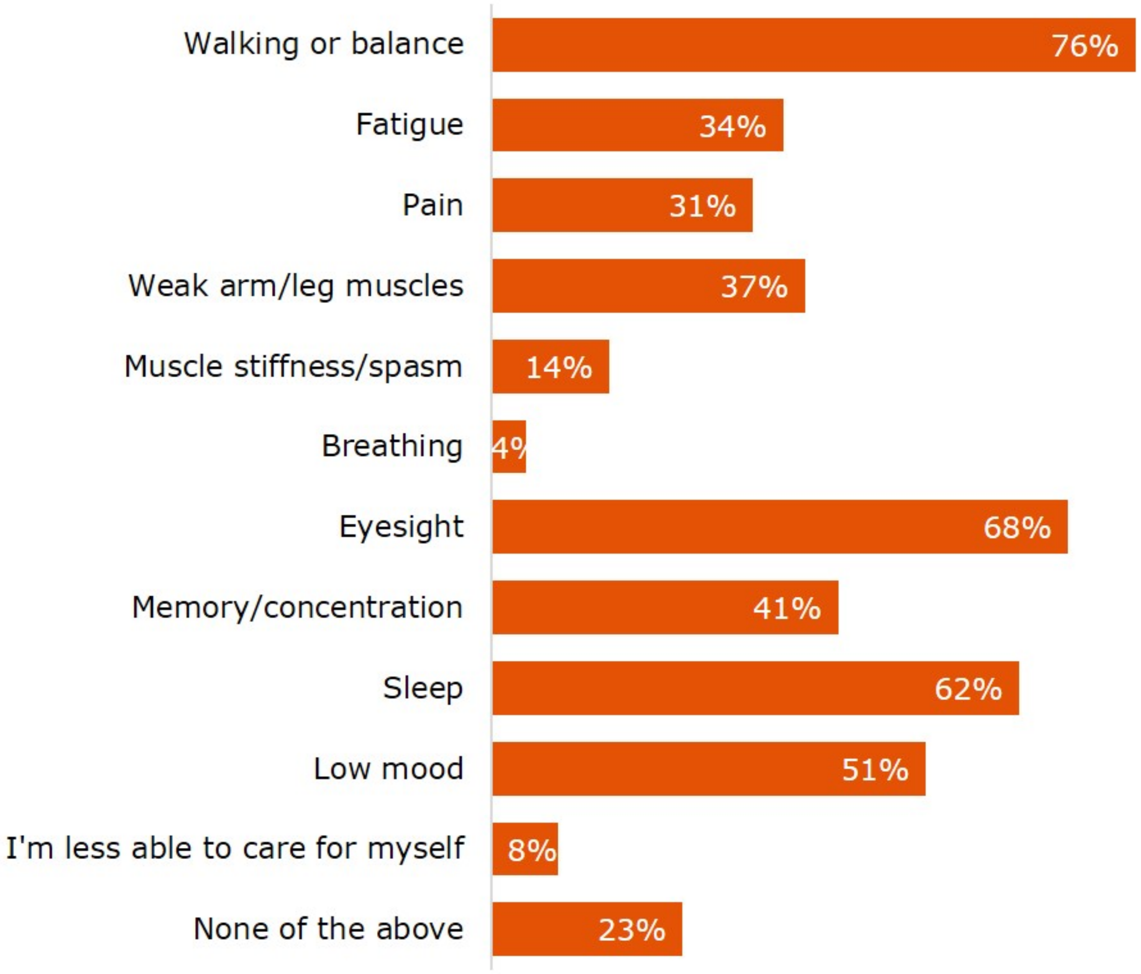
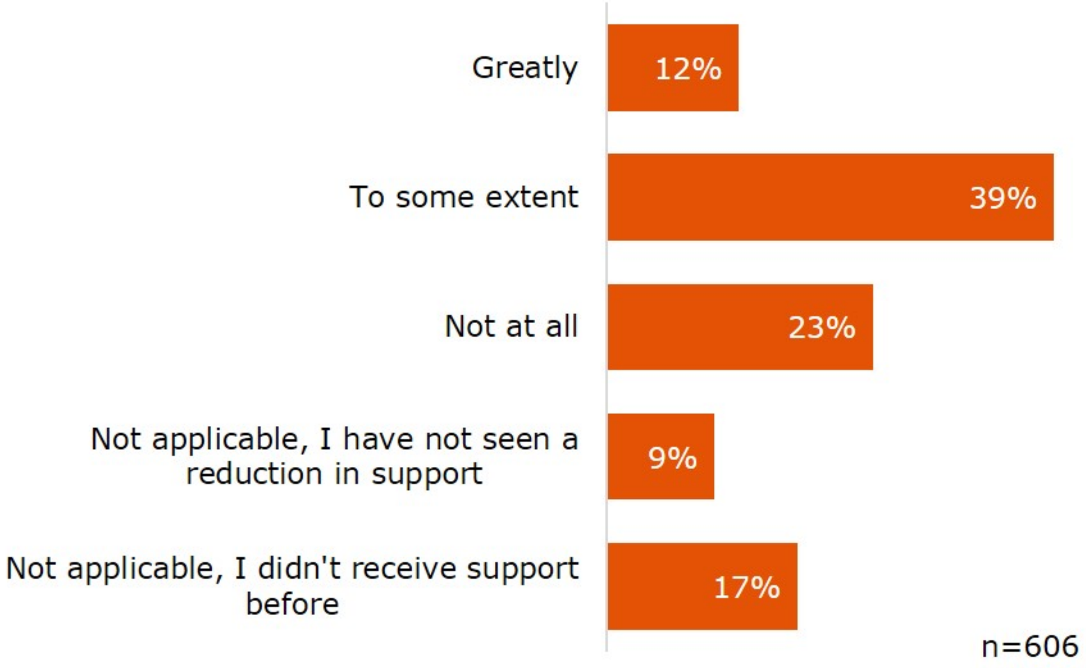


Figure 23. Can you identify which of your symptoms has got worse during lockdown from the list below?



> ***"Go to aqua fit and power plate classes four times a week, due to lockdown have been unable to go since March and this has impacted my mobility. I do exercises at home and have a home power plate, although not as good as the ones at my leisure centre"***

Figure 25. To what extent do you think that a reduction in or changes to the specialist support you received before contributed to your symptoms getting worse?



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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