Impact of the COVID-19 pandemic on multiple sclerosis (MS) management: MS community perspectives

Survey of over 1000 people living with MS reveals how the ongoing pandemic is impacting the MS community

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Executive summary

Objectives

The impact of the COVID-19 pandemic has been challenging for all, but there are added difficulties for those with pre-existing healthcare needs, including MS.

The broad objectives of this investigation were to:

1. Establish a deep understanding of how the ongoing coronavirus disease 2019 (COVID-19) pandemic is impacting the MS community from the perspective of people living with MS (MSers), with a focus on access to MS clinical care, and
2. Discuss future opportunities that MS healthcare professionals (HCPs) can adopt to best support MSers during the COVID-19 pandemic.

Approach

MSer survey: A survey developed by the charity Shift.ms was shared with Shift.ms' international membership in early September 2020 for one week. A total of 1359 MSers responded to the survey. Respondents were predominantly UK-based (61%; USA 18%, Canada 8%), 18 to 55 years (68%), female (76%), white (91%), diagnosed with relapsing-remitting MS (RRMS; 67%), and had received a diagnosis within the last 10 years (56%).

HCP interviews: In addition, video interviews with four specialist MS HCPs in Europe and the USA, led by an MSer, gathered MS physicians' perspectives of the impact of the pandemic on MS care and holistic support.

Key insights

Gleaning insights from the MS community has enabled identification of specific challenges faced by MSers as a result of the pandemic.

The findings highlight the importance of clear messaging and up-to-date guidance for MSers who may be struggling to get to grips with what the pandemic means for their daily lives.

Disrupted exercise routines, difficulties with medical care access, and lack of support were highlighted as major challenges faced by MSers as a result of the pandemic. For those receiving, or due to receive disease modifying therapies (DMT), treatment delays, changes to their treatment regimen, and disrupted monitoring represented additional challenges.

With regards to telemedicine, both MSers and MS HCPs recognised the benefits associated with remote consultations, particularly for certain appointment types that do not require physical examination.

Going forward in the post-pandemic setting, many appointment types were deemed appropriate for remote consultation, but for a few (including those requiring physical examination, involving newly diagnosed MSers, and for subtle symptom presentation or neurological assessment), in-person appointments were favoured.

Key opportunities

This investigation highlighted future opportunities for healthcare providers to best support MSers during the COVID-19 pandemic and beyond.

1. **Help MSers obtain clear information:**
   - Provide improved clarity through MS-specific information channels
   - Report on the impact of COVID-19 on MS/the impact of MS on COVID-19, including available data on MSers who have had COVID-19
   - Provide up-to-date information on potential COVID-19 vaccine and individualised discussion
   - Discuss social distancing/self-isolation/shielding
   - Ensure access for all to essential communications

2. **Provide support for MSers regarding MS-specific challenges:**
   - Support to manage uncertainty during a time of limited evidence-base
   - Suggest resources for improved wellbeing (including exercising)
   - Ask MSers about the wider implications of the pandemic on their day-to-day lives to best provide tailored support

3. **Improve access to MS care, where possible, including:**
   - MS HCP contact (including relapse management)
   - Mental wellbeing support

4. **Provide clear directives for MSers on how MS DMT treatment is being adapted throughout the pandemic, and the reasons behind these, including DMT delays, changes, and monitoring.**

5. **Prioritise appropriate appointment types for telemedicine, with a focus on:**
   - Those not requiring physical examination
   - Preferential conduct of video over telephone consultation for certain appointment types
   - Where possible, provide choice for MSers on how their care is delivered (i.e. remotely or in person)

6. **Considerations for the use of telemedicine in the post-pandemic setting for MS, including:**
   - Preferential selection of remote versus in-person contact for particular appointment types
   - Preferential conduct of video over telephone consultation for certain appointment types.
   - Consider group-based remote care for general Q&As

Background

We are living through the first recorded, non-influenza viral pandemic in human history, and with this unparalleled public health event comes enormous challenges for healthcare provision globally.

Acute respiratory infection caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was first recorded in Wuhan, China, in December 2019. Within weeks, the disease (subsequently named COVID-19) had spread to multiple countries and was declared a pandemic by the World Health Organization on 11th March 2020.

Whilst an estimated 80% of infections appear to be asymptomatic or cause only mild illness, for those suffering from a severe course of COVID-19, the infection can cause progressive respiratory failure, multiple organ dysfunction, and even death.[1] Over 59 million cases have now been reported worldwide, with a global death toll of ~1.4 million (24th November 2020, Johns Hopkins University and Medicine Coronavirus Resource Center). Severe COVID-19 susceptibility increases with age and certain comorbidities, and populations at higher risk have begun to be identified.[2,3]

MS is an inflammatory demyelinating and neurodegenerative disorder that is commonly treated with immunomodulatory disease modifying therapies (DMTs). It has been suggested that people living with more severe MS may be at higher risk of developing severe COVID-19, relative to the general population.[4,5] MSers represent a population of particular interest in the context of COVID-19, for several reasons:

- The potential effects of iatrogenic compromised immunity on COVID-19 susceptibility/severity[6]
- The potential effect of pre-existing neurological disability[2]
- The potential effects of SARS-CoV-2 infection on MS disease activity[7]
- Pre-existing neuropsychiatric symptomatology effects on the neuropsychiatric concomitance of COVID-19[8]
- Potential COVID-19 vaccination response[7]

The current lack of clinical or popular understanding around these research priorities leaves open questions about the impact of the COVID-19 pandemic on MS disease management, for both HCPs and MSers alike.

Additional societal challenges imposed by the pandemic include disruption to standard levels of specialist MS care, and to MSers' ability to best manage their condition within globally-imposed restrictions on social distancing and stay-at-home measures. There is an urgent need for more data on the impact of the COVID-19 pandemic on MSers' care delivery and self-management.

Surveys targeted at patients[9–20] and HCPs[21–23] are being used to understand MS population needs at this current time, and how MSers are adjusting to the challenges the pandemic poses to their disease management and daily lives. To date, most of these studies are restricted to localised MS populations per individual countries or regions, but of those providing a global perspective, a picture of worldwide disruption to MS clinical care is emerging.[9,13,16]

MSer survey: Understanding the extent of MS clinical care disruption and how this is impacting MSers was the primary focus of this study. A survey was developed by the charity Shift.ms, with input from the MS community, to investigate and unearth deeper community-specific insights into:

- MSers' evolving assessments of perceived risk in regards to COVID-19
- MSers' perspectives of the greatest challenges they are facing in managing their MS as a result of the pandemic
- How the pandemic has impacted MSers' access to clinical care
- MSers' experiences of any changes to delivery of care implemented by their healthcare provider

The voluntary survey (hosted in English language) was shared on September 8th 2020 with an international population of ~35, 000 potential MSers respondents. The survey was disseminated via email to the Shift.ms member database and through advertising on Shift.ms social media and was available for one week (until September 16th 2020). It was open to adults (18+ years) who self-reported an MS diagnosis. Questions that specifically referred to MSers' perspectives "when the COVID-19 pandemic began", refer to when COVID-19 was first declared a global pandemic (11th March 2020). Where questions specifically referred to MSers' perspectives "of the present day", this refers to the timeframe the survey was open (8-16th September 2020); approximately six months since the start of the pandemic.

For further information on the survey design and analyses, refer to **Supplemental information**.

Survey responders: Of the self-reported MSers who were sent a questionnaire, a total of 1359 responded (1031 fully completed the survey and a further 328 partially completed it [at least all demographics plus two questions regarding the COVID-19 pandemic]). Respondents were predominantly UK-based (61%; USA 18%; Canada 8%), 18 to 55 years (68%), female (76%), white (91%), diagnosed with relapsing-remitting MS (RRMS; 67%), and were 0 to 10 years since diagnosis (56%; see **Supplemental table 1** for sample demographics).

Six key insights were identified by the MS community through the MSer survey and HCP interviews (**Table 1**). These insights identify opportunities for the wider MS community to develop services that best support MSers, at a time when global healthcare systems are adapting to new operating conditions imposed by the COVID-19 pandemic.

HCP interviews: In addition to the MSer survey, video interviews with four specialist MS HCPs in Europe and the United States of America gathered physicians' perspectives on: MSers' access to clinical care in different territories; best practice adaptations (both in how clinical care is provided and treatment decisions); and evolving professional assessment of COVID-19 risk to MSers during the pandemic. Top line findings from the MSer survey fed into the video interview questions. Four MS HCP interviews led by an MSer were conducted (one each with a clinician from the UK, USA, Germany, and Finland).

Table 1: Six key insights on the opinions and challenges faced by the MS community in response to the COVID-19 pandemic

Insight Topic	Key Insights
1. Concerns about contracting SARS-CoV-2	MSers are concerned about the risks and consequences of contracting SARS-CoV-2, with many continuing to 'shield' on their own accord
2. Impact on daily life	Lack of unified MS-specific guidance and exercise disruption impact day-to-day living for MSers, along with wider ramifications of the stay at home measures and increased stress/anxiety caused by the pandemic
3. Clinical care satisfaction	MSers are less satisfied with their clinical care during the COVID-19 pandemic, with most experiencing disruption to healthcare access
4. DMT treatment	MSers have experienced disruption to DMT treatment during the COVID-19 pandemic
5. Remote medical appointments	The increase in remote medical assessments with HCPs during the COVID-19 pandemic left some MSers with concerns regarding the quality of certain consultations, but overall MSers recognise the benefits of remote appointments
6. Post-pandemic use of telemedicine	MSers' opinions on the post-pandemic use of telemedicine are mixed, with a preference of in-person consultations expressed for physiotherapy, first visits post-diagnosis, and neurological assessment

COVID-19, coronavirus disease 2019; DMT, disease modifying therapy; HCP, healthcare professional; MS, multiple sclerosis; MSers, people living with MS.

Insight 1: Concerns about contracting SARS-CoV-2

MSers are concerned about the risks and consequences of contracting SARS-CoV-2, with many continuing to 'shield' (i.e. to minimise all interaction between them and others) of their own accord.

The survey findings suggest a reduction in the level of concern regarding COVID-19 amongst MSers since the start of the pandemic (12% drop in concern over 'risk of catching' SARS-CoV-2 and 13% drop in concern over the 'consequences of catching' the virus since the pandemic began; **Supplemental figure 1**).

Yet, at the time of survey participation (early September 2020), one third remain 'very' or 'extremely' concerned regarding the 'risk of catching' SARS-CoV-2 disease specifically as someone living with MS, and nearly half about the 'consequences of catching' the virus (**Supplemental figure 1**). MSers raised a number of common questions regarding the impact of contracting SARS-CoV-2 for their condition and if having MS might increase their COVID-19 risk, including concerns about the efficacy of a potential COVID-19 vaccine in use alongside MS treatment regimens (**Supplemental figure 2**).

Subgroup analysis showed that people living with RRMS were slightly more likely to have heightened levels of concern (in line with other findings)[15] at the start of the pandemic versus those with other types of MS, but this did not persist over the six months since the start of the pandemic.

Concerning MSers' age, the only difference observed in relation to level of anxiety or concern was that those over the age of 55 were less likely to be concerned about the consequences of contracting SARS-CoV-2, despite potentially being in a higher risk category for severe COVID-19. This age group has previously been shown to demonstrate higher adherence to social distancing and self-isolation,[9,16,17] possibly indicating that their perceived risk might be lower due to the precautions they are taking.

USA-based MSers were generally more concerned (risk of catching and consequences of catching SARS-CoV-2) at the start of the pandemic (e.g. 60% of USA MSers concerned about the risk of contracting the virus) than those in other countries (46% for total MSers), and this trend was the same 6 months later at the time of survey (**Supplemental figure 1**). This finding may be reflective of the general USA population, who at the start of the pandemic were shown to have higher concern about the 'personal threat' of COVID-19 ('moderate' to 'very high threat'), compared with some other countries, including the UK).[24] No differences in levels of concern were observed between geographical residencies within countries, including MSers living in rural areas compared with those in large cities.

We looked specifically at the UK population responses to understand MSers' attitudes towards 'shielding' (as the UK government actively advised 'clinically extremely vulnerable' groups to 'shield' during the first few months of the COVID-19 pandemic). At the time of the survey, just under one third of UK-based MSers continued to shield (29%; 23% of their own accord, and 6% based on advice from their MS healthcare team). This was a reduction from 85% at the start of the pandemic (41% completely and 44% to some extent). We speculate that individuals who are shielding are potentially more likely to have extra available time to fill in a survey, so this finding may not be representative of the wider population of MSers. Interestingly, 7% of UK-based MSers who were advised to shield at the start of the pandemic chose not to, potentially indicating a lack of perceived risk from COVID-19 by these individuals. A variety of reasons were cited for not shielding (**Supplemental table 2**).

When looking at the total population of MSers across other countries, the findings around shielding were similar (despite governments outside the UK not providing detailed advice around shielding during the pandemic). Further subgroup analysis of the total respondents (i.e. not only UK) showed that 28% continued to shield of their own accord; which was more common for MSers living in North America, those aged over 55, those with progressive MS, and those who were >5 years post-diagnosis. A further 10% were continuing to shield following HCP advice.

MSers have sought MS-related information during the COVID-19 pandemic. 45% of respondents reported that they have spent more time reading about MS-related topics online, 37% spent more time learning about MS disease management, and a further 23% have increased their interaction with fellow MSers via online patient groups or forums.

This thirst for information and connection likely reflects MSers' heightened concern regarding the potential impact of the pandemic on their MS. In general, MSers reported gathering their information from trusted online sources, in particular MS HCPs with an online presence and MS-specific charities (**Supplemental table 3**).

HCPs' perspectives, obtained through the MS HCP video interviews, highlighted that some MS HCPs conduct outreach via social media and/or microsites, but it was acknowledged that not all MSers may have access to these platforms. The MS HCPs interviewed also noted that risk factors for moderate to severe COVID-19 in the MS population appear to mirror those in the general population (including increased age and comorbidities), and MS HCPs should continue to observe the emerging data on this. However, all MSers should prioritise prevention in order to protect themselves and precautions of washing hands, wearing a mask in public spaces and social distancing are vitally important preventative measures. Finally, many physicians and MSers are speculating on 'vaccine-readiness'. However, whilst immune response may vary between DMTs, preliminary COVID-19 vaccine trial data reported by Pfizer and BioNTech 18th November 2020 suggests a 94% response rate, which may be more successful than vaccines for influenza virus, a common vaccination in MSers that has a high success rate.

> *"Shielding is the worst-case scenario for my brain. I need to be able to move my body and be sociable to maintain cognitive and general health.*
>
> [Female, UK, RRMS]

Opportunities for MS HCPs to best support MSers:

Despite a reduced level of concern since the start of the pandemic, a large proportion of MSers remain concerned about risks and consequences of COVID-19. MSers seek information about MS and the pandemic from trusted sources. These insights have highlighted a number of opportunities for MS healthcare teams to better support MSers during this time:

1. Sharing experiences of MSers who have had COVID-19 to highlight the impact on MS symptoms and severity of the disease
2. Consideration of a potential COVID-19 vaccine on 'vaccine readiness' of MSers, which should be balanced with the priority of treating MS, and should take place as an individualised discussion on risk and personal choice
3. As large numbers of MSers appear to continue to 'shield' (even when not formally advised to), it is important for HCPs to establish which patients in their care are shielding (as perceived risk versus actual risk may vary)
4. Keep in communication with your patients to provide information; this can be done in innovative ways e.g. through podcasts. However, do consider the 'digital divide' to ensure all essential communications with MSers outside consultations are 'lowest-common-denominator' in technology terms (e.g. SMS, postal service), to ensure no one is left behind

Insight 2: Impact on daily life

Lack of unified MS-specific guidance and disruption to exercise impact day-to-day living for MSers, along with wider ramifications of the stay at home measures and increased stress and anxiety caused by the pandemic.

The most commonly reported COVID-19 pandemic challenge for daily life for MSers (i.e. non-medical care-related) was a lack of unified MS-specific guidance from governments (48%) and HCPs (37%; **Figure 1**).

This was, in fact, considered the single greatest challenge by 20% of MSers (13% lack of unified guidance from governments and 7% lack of unified guidance from HCPs). This mirrors findings from a UK-based survey of patients with long-term conditions (June 2020, N=800), which found three quarters of respondents described COVID-19 information as conflicting and only 7% felt it was consistent.[25]

The MS HCPs interviewed shared similar sentiments with the survey findings, suggesting that there is a real need for clear information amongst the MS community at a time of accelerated misinformation and disinformation online. More trusted and direct channels of communication are required for information pertaining to COVID-19 and MS.

Furthermore, improved education from MS teams on what MSers might expect from health information at a time with little-to-no evidence base would help. This is particularly apposite in reference to individual clinicians' advice which is not standardised, and with reference to guidelines MSers may be provided with by public health bodies or MS organisations. Such guidance may be non-specific or delayed (in order to contain consensus-driven, validated and evidenced-based guidance).

45% of MSers also reported being unable to implement a normal exercise routine as a pandemic-imposed challenge with respect to living with MS (**Figure 1**), with 20% citing it as their single greatest challenge during the COVID-19 pandemic. The negative impacts on exercise during the pandemic has already been reported by MSers.[9]

Survey respondents also commonly reported challenges in relation to worsening symptoms and managing their MS as a result of the wider ramifications of the pandemic (**Figure 1**).

These include:

1. Difficulties accessing the care or support they would normally receive from family and friends (36%)
2. Worsening symptoms/difficulty managing symptoms as a result of the impact of the COVID-19 pandemic on stress levels/anxiety/wellbeing (33%)
3. Worsening symptoms/difficulty managing symptoms as a result of lockdown/stay at home, social distancing or shielding measures in place (32%)

Opportunities for MS HCPs to best support MSers:

MSers reported a paucity of information around the impact of COVID-19 on MS, and of MS on COVID-19, and a lack of unified guidance. This lack of clear information was echoed by MS HCPs. MSers also reported difficulties implementing a normal exercise routine due to the pandemic.

Greater awareness of the most common wider implications of the global pandemic on the day-to-day lives of MSers provides an opportunity for HCPs to provide holistic advice and support, such as:

1. Improving channels of dissemination for MS-specific guidance and information with an aim of unifying messaging for the MSer community, and provision of up-to-date MS-specific data on COVID-19
2. A possible need for HCPs to counsel MSers on how they can manage uncertainty and expectations of standardised guidance in an evidence-free space
3. Supporting MSers in the implementation of exercise into daily routines when isolating or in 'lockdown'
4. Ask MSers about the wider implications of the global pandemic on their day-to-day lives (such as worsening symptoms/difficulties managing MS because of 1) reduced support networks, 2) increased stress/anxiety, 3) impact of lockdown/stay at home measures) to provide tailored support

Figure 1: Top 5 non-clinical-related challenges reported by MSers during the COVID-19 pandemic

1. **48%** Lack of MS-specific guidance from government/public health organisations
2. **45%** Inability to maintain normal exercise levels
3. **37%** Lack of MS-specific unified guidance from HCPs
4. **36%** Difficulty in accessing support network of friends/family
5. Worsening MS symptoms/difficulty managing symptoms as a result of the pandemic on:
   - **33%** i) Stress/anxiety/wellbeing
   - **32%** ii) Lockdown/staying at home/social distancing

n=1359.
COVID-19, coronavirus disease 2019; HCP, healthcare practitioner; MS, multiple sclerosis; MSers, people living with MS.

> *Pre-COVID-19 we had carers here four times a week, and a cleaner once a week for three hours. We stopped both for the first three months of lockdown. Cleaner has returned, but too worried about carers having a greater risk of being carriers.*
>
> *My husband has been completely overloaded looking after me/doing housework etc (I am very disabled) and we haven't had much in the way of visitors (too worried) and are both going out of our heads.*
>
> [Female, UK, RRMS]

Insight 3: Clinical care satisfaction

MSers are less satisfied with their clinical care during the COVID-19 pandemic, with most experiencing disruption to healthcare access.

Worldwide, government-enforced confinement of the population during the pandemic has disrupted healthcare across multiple treatment areas beyond COVID-19, including MS care. Perhaps unsurprisingly, survey findings indicate that MSers are less satisfied with their medical care (at the point the survey was conducted) compared with pre-COVID-19 satisfaction levels (**Supplemental figure 3**). USA-based MSers possessed a higher satisfaction rate before and throughout the pandemic, compared with those in the UK (**Supplemental figure 3**). This suggests geographical variations in how MS clinical care is perceived in response to the pandemic, which might reflect variations in how the general public of different countries perceive health system performance in general.[26,27] No other differences in clinical care satisfaction between subgroups was observed.

Over a quarter of MSers cited a lack of access to regular routine MS clinical appointments as one of the top clinical challenges they have faced due to the pandemic, along with difficulty accessing regular monitoring and testing in relation to MS medication (**Figure 2**). Not having what was perceived to be sufficient contact with their neurologist was also a challenge (**Figure 2**), particularly for those newly diagnosed with MS (<2 years; 32%).

More than a quarter of MSers (26%) with scheduled in-person appointments had them cancelled or postponed by their healthcare provider due to the pandemic, with a further 54% having their appointments switched to remote/virtual consultations. 20% of MSers reported that their in-person appointments went ahead. In addition, 16% of MSers cancelled an in-person appointment themselves, citing that 'they did not want to put themselves at risk' as the main reason for cancelling (37%). MSers cancelling their own appointments was more common in the USA (37%) compared with the UK (8%), again highlighting geographical differences in the way some MSers have responded to the pandemic.

Of those MSers who required medical help during the lockdown (n=854), 70% delayed accessing help. Not wanting to burden HCPs (51%), and concern about catching SARS-CoV-2 if attending clinic in-person (46%) were cited as the top two reasons for not seeking medical help. At the time the survey was taken, only 48% reported that they would delay seeking medical help in the future, suggesting MSers might feel more confident in accessing medical care going forward in the pandemic.

In the 6 months from the start of the pandemic to the time of the survey, one third of MSers (32%) reported experiencing a relapse or suspected relapse, yet 40% did not seek medical care for this. The pandemic was specifically cited as a reason for not seeking relapse care in just under 20% of cases, but most commonly MSers felt comfortable managing relapses themselves (34% of those who did not seek help). Whilst 49% of MSers who experienced a relapse thought there was no difference in the clinical care they received compared with pre-COVID-19 care, 34% felt their clinical care experience of relapse was worse than before the pandemic. Lack of access to clinical care was most cited as the reason for this (23%; **Table 2**).

The MS HCP interviews touched on opportunities that may improve MSers' experience of clinical care during the pandemic, which included identifying and promoting helpful mental health resources and supplementary wellbeing resources.

Opportunities for MS HCPs to best support MSers:

This survey has raised concerns surrounding the perceived quality of clinical care MSers have received since the start of the COVID-19 pandemic (including for some who have experienced a suspected relapse). Difficulty accessing medical care was reported as one of the main reasons MSers deemed clinical care worse than before the pandemic began. This raises opportunities to better support healthcare access for MSers during this time:

1. Improve access to healthcare provision for MSers during the pandemic and in particular, timely access for relapse management where required.
2. Provide communications which support and encourage MSers not to cancel appointments or delay seeking medical support during the pandemic
3. Provide clearer directives about how HCP contact will adapt for MSers moving forward throughout the pandemic and beyond
4. Promotion of helpful wellbeing resources (e.g. mindfulness, yoga, mental health apps, and mental health support videos)

Figure 2: Top 5 clinical-related challenges reported by MSers during the COVID-19 pandemic

1. **28%** Difficulty accessing routine clinical appointments
2. **26%** Difficulty accessing regular MS medication monitoring/testing
3. **23%** Not enough contact with neurologist
4. **20%** Not enough contact with physiotherapist
5. **18%** Not having physical examinations in person to start/adjust MS medication

n=1280.
COVID-19, coronavirus disease 2019; MS, multiple sclerosis; MSers, people living with MS.

> *Unable to have any real support and planned infusion postponed. Emotional impact of this has been huge*
>
> [Female, UK, RRMS]

> *My MS team have all been delegated to front line COVID staff, so my MS support has gone*
>
> [Female, UK, RRMS]

> *Health care professionals have been redeployed for COVID-19 duties, appointments are by phone/ cancelled and diagnostic exams have been pushed or postponed*
>
> [Female, Canada, Clinically Isolated Syndrome]

> *Stress of pandemic brought on a flare up resulting in me changing my MS medication*
>
> [Female, USA, RRMS]

> *I thought I knew why the relapse occurred (stress) and dealt with it in my own way*
>
> [Male, UK, PPMS]

Table 2: Reasons why MS relapse/suspected relapse care deemed worse than before the COVID-19 pandemic

Reason	% MSers*
Lack of access to HCPs/lack of contact impossible to access care	23
No face-to-face appointments/phone only	17
Delay in testing or treatment: took over a week for a prescription to be processed/MRI postponed/delay in receiving pain management	15
No treatment offered: MRI was cancelled / no treatment due to pandemic / not invited for tests	11
Not possible to get steroids during lockdown	11
No interest from HCPs/no one understood	11

*Survey respondents who experienced a relapse/suspected relapse in the 6 months from the beginning of the pandemic to when the survey was taken, and deemed clinical care received was worse than before the pandemic (n=66).

Insight 4: DMT treatment

MSers have experienced disruption to DMT treatment during the COVID-19 pandemic.

More than half of MSers were receiving or due to receive DMTs at the start of the pandemic (54%; **Supplemental table 4**). The majority of respondents receiving or due to receive DMTs lived in the USA (63%), 53% in Canada, 48% in the UK, and 68% in the rest of the world.

One third experienced treatment disruption as a result of the pandemic (32%). Of these 32%, the majority experienced a treatment delay, either their next dose (40%) or when starting treatment (21%). These delays were less common in the USA relative to the total population of MSers, where only 25% experienced a delay in their next dose, and 9% for those starting their DMT. A further 11% of all MSers who were receiving/due to receive DMTs had their DMTs switched to another drug, and 6% had their treatment stopped altogether.

DMT monitoring was also affected (e.g. blood test or other observation), with almost half of MSers (52%) who normally receive regular monitoring reporting disruption since the pandemic began (9% experienced significant impact and 43% experienced some impact).

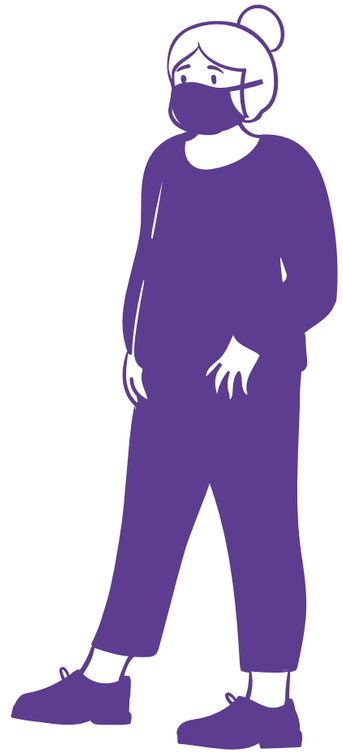
MS HCP interviews suggested that HCPs should continue to balance proactive MS care and therapies on the principle that 'time matters'. Furthermore, HCPs should continue to inform and support MSers on their choices on DMT treatment, particularly in light of possible changes, pauses or cessations of treatments due to the pandemic, where discussions of risks and benefits should be individualised.

Opportunities for MS HCPs to best support MSers:

Treatment disruption due to the pandemic is common amongst MSers receiving DMTs, and in particular treatment delays. Similarly, routine DMT monitoring has also been affected by the pandemic.

Like other MS clinical disruptions reported in this survey, providing clear directives about how regular DMT treatment will be adapted throughout the pandemic and the reasons behind these will help MSers at this time.

> *Monthly monitoring tests for alemtuzumab have been difficult to organise and I have therefore missed a few.*
>
> [Female, UK, RRMS]



Insight 5: Remote medical appointments

The increase in remote medical assessments with HCPs during the COVID-19 pandemic left some MSers with concerns regarding the quality of certain consultations, but overall MSers recognise the benefits of remote appointments

Due to measures taken by governments to reduce the spread of the SARS-CoV-2 virus, MSers have seen their healthcare appointments shift from face-to-face (pre-COVID-19) to remote consultations during the pandemic (**Supplemental figure 4**). To reduce the risk of viral transmission, telemedicine has been promoted and scaled-up during the pandemic, especially in the UK[28] and USA,[29] which represent the largest geographical subset of MSers in this survey (79%).

Telephone consultations were reported as more common than video calls. However, as pre-pandemic video calls were relatively uncommon, the fold-increase in video call consultations was greater than that observed for telephone consultations; approximately 3-fold across all care practitioners for telephone consultations, versus approximately 7.5-fold for video calls (**Supplemental figure 4**).

Interestingly, satisfaction with MS care via telemedicine varied according to speciality (**Figure 3**). In general, remote appointments with HCPs involved in medical-management of MS (neurologists, MS nurses, and primary care practitioners), rated higher in satisfaction (62%-71%) than appointments scheduled with allied health professionals (28%-54%).

MSers report recognising the benefits of remote consultations (**Table 3**). The top benefit was listed as limiting exposure to SARS-CoV-2 (65%), whilst the others were independent of the COVID-19 pandemic (saves travel time, reduces fatigue/other symptoms from traveling, saves money, saves me having to take time off work/study). Notably, no MSers reported that there were no benefits of remote consultations.

Although some MSers did express concerns over the quality of remote medical assessments, almost one quarter (23%) reported no drawbacks at all (**Table 3**). The largest drawback was reported as remote medical assessments not being as thorough as in-person consultations (54%), which aligns with other clinical-related challenges reported by MSers (e.g. not having physical examinations in person to start/adjust MS medication; 18%; **Figure 2**).

HCP insights mirrored many of the same perceptions as MSers regarding the use of telemedicine, describing it as a successful approach for many types of appointments, including counselling, discussing results, e.g. lab and Magnetic Resonance Imaging (MRI), and possibly digital monitoring tools such as virtual Expanded Disability Status Scale (EDSS) assessment. However, HCPs could consider where in-person consultations may be more appropriate. While telephone consultations can be effective and appropriate, HCPs could consider where telephone appointments may be moved to a video appointment, such as in cases where physical assessment is needed.

A recent survey of 114 UK-based HCPs found that 70% felt videoconferencing exceeds telephone consultation for effective communication with patients,[30] and patient satisfaction of video consultations in the USA have been shown to be high during the pandemic.[31] Collectively, these findings suggest that the use of videoconferencing in telemedicine is a favoured approach for many types of remote consultations.

Opportunities for MS HCPs to best support MSers:

Since the COVID-19 pandemic began, MSers have seen their healthcare appointments change from being predominantly in-person visits to remote consultations. Although telephone appointments were more common, there was a higher uptake in video consultations relative to pre-COVID-19 remote medical care provision.

This investigation gathered the MS community's opinions on these changes. All survey respondents recognised the benefits associated with remote consultations, although some expressed concerns over the quality of remote medical assessment, where the satisfaction for consultations with allied healthcare professionals was lower relative to those with MS clinical HCPs.

These findings highlight a few opportunities for healthcare providers to support MSers with remote medical care during the pandemic:

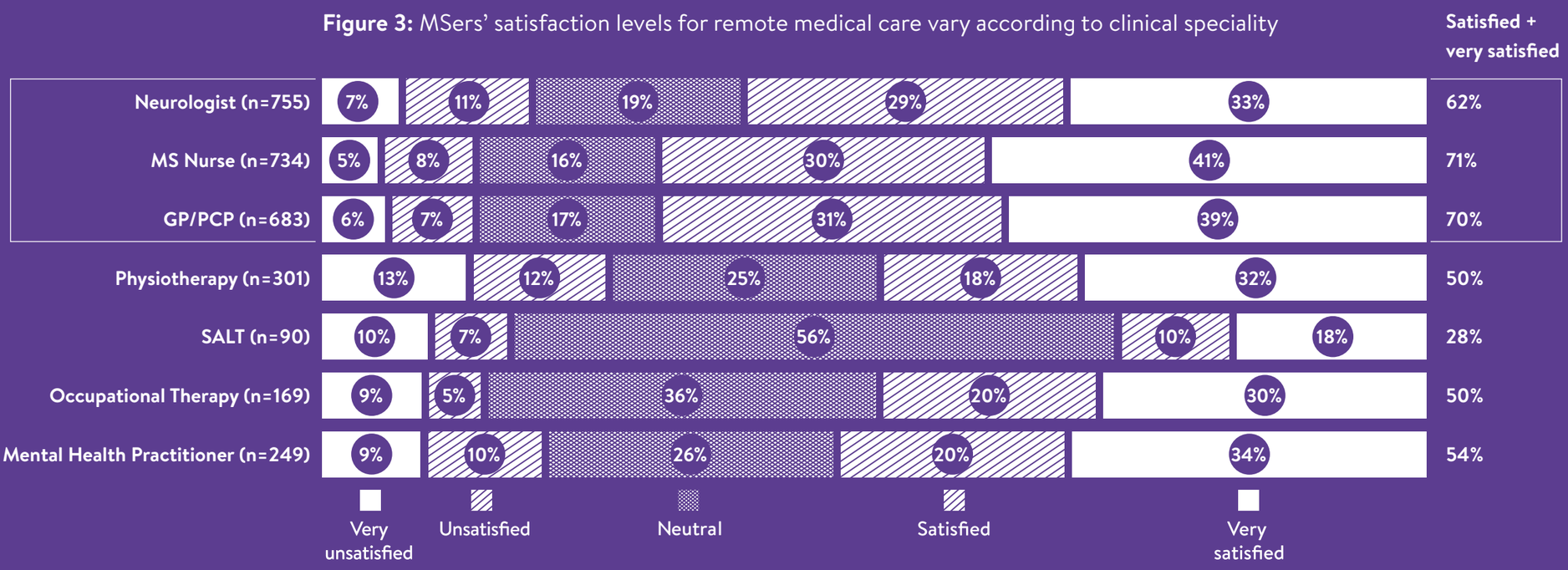
1. MS healthcare teams should try not to make general rules for care delivery approach, such as complete shut down of physical, in-person practice; and HCPs could consider where in-person consultations may be more appropriate, particularly in cases of subtle symptom presentation, physical examinations, or for those newly-diagnosed with MS
2. Aim for a preferential focus on certain appointment types to be conducted remotely over others (e.g. appointments with clinical HCPs over those with allied health professionals), and how they are conducted remotely (e.g. video versus telephone)
3. Where possible, provide choice for MSers on how their care is delivered (i.e. remotely or in person), so they can make a decision related to their individual needs and preferences
4. Circulate resources that can help to help MSers get the most from their telemedicine consultations

> *Unable to access physio when needed. Email and video appointment was not sufficient.*
>
> [Female, UK, RRMS]

Table 3: Benefits and drawbacks of remote consultations reported by MSers

Benefits	**% MSers**
Do not have to go out and be exposed to virus	65
Saves travel time	55
Do not need to sit in waiting room	55
Reduced fatigue/other symptoms of having to travel	45
Can still attend if isolating/quarantining	36
Saves money spent on travel	30
Saves having to take time off work/study	28
Drawbacks	
Medical assessment not as thorough as when done in person	54
Prefer personal interaction	43
Believe the discussion is less in-depth when not in person	38
Technology can be unreliable	11
None- no drawbacks	*23*

Figure 3: MSers' satisfaction levels for remote medical care vary according to clinical speciality



GP, general practitioner; MS, multiple sclerosis; MSers, person living with MS; n, number; PCP, primary care practitioner; MSers, people living with MS; SALT, speech and language therapist.

Insight 6: Post-pandemic use of telemedicine

MSers' opinions on the post-pandemic use of telemedicine are mixed, with a preference of in-person consultations expressed for physiotherapy, first visits post-diagnosis, and neurological assessment

Throughout the pandemic to the point of the survey, MSers reported that they preferred routine healthcare appointments to be conducted remotely rather than in-person for the duration of the pandemic ('strongly/somewhat agree;' 62%). For more urgent appointments, this dropped to 49%. However, the survey also sought feedback from MSers regarding their attitudes towards remote medical care once the COVID-19 pandemic was over.

In the post-pandemic setting, approximately one third of MSers would prefer their routine healthcare appointments to continue to be conducted remotely (36%), and 32% would prefer this for more urgent appointments too. This appears to be a general observation across the population of MSers, as no obvious differences were observed between type of MS, age group, and gender. However, USA-based MSers did indicate a higher preference for remote-based routine appointments (44%) compared with respondents from the rest of the world (31%).

Approximately one half or more of MSers consider certain medical appointment scenarios appropriate for remote consultation in the post-pandemic setting (**Table 4**). In particular, continued use of remote appointments to arrange repeat prescriptions, was considered appropriate by the vast majority of MSers (94%; **Table 4**).

However, other remote appointment scenarios were less favoured. Less than one third of MSers considered remote consultations to be suitable for physiotherapy sessions (28%), first visits (following an MS diagnosis; 27%), and neurological assessments (27%). This suggests that after the pandemic, in-person consultations are a preferred option for these types of appointments by most MSers.

MS HCPs who took part in Shift.ms video interviews reported that a priority in future should be to ensure that any amalgamation of telemedicine and face-to-face contact does not delay getting MSers through medical pathways (diagnosis, treatment, monitoring and escalating treatment where necessary), to ensure that HCPs can deliver care in a timely a manner. MS teams could also consider adapting telemedicine consultations to include group-based care. This would allow for multidisciplinary HCP perspectives on MS care, dependent on the expertise within the team (e.g. joint MS neurologist and nursing, joint neurologist and urologist, joint social support and talk therapy, and joint rehabilitation therapy sessions).

Opportunities for MS HCPs to best support MSers:

MSers responded positively to having remote medical appointments during the COVID-19 pandemic, but in the post-pandemic setting, opinions on the use of telemedicine appear to be mixed. The majority of MSers indicated they would prefer in-person appointments once the pandemic is over. However, this may depend on the type of medical consultation, as the MS community reported particular appointment scenarios as more appropriate for telemedicine over others. These findings provide options for healthcare providers when considering access to MS clinical care in the future:

1. Provide advice and possible preference selection of remote versus in-person contact in the post-pandemic setting
2. Preferential focus on how certain appointment types should be conducted remotely (e.g. video versus telephone) in the future
3. Providing group-based, remote care could be beneficial from a resources standpoint, but also allow MSers to ask general questions in a group setting to obtain insights from others with MS

Table 4: Post-pandemic appointment scenarios, considered appropriate for remote medical consultations according to MSers

Scenario	% MSers
Arranging a repeat MS medication prescription	94
DMT monitoring and/or adjustment	65
Routine/regular check-up appointments with neurologist/MS nurse (not related to DMT monitoring)	61
Appointments with mental health professional	61
Arranging a new MS medication prescription (initiating or switching)	59
Speech & language therapy	54
Non-routine appointments with my neurologist/MS nurse to discuss new MS symptoms and/or relapses	53
Occupational therapy	47

n=1060.
MS, multiple sclerosis; n, number; MSers, people living with MS.

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The HCP interview development was led by Shift.ms (Fiona Brown, UK) in collaboration with Dominic Shadbolt (MS Reporter, UK); the HCP interviews were conducted by Dominic.

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About Shift.ms

Shift.ms is the social network for people living with MS (MSers).

Founded by MSers, for MSers, the charity supports many thousands of recently diagnosed people across the world as they make sense of MS. It's independent and it's free.

Shift.ms equips people to make sense of MS as soon as possible after diagnosis. At Shift.ms we believe that MS doesn't mean giving up on ambitions, just rethinking how to achieve them. For more information and contact details, please visit www.Shift.ms

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Supplemental information

Survey design and analyses

The survey included basic demographic questions (age, gender, MS type, medication, geographical location, ethnicity, disease duration and COVID-19 testing), along with questions related to the pandemic; investigating the main challenges with respect to MS during the pandemic, the impact of COVID-19 on day-to-day life, wellbeing, 'shielding', healthcare access, DMT treatment and monitoring, MS relapse, appointments conducted via telemedicine, and on general information and support in relation to the pandemic and MS.

To try to minimise potential discrepancies between definitions amongst an international population of MSers, terminology that might not be universally understood was defined in the footnotes alongside relevant questions. For example, the term '*shielding*,' which is predominantly used by the UK Government to advise 'clinically extremely vulnerable' groups to protect themselves from SARS-CoV-2 exposure was defined in the survey as: '*a measure to protect those at very high risk of severe illness by minimising all interaction between them and others. It means staying at home as much as possible and keeping visits outside to a minimum.*'

The questionnaire consisted predominantly of closed-ended questions, although respondents had the option to free type if selecting 'other' where required. Results are presented as percentages or mean (± SD) where applicable. Percentages are calculated on total population as the denominator (or relevant subgroup total in the case of any subgroup analysis). Denominator sizes vary as not all questions were applicable to all respondents and not all respondents completed the survey. Rounding of percentages may mean not all totals add up to 100%. Statistical analyses between samples/subgroups were conducted by z-tests (distributions) and t-tests (means); 95% CI.

Supplemental tables

Supplemental table 1: Socio-demographic and clinical characteristics of the MSer respondents

Variables	N = 1359
Age in years;[a] mean ± SD	49 ± 11.74
RRMS	46 ± 11.19
PPMS	55 ± 9.87
SPMS	57 ± 9.26
Sex (M/F; %)	24/76
Ethnicity, n (%)	
White	1230 (91)
Black	34 (3)
Mixed	28 (2)
Asian	28 (2)
Other	20 (1)
Unknown[b]	19 (1)
Geographical location, n (%)	
UK	831 (61)
USA	246 (18)
Canada	109 (8)
Republic of Ireland	58 (4)
Australia	24 (2)
The Netherlands	10 (1)
Other	81 (6)
Residential location, %	
Large city	21
Large city suburb	24
Small city/town	36
Rural	20
COVID-19 status, %	
Positive	1
Negative	19
Not tested	79
Unknown[b]	1
Type of MS (%)	
RRMS	67
PPMS	11
SPMS	18
Unknown	4
Disease duration, %	
≤5 years	33
6–10 years	21
>10 years	44
Currently taking or due to begin DMT when pandemic began, %	54
RRMS	68
PPMS	25
SPMS	23
Experiencing swallowing and/or breathing difficulties, %[c]	28
RRMS	25
PPMS	29
SPMS	37
Most common DMT prescribed, drug (%)	
UK	Dimethyl fumarate (24)
USA	Ocrelizumab (42)
Canada	Ocrelizumab (29)
Other	Ocrelizumab (20)

[a]Percentage split by age group: 18–25 (1%); 26–35 (13%); 36–45 (25%); 46–55 (29%); 56–65 (24%); 65+ (7%).
[b]Prefer not to say.
[c]Clinically extremely vulnerable group, defined as having swallowing/breathing difficulties and/or taking specific DMTs.
COVID-19, coronavirus disease 2019; DMT, disease modifying therapy; F, female; M, male; MS, multiple sclerosis; N, number; PS, primary progressive MS; MSers, people living with MS; RRMS, relapsing-remitting MS; SD, standard deviation; SPMS, secondary progressive MS.

Supplemental table 2: Main reasons UK-based MSers chose not to shield

Reason	% MSers*
Consultant said it was an error that I had been asked to shield/I knew it was an error	32
Left home for food/doctor appointments/family commitments	21
Cannot live shut at home/not good for mental health	11
Advice was given too late (weeks into lockdown)	11
No need (had already had COVID-19/assumed would get it anyway)	11
Required to work/worked	5

*Asked to shield, but chose not to (UK-based; n=19).
COVID-19, coronavirus disease 2019; MS, multiple sclerosis; n, number; MSers, people living with MS.

Supplemental table 3: Commonly accessed MS-related information sources throughout the COVID-19 pandemic

MS-related Information Source/Tool/Service*	% MSers
MS HCPs online	43
MS charities	39
HCP consultations	32
Other MSers	26
Online searches	24

*Most commonly cited websites included: MS Society, Shift.ms, Bart MS Blog, MS Trust, Twitter/Instagram MS communities, You Tube (e.g. real patient videos and MS physician videos), Facebook communities (e.g. group for Tysabri), and Positive Living with MS. n=1031.
COVID-19, coronavirus disease 2019; HCP, healthcare professional; MS, multiple sclerosis; n, number; MSers, people living with MS.

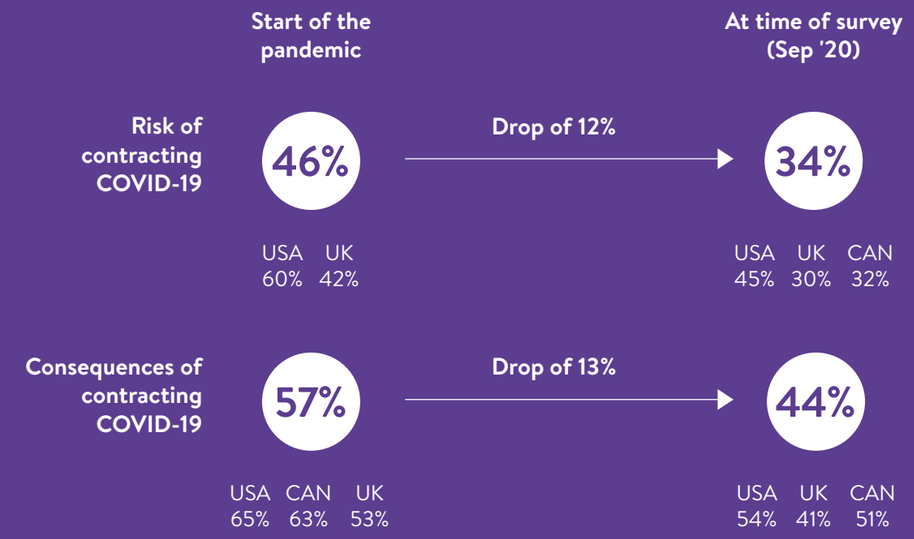
Supplemental table 4: MS DMT treatments at the start of the COVID-19 pandemic

DMT	% MSers*
Ocrelizumab	25
Dimethyl fumarate	19
Fingolimod	12
Natalizumab	10
Glatiramer acetate	9
Teriflunomide	6
Cladribine	5
IFN-ß1a	3
Alemtuzumab	3

*54% of survey respondents (n=648), receiving or due to receive treatment at the beginning of the pandemic.
COVID-19, coronavirus disease 2019; DMT, disease modifying therapy; IFN, interferon; MS, multiple sclerosis; n, number; MSers, people living with MS.

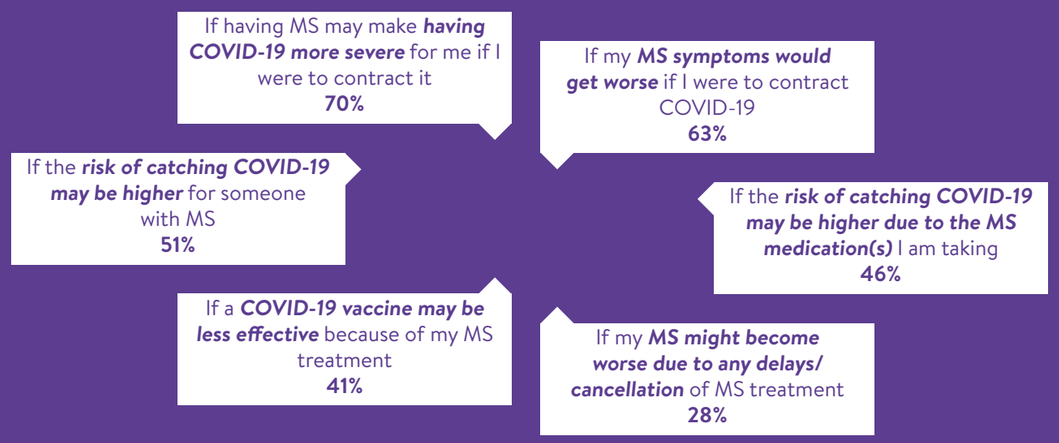
Supplemental figures

Supplemental figure 1: Level of COVID-19 concern by MSers*



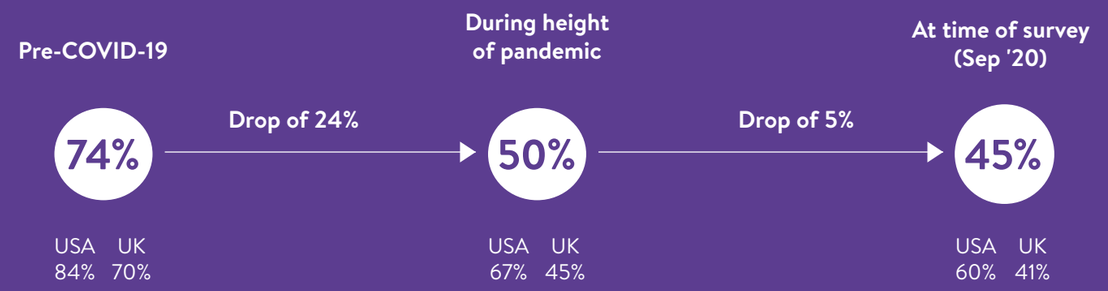
*'Extremely' or 'Very' concerned MSers regarding COVID-19.
n=1359.
COVID-19, coronavirus disease 2019; CAN, Canada; MSers, people living with MS.

Supplemental figure 2: MSers are keen to know if COVID-19 increases the severity of their MS, and if MS might increase COVID-19 risk



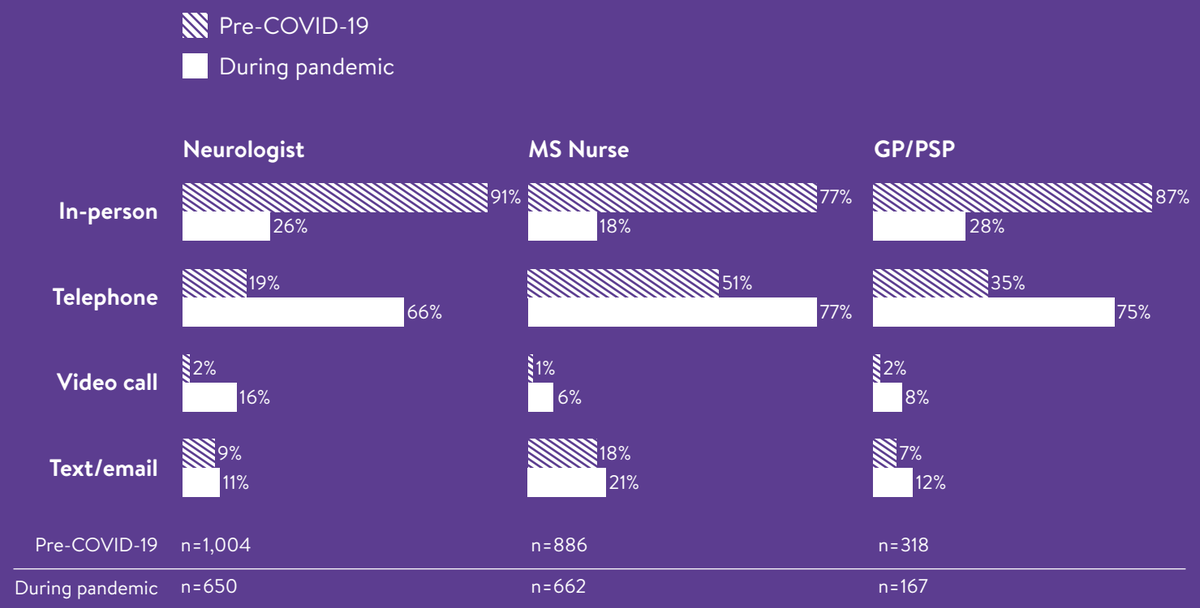
n=1031.
COVID-19, coronavirus disease 2019; MS, multiple sclerosis; n, number; MSers, people living with MS; SARS-CoV-2, severe acute respiratory syndrome coronavirus 2.

Supplemental figure 3: Satisfaction* with MS clinical care was higher before the COVID-19 pandemic



*'Very satisfied' or 'Satisfied' with MS medical care.
COVID-19, coronavirus disease 2019; MS, multiple sclerosis.
n=1216.

Supplemental figure 4: Changes in MSers' healthcare consultations during the COVID-19 pandemic



COVID-19, coronavirus disease 2019; GP, general practitioner; HCP, healthcare practitioner; MS, multiple sclerosis; PCP, primary care practitioner; MSers, people living with MS.

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