



# Findings of a survey of MS healthcare professionals on the impact of Covid-19 on MS services in the UK

July 2020

### 1. About the survey

The MS Society and MS Trust surveyed MS Health Care Professionals (HCPs) in June about the impact of Covid-19 on MS services in the UK.

The purpose was to understand current service capacity, prospects for and barriers to return to pre-Covid capacity, and how our organisations can support HCPs throughout this period. We targeted promotion of the survey at all HCPs that normally support people with MS except neurologists, because the Association of British Neurologists (ABN) was in the process of surveying its members.

The survey was only available on online. It opened 2 June and closed 21 June 2020. It was promoted by the MS Trust on social media, sent to UK MS Specialist Nurses Association (UKMSSNA) members, both MS Trust and MS Society professional newsletter subscribers and the MS Academy's professional network newsletter subscribers.

### 2. Demographics

There were 181 responses. Nearly half of respondents were MS Nurses, with significant proportions of Physiotherapists and Occupational Therapists. Almost three-quarters of respondents were based in England, with 19 from Scotland, 8 from Northern Ireland and 6 from Wales. Due to the low numbers of respondents from the devolved nations, this briefing tells us less about the situation in nations outside of England. The proportion of responses from different regions of England are not representative of the number of professionals in those regions. 40% of respondents were employed by Acute NHS Trusts, 33% Community NHS Trusts, 12% Neuroscience Centres and 15% by another type of employer.

Table showing the number of occupation of UK respondents

MS Nurse		89
Neurology Nurse		9
MS coordinator		1
Physiotherapist		33
Occupational Therapist		21
Dietician		1
Speech and Language Therapist		2
Pharmacist		4
Psychologist	-	2
Counsellor	_	1
MS Service manager		4
Social worker		1
Other		13

# Table showing the number of respondents in each region in England

North East	13
North West	16
Yorkshire and The Humber	12
East of England	20
Greater London	18
Greater Manchester	23
West Midlands	13
East Midlands	6
South East	26
South West	17

# 3. Summary of UK findings

Redeployment

- A quarter (24%) of respondents said more than half of the workforce in their MS service was still redeployed away from MS care.
- 23% of MS professionals responding to the survey were currently redeployed away from supporting people with MS
- Of those who were redeployed, 29% said they did not feel their time was being well used.

#### Capacity

 Over half (55%) of respondents said their MS service was below pre-Covid capacity while almost a third (31%) felt they were at pre-Covid capacity.

Impact on treatment and care

- 70% of MS professionals responding to the survey did not think the MS service they work in or with was able to meet the needs of people with MS to the extent it was pre-Covid-19.
- Less than 5% of respondents said that no services, treatment or care had been limited, delayed or cancelled at any point during the pandemic so far.
- The most common type of care that had been cancelled, delayed or limited during the pandemic was rehabilitation. 73% of professionals responding to the survey said rehab had been affected and it was the service most of them wanted to see resume as soon as possible.
- Certain time critical services were among the most commonly selected by respondents as having been affected. For instance, 42% said Disease Modifying Treatments had been affected, 35% said symptom management and 29% said support for patients experiencing a relapse.

Recovery

- 67% didn't know when their MS service would return to pre-Covid capacity, with 18% saying it would be 7 weeks or more.
- Respondents identified the key challenges in returning to pre-Covid capacity as the backlog of patients (75%), lack of physical space to deliver care safely (66%), patients being reluctant to attend appointments/hospital (60%) and lack of staff (37%)
- 87% of professionals said conversations had already started about resuming services that had been limited, cancelled or delayed during the pandemic.
- 57% of professionals said their service planned to involve patients in decisions about service redesign, indicating a significant minority of services are not planning to involve patients.

- 88% of professionals want to see virtual appointments continue after the pandemic

### 4. Analysis

It is important to note that the findings reflect a particular period of time and service capacity will have changed since the survey was carried out, given the fast moving nature of the pandemic and response to it.

The pandemic is clearly having a huge impact on the ability of MS services to meet the needs of people with MS. Over half of respondents said their MS service was below pre-Covid capacity. However, almost a third of respondents said they were now back at pre-Covid capacity. The findings suggest various factors are contributing to capacity and affecting different services to varying degrees. Workforce redeployment continues to be prevalent, which would naturally limit capacity. Anecdotally we know many appointments are taking place by phone or video conference instead, but these are not clinically appropriate or possible for all aspects of care or all patients. The inability to deliver face to face treatment and care as a result of measures to stop the spread of the coronavirus may have contributed to some aspects of MS services being less busy than usual for a period of time. Added to the equation is reluctance among some patients to attend hospital appointments due to fear of infection. Given this, and the fact most respondents identified the backlog of patients as a key challenge in getting back to pre-Covid capacity, the ability of services to meet the needs of people with MS is going to continue to be challenging for an unknown period of time to come.

The findings suggest the pandemic has impacted all aspects of MS care to varying degrees. Rehabilitation services have been particular badly affected according to respondents. Routine appointments like annual reviews have been greatly affected which is perhaps unsurprising, but more worrying is the significant proportion of respondents saying services that by nature require timely intervention, have been impacted (such as relapse support, DMTs and symptom management treatments). The backlog of patients resulting from care which had to be limited, cancelled or delayed during the pandemic was identified as a challenge by the overwhelming majority of respondents.

There are many unknowns regarding when services will be able to resume a 'new normal'. It is clear that respondents want to see rehabilitation resume as a top priority, followed by DMTs, relapse support and symptom management. The future capacity of MS services and their ability to meet the needs of their whole MS population will depend on a range of factors. These factors include the ability of services to adapt settings to resume necessary face to face safely, and the speed at which patients regain confidence to attend and staff are allowed to return from redeployment. It will also depend on the uptake of more efficient models of care such as virtual clinics and improved triage processes, for which there was great appetite to see continue for among respondents.

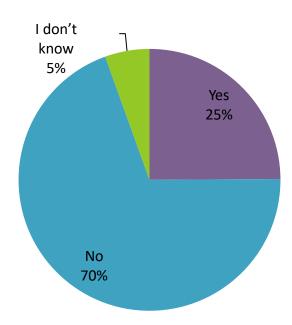
# 5. Using the findings

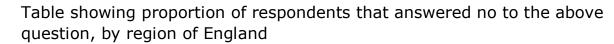
The MS Society and the MS Trust want to support MS professionals in the period ahead, to address the unmet needs and challenges that the pandemic has added to.

Respondents said charities continuing to provide information to patients on Covid-19 was the best way in which we could support them, and also wanted to see us continuing to provide services for people with MS and information for professionals. We also want to support people affected by MS to be involved in decisions about the future of MS services postpandemic, which a significant proportion of respondents said was not happening at present.

# 6. Full findings

1. Do you think the MS service you work in or with is able to meet the needs of people with MS to the extent it was pre-Covid-19?





Region of England	% respondents that don't think the MS service is able to meet the needs of people with MS to the extent it was pre-Covid-19
North East	75
Yorkshire & the Humber	75
South West	71
East of England	70
L7. ondon	67
North West	64
South East	68
East Midlands	50
Greater Manchester	33

2. Are you currently redeployed outside of your normal role?

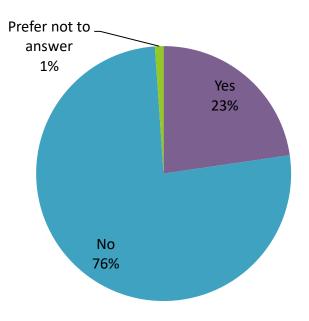
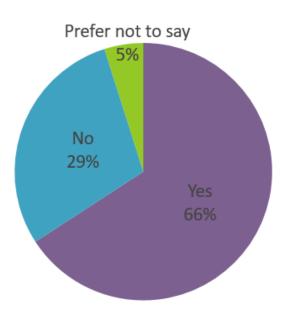


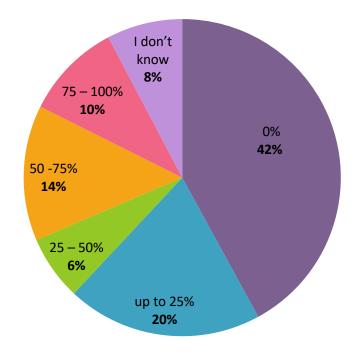
Table showing proportion of respondents that answered yes to the above question, by region of England

Region of England	% respondents who were redeployed at time of answering
East of England	60
Greater Manchester	33
Yorkshire & the Humber	33
North East	25
South West	18
London	17
South East	16
North West	7
East Midlands	0

3. If you have been redeployed, do you feel your time is being used well?



**4.** Thinking about the MS service you work in or with, approximately what proportion of the workforce is currently redeployed away from MS support**?** 



#### Free text comments on workforce and redeployment

Comments demonstrated the wide variety of experiences, with some MS services experiencing total redeployment and others none at all, with most somewhere in between. Many respondents said that they and/or their redeployed colleagues were beginning to return to MS care to deal with the backlog and challenges of delivering a service with ongoing social distancing and safety measures. A number of MS Nurses mentioned they were the only member of their 'MS service' and had still been redeployed during this time.

A selection of quotes that demonstrate the range of responses:

"It sounds very bleak but really it is just that much of our normal work is on hold until we are allowed to move freely again. We have not abandoned our clients; we are merely attending to different problems and crises where appropriate instead of completing other work" "Our service has been prioritised to dealing with urgent work to facilitate hospital discharges and prevent admission. Making patients safe at home, and if able giving self-management plans - but non-urgent assessments/rehab was on hold for approximately 8 weeks before recently restarting - with a significant backlog"

"I feel that community MS services are undervalued and redeployment to other general services was inappropriately decided. This is mainly because vulnerable and unstable patients and families were left unsupported at a time when they really need MS-specific support. Instead time has been wasted on indecisive plans where less complex patients care was taking priority over people with MS who had very difficult complex issues. The MS profile really does need to be greatly raised urgently to avoid this happening in the future."

"My MS service only consists of myself. I have not been redeployed but have been put on standby for the red covid team if required. My service supports patient through the whole trajectory of their disease. For advanced stage MS patients I rely on AHP's for support, physiotherapists, occupational therapists and others but at present they are triaging any referrals and only supporting patients who have the greatest needs. Only reactive medical care being supported at present"

"Our Physio team were redeployed to acute wards but have now resumed working in MS service as of this week. As a result we have had no input into MS patients during this time and are only restarting now."

"We are able to respond to urgent queries from people with MS, but our regular monitoring has been reduced. This is now proving detrimental to some patients."

5. How would you best describe the current capacity of the MS service you work in or with (considering caseload and staff)?

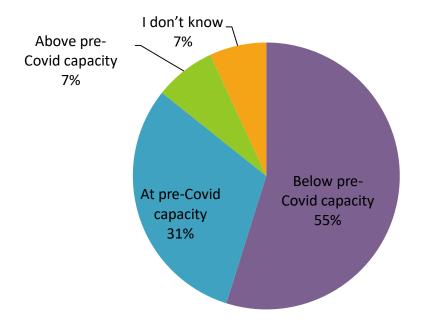
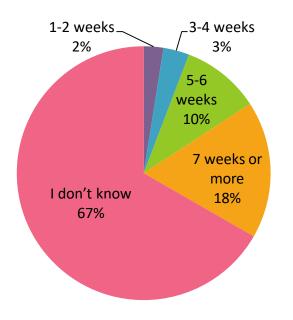


Table showing proportion of respondents describing the current capacity of the MS service as below pre-Covid capacity.

Region of England	% respondents describing service as below pre-Covid capacity
North East	33
North West	64
Yorkshire & the Humber	42
East of England	72
London	59
Greater Manchester	33
East Midlands	56
South East	46
South West	47

6. Are you able to estimate when the MS service as a whole will return to pre-Covid capacity?



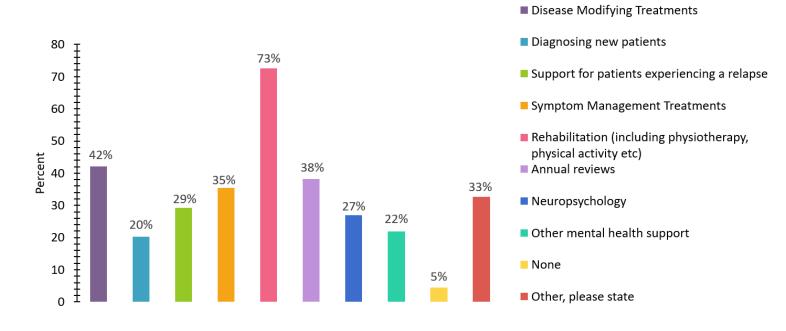
7. What challenges does the MS service face in returning to pre-Covid capacity?

Not enough staff	37%
Lack of physical space to deliver safe care safely i.e. following social distancing	66%
Lack of PPE to deliver care safely	10%
Patients reluctant to attend hospital/appointments	60%
Backlog of patients	75%
Other, please state	30%

Among 'other', comments included:

- A lack of suitable technology/IT to carry out virtual consultations
- Patients finding it difficult to access Virtual Clinic appointments
- Inability to carry out home visits due to ongoing social distancing measures
- Restrictions on face to face appointments/services

8. Which services, treatment or care has your MS service had to cancel, delay or limit at any point during the past 9 weeks? Please select all that apply.



Among 'other', comments included a variety of services that had also been limited, delayed or cancelled:

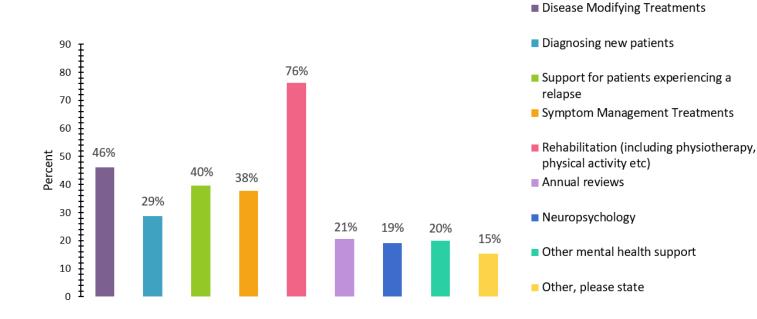
- Face to face appointments
- Social support
- Support to families and carers
- Home visits
- Support to newly diagnosed

Selection of quotes that demonstrate the range of responses:

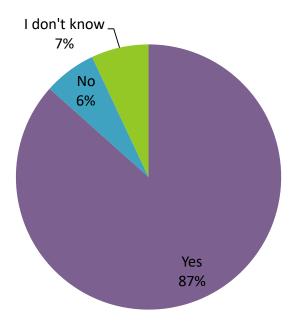
"A lot of the above services have been available via remote means, so have been available to a certain extent."

"Our MS Centre users attend to use specialist equip such as standing frames and tilt tables. They have 1:1 physio too. Since covid they have had exercise classes online and remote support/advise only but to a higher frequency (daily in some cases)"

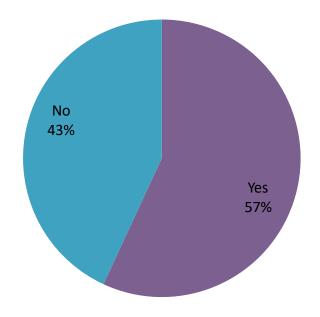
"Routine work is being delivered via the phones or video, but this isn't as adequate as face to face, so things are being done but not to our satisfaction or the patient's satisfaction, however the patients really appreciate the calls." 9. Which of the following do you want to see resume to pre-Covid capacity as soon as possible? Please select your three top priorities.



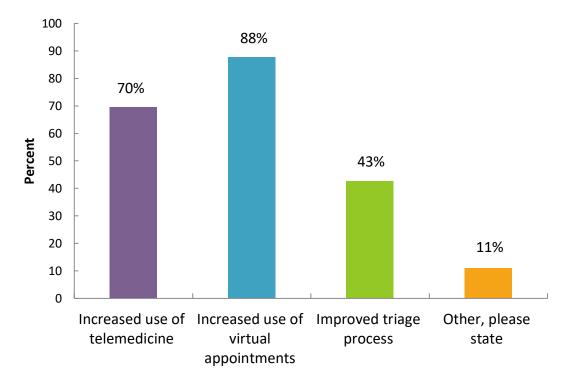
10. Have conversations started in your service about resuming delivery of treatment, care and services for people with MS which have been cancelled, delayed or limited for Covid-related reasons over the past 9 weeks?



11. Do you have any plans to work with patients to help shape how services resume and/or find out which ways of working have been beneficial and should remain in place?



12. What ways of working during Covid do you want to see continue, if any? Please select all that apply.



13. How can MS charities support you during this time? Please select all that apply.

