



# **Findings from a survey of allied health professionals delivering rehabilitation to people with progressive neurological conditions in the UK**

September 2020

## **About the survey**

We conducted a survey of 149 rehabilitation professionals in UK. The survey was available online from 26 August to 16 September.

The survey was developed in consultation with a number of different health professionals and professional bodies across the rehabilitation sector. The survey was promoted via direct mail and social media or by professional contacts. It was shared by the MS Trust, Therapists in MS, MS Therapy Centres, Parkinson's UK, Motor Neurone Disease Association, Chartered Society of Physiotherapy, Royal College of Occupational Therapists, Royal College of Speech and Language Therapists, Sue Ryder and Association of Chartered Physiotherapists in Neurology.

Although many of the professionals represented in the survey will provide services to patients with a number of different conditions, we asked them to specifically think about their patients with progressive neurological conditions when responding to the questions in this survey.

Unless otherwise stated the sample size represented by the data in following pages is the full respondent sample of 149 professionals.

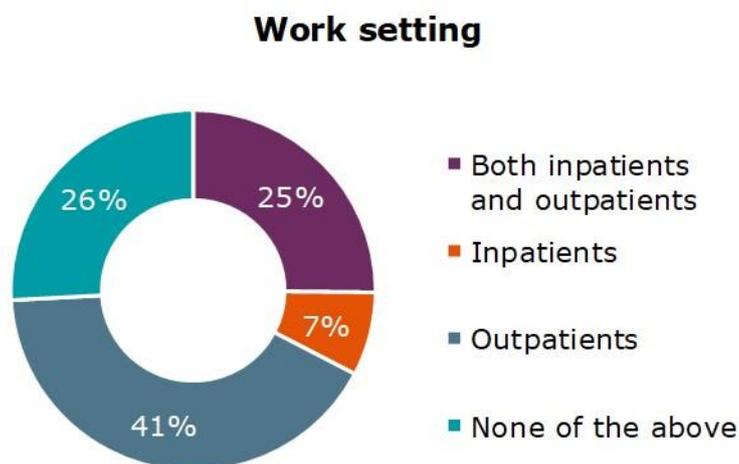
## About the respondents

The majority of respondents were physiotherapists (62%) and based in England (80%) – see Figures 1 and 3. There were a large amount of respondents working in community settings, but a variety of other settings were represented too (see Figures 2 and 4). Exactly half of respondents said they spent over 50% of their time supporting people with progressive neurological conditions.

**Figure 1.** What is your occupation?



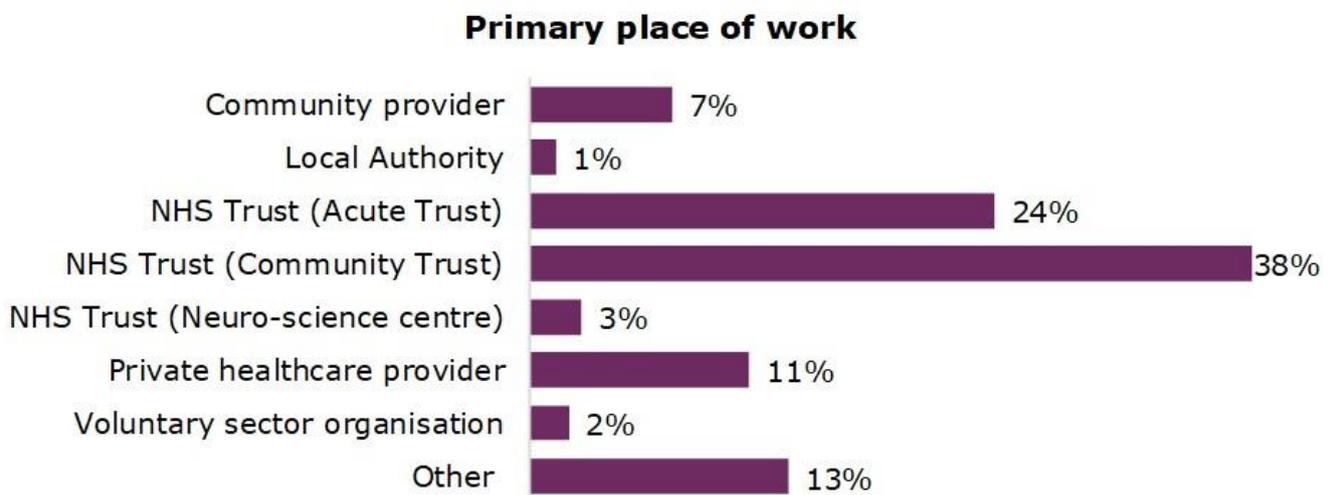
**Figure 2.** Which most accurately describes the setting in which you work?



**Figure 3.** Where is your work based?



**Figure 4.** What type of organisation do you primarily work for?



## Key findings

- **76% of respondents said they were aware of a deterioration in the mental or physical health of their patients due to not accessing rehabilitation therapies during lockdown.**
- **44% said their service had cancelled over half of their appointments for people with progressive neurological conditions.**
- **34% said the phone or video appointments they had provided in place of in-person appointments during the pandemic were 'not quite as good' for the patient as in-person appointments and 33% said they were 'much less useful'.**
- Half to 60% said they had continued routine, review or new assessments during lockdown either in person or by phone or video.
- Since the end of March, 90% have conducted phone or video appointments that would normally have been in-person.
- Half of respondents said they had been able to see less than 25% of their patients with progressive neuro conditions in-person during the pandemic.
- When asked to estimate the severity of the deterioration they were aware of in their patients, 49% of respondents reported they had seen severe deterioration in some of their patients.
- Of those who reported deterioration in 50% or more of their patients, 22% had seen minimal deterioration, 20% moderate, 10% significant and 5% severe.
- The most commonly reported deterioration was in walking/balance (85%), mood (77%) and weakness or stiffness in arms or legs (67%).
- When asked what their top three priorities for improving access to rehabilitation were, over three quarters (76%) of respondents said commissioning more community based rehabilitation. Nearly half (48%) said recruiting more professionals and providing services in a more innovative way (46%).
- 4 in 10 (39%) had offered reassessment appointments to patients with progressive neurological conditions who were discharged from neuro-rehabilitation services at the start of the pandemic.

## Commentary

The most striking finding was the proportion of professionals aware of deterioration in their patients since the start of lockdown. Progressive conditions deteriorate over time by their nature, but three quarters (75%) of respondents said they were aware of a deterioration in the mental or physical health of their patients directly due to not accessing therapy during lockdown.

This is echoed in what people with MS have told us. In survey of people with MS in August, a third (34%) felt their symptoms had changed or worsened since the beginning of lockdown. Of those, over half (51%) said that a reduction in, or changes to, accessing specialist rehabilitation support had contributed to this.<sup>i</sup>

While most deterioration reported was not severe, 49% of professionals reported that they had seen severe deterioration in at least some of their patients. In our recent 'Too Much to Lose' report, the MS community told us about the impact of physical and mental deterioration over the past months on their lives, walking, pain, mood, and the ability to do things they enjoy.<sup>ii</sup>

44% of professionals responding to this survey said their service had cancelled over half of appointments for people with progressive neurological conditions since the start of lockdown. This was despite the majority of respondents (90%) having delivered what would have been in-person appointments over phone or video instead. These findings are again echoed in 'Too Much to Lose' with 7 in 10 (69%) people with MS unable to see a rehabilitation professional since the start of the pandemic when they needed to.<sup>iii</sup>

Services are now handling this backlog of appointments from the first wave of the pandemic, with the potential of a second wave compounding waiting lists further. It is encouraging that 59% of respondents said they had already offered a reassessment appointment to people with progressive neurological conditions who were discharged from neuro-rehabilitation services at the start of lockdown. Many respondents commented in the free text that they were now able to offer more patients the in-person appointments they needed again. However, many also described capacity remaining a challenge and 3 in 10 (31%) said they had not offered reassessments yet, pointing to a risk that some people may still be going without the support they need.

Loss of function and quality of life can be regained - with the right treatment, and support to self-manage and remain physically active. When, and whether, everyone will be able to access that treatment and support is an ongoing concern, particularly given the existing capacity challenges in health services pre-pandemic.

## Virtual appointments

On the efficacy of virtual appointments, respondents were neither overly positive nor overly negative - with 34% saying they were 'not quite as good' for the patient as in-person appointments and 33% saying they were 'much less useful'. Understandably this will vary depending on the patient and 21% of professionals couldn't it varied too much to say whether virtual appointments were better or worse in general. The free text responses reflected this, with many professionals saying virtual appointments are an important part of a blended approach to service delivery, but only alongside in-person care and according to the needs and preferences of the patient.

People with MS expressed similarly mixed views about virtual appointments in 'Too Much to Lose'. Of those who had appointments by phone or video, 6 in 10 (63%) said they had received all the support and information they needed – but 3 in 10 (35%) said they hadn't had enough support through virtual or telemedicine. The majority said they would prefer an in-person appointment in the future.<sup>iv</sup> As the NHS seeks to embed learning from the pandemic into the way services are delivered in future, there is a need to bring patients with neurological conditions and clinicians together to understand what works in terms of virtual appointments.

## Implications for the future

We asked respondents to tell us their priorities for improving rehabilitation. They reflected the fundamental challenges that have faced provision of rehabilitation across the UK for some time. Most (76%) identified commissioning more community-based rehabilitation as a priority and almost half (48%) said recruiting more professionals.

They also identified ways in which services could improve their ways of working - 42% would prioritise better communication between professionals in different settings, and 46% said delivering rehabilitation in a more innovative way was key. Many respondents shared examples of the way in which they have adapted to meet the needs of their patients during the pandemic and ways of working they planned to continue. These commonly included telephone/video calls for triage and review appointments, and recommending exercise videos and apps to help patients remain physically active and self-manage at home.

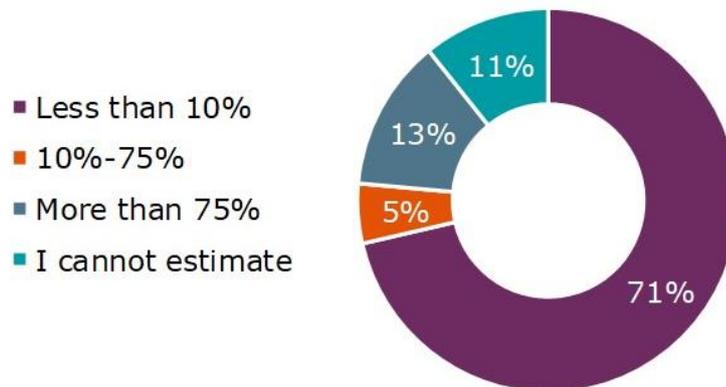
Their comments demonstrate the ingenuity and passion amongst professionals to keep supporting their patients during an incredibly challenging time. By listening to the experiences of healthcare professionals and patients there is an opportunity to rebuild more effective, efficient NHS rehabilitation services that can meet the needs of more people with neurological conditions.

## Full results

The following graphs represent the results of the survey. The figure legends are a direct reference to the question as it was displayed in the survey. Where answers have been aggregated or suppressed due to low numbers this is indicated underneath the graph.

**Figure 2.** Can you estimate what proportion of your patients are paying privately for your services?

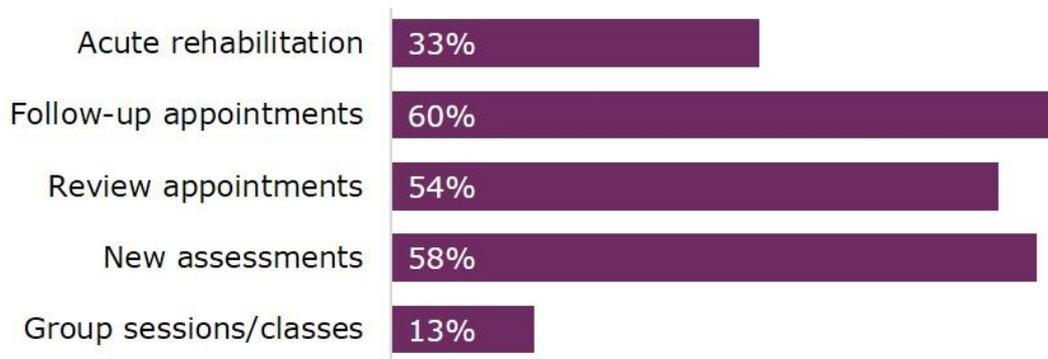
### Proportion of patients paying privately for services



Brackets between 10%-75% have been aggregated due to small numbers.

**Figure 6.** Since the end of March, what appointments for people with progressive neurological conditions have you been continuing (either in person or by tele/video)?

**Appointments continued (in person or virtually)**

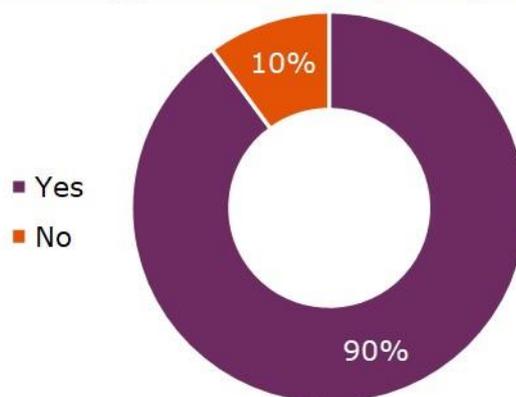


Other = 17%, None of the above = 5%

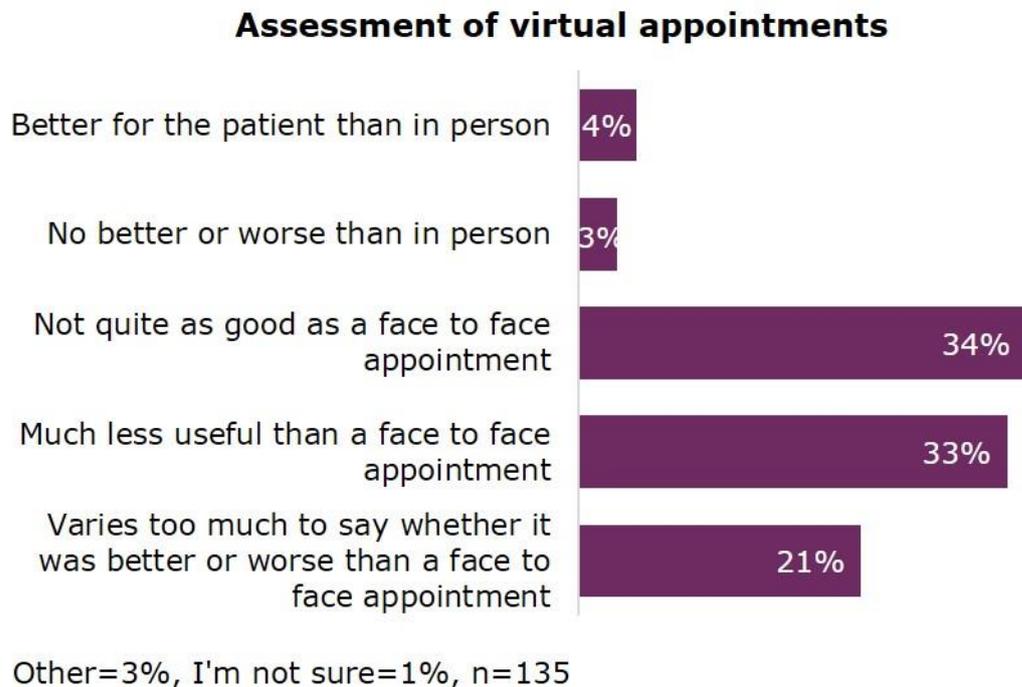
Acute rehabilitation = intensive rehabilitation such as after an incident or relapse

**Figure 7.** Since the end of March, have you had to conduct appointments by telephone or video that you would normally conduct in person?

**Conducted appointments by telephone or video**



**Figure 3.** Thinking about the service you provide for people with progressive neurological conditions, on average, how do you feel these virtual appointments were.



**A selection of free text responses on new ways of working during the pandemic that have benefited patients and which professionals plan to continue**

“Conducting telephone consultations to complete reviews - using a review template to ensure full review is completed - this encourages self-management, allowing face to face time to be allocated to those who require active input. Sending home exercise programmes in the post and reviewing by telephone.”

“I am back to face to face as much as risk assessment will allow. We are a hands on service often assisting very disabled clients where virtual consultations are of limited value. Although the pandemic has opened our eyes to the use of this with some clients, we also used it to give reassurance and help to problem solve but not treatment.”

“Increased awareness of on-line tools such as videos. I could recommend on YouTube or Apps.”

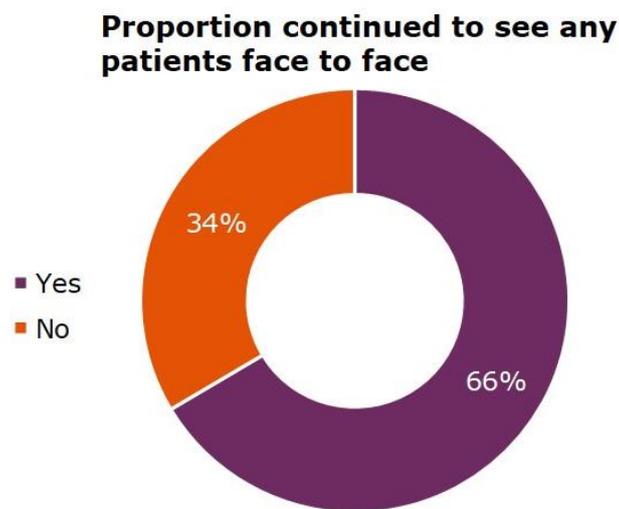
“Some of our patients found a virtual meeting more beneficial due to travel/time and feeling fatigued. However some have not, in particular our newly diagnosed patients have found not having a face to face most distressing.”

“Assessment screens and phone calls at the triage stage have helped us quickly and efficiently more easily identify priority needs.”

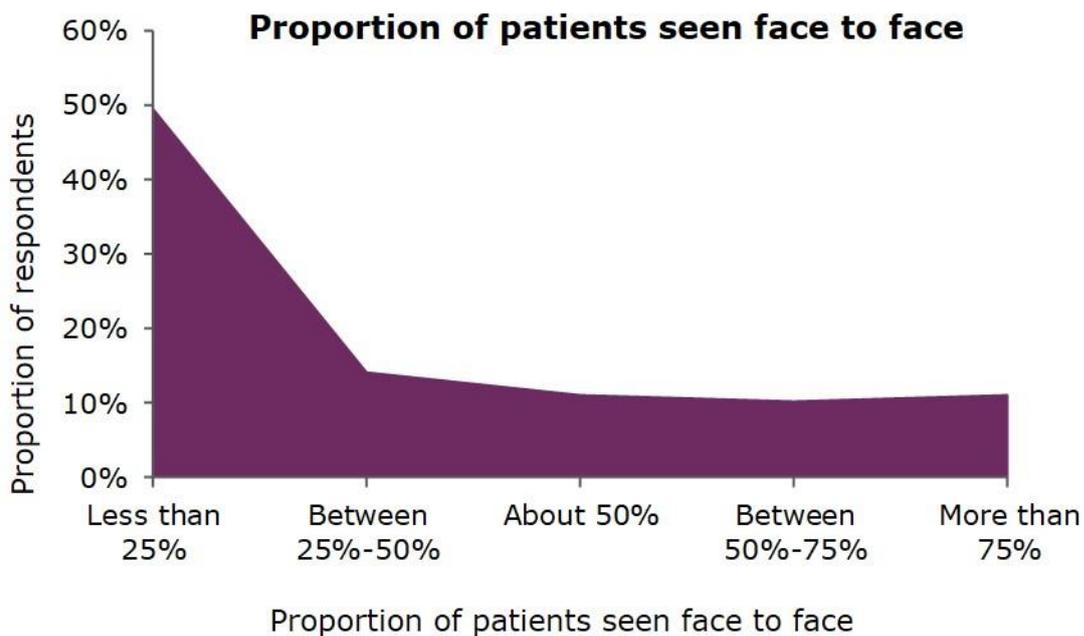
“A mixed approach is more favourable - home visits and video consultations.”

“We are now completing either a telephone or video assessment at first and identifying needs so that the face to face visits are more targeted.”

**Figure 4.** Since the end of March have you been able to continue to see any of your patients with progressive neurological conditions face to face?

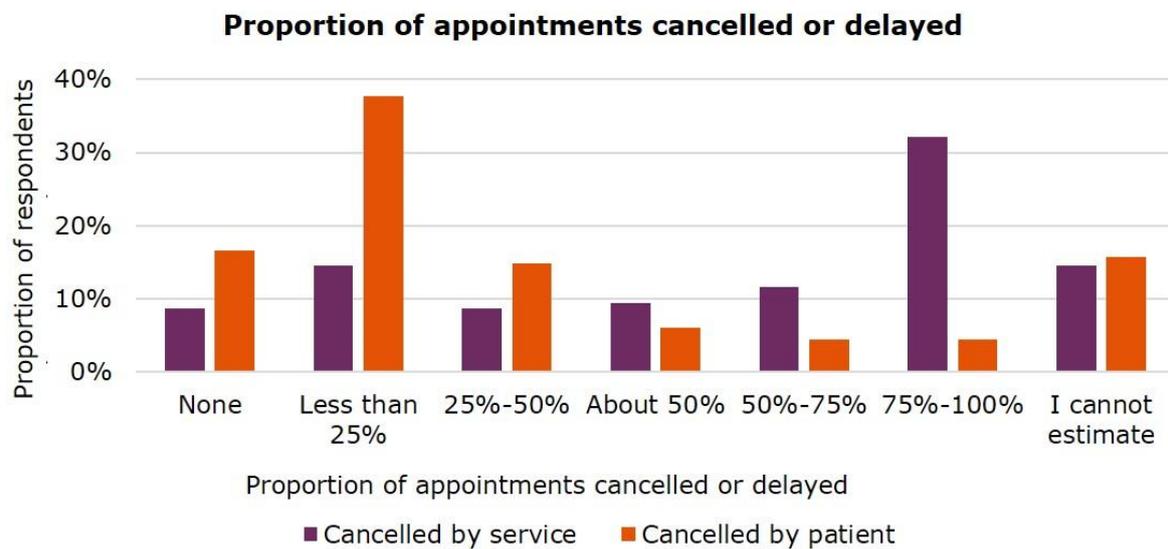


**Figure 5.** What proportion of your patients with progressive neurological conditions have you been able to continue to see face to face?



I cannot estimate=4%, n=99

**Figure 6.** Since the end of March, what proportion of your appointments with people with progressive neurological conditions have been cancelled or delayed?



Cancelled by service, n=137. Cancelled by patient, n=114  
 n numbers vary as non-compulsory question. % is total of those answered.

**A selection of free text responses on the impact on patients that have not being able to access the support they need.**

“Reduced footfall into the department means that the majority of my patients have deteriorated. I am now trying to see my patients face to face and they are happy to come in but I can only see the critical patients. More admissions have occurred due to falls because of reduced mobility. Covid-19 has had a significant impact on my patients.”

“I now work independently having worked in the NHS for over 20 years. I have had several inquiries from people who have been discharged by NHS outpatient rehabilitation services and told they cannot be seen because of Covid and are told that it is unclear when they will be seen again. I am concerned that the focus is off long-term conditions and rehabilitation even more than pre-Covid.”

“We thought our patients were staying safe and well as they weren't falling, but it's looking like this is only because they were not mobilising as much, which has the knock on effect of more deterioration in strength, balance, exercise tolerance, and confidence. That and they were underreporting issues as had cancelled carers or were avoiding HCPs for fear of COVID. Ability to self-manage has reduced due to increased LTNC associated anxiety and depression, use of negative coping strategies (our known drinkers are drinking more and presenting with falls when they are usually self-managing) which have been exacerbated during COVID. And

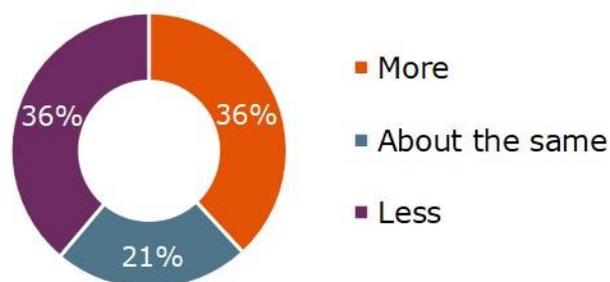
disruption to their usual maintenance programmes – physical activities, day centres etc. Feels like we are starting at square one again for a lot of people who were self-managing.”

“Much of neuro is maintenance. Therefore this is a major issue. I have found some new referrals to be due to increased weakness and lack of normal activity during lock down. Definitely worsening of contracture due to untreated increased tone and lack of stretching.”

“There is still a lack of community services so patients are unable to manage their long term conditions themselves as well e.g. day centres, specialist groups and gym services, exercise classes are still not running.”

**Figure 7.** Since the end of March, do you feel you have had more or less contact with patients with therapy queries outside of appointments e.g. email or phone conversations?

### Change in amount of contact outside of appointments

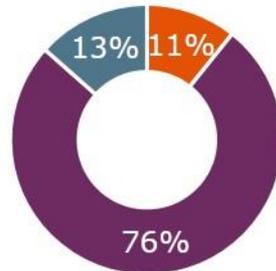


NA, I don't have contact with patients outside of appointments=5%,  
I'm not sure=1%

**Figure 8.** In your opinion, do you think that you have seen or been made aware of a deterioration in the physical or mental health of any of your

patients with progressive neurological conditions due to not accessing therapy during lockdown?

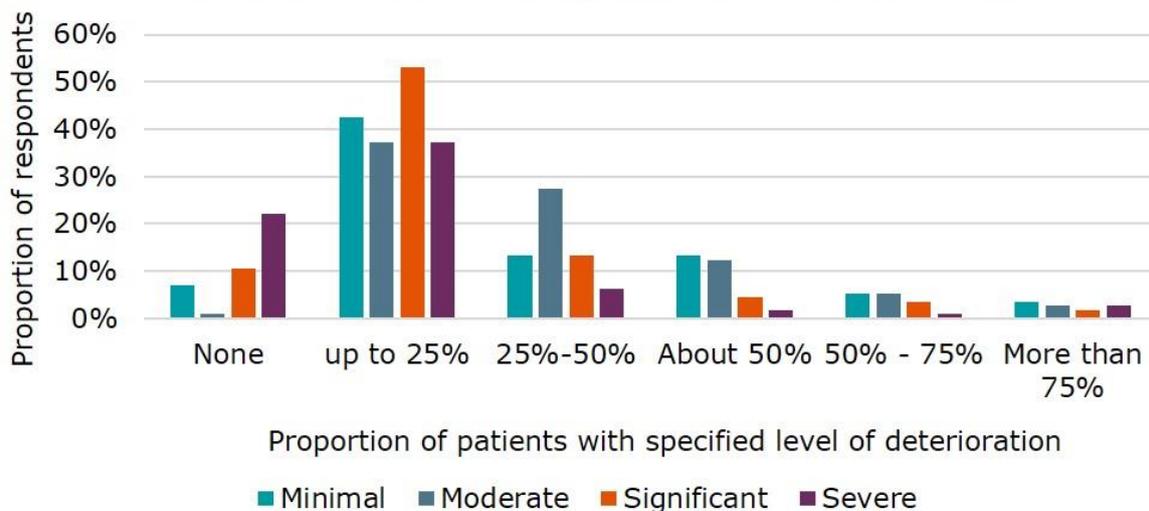
### Apparent deterioration in physical or mental health



■ No ■ Yes ■ I don't know/I haven't been in contact with my patients

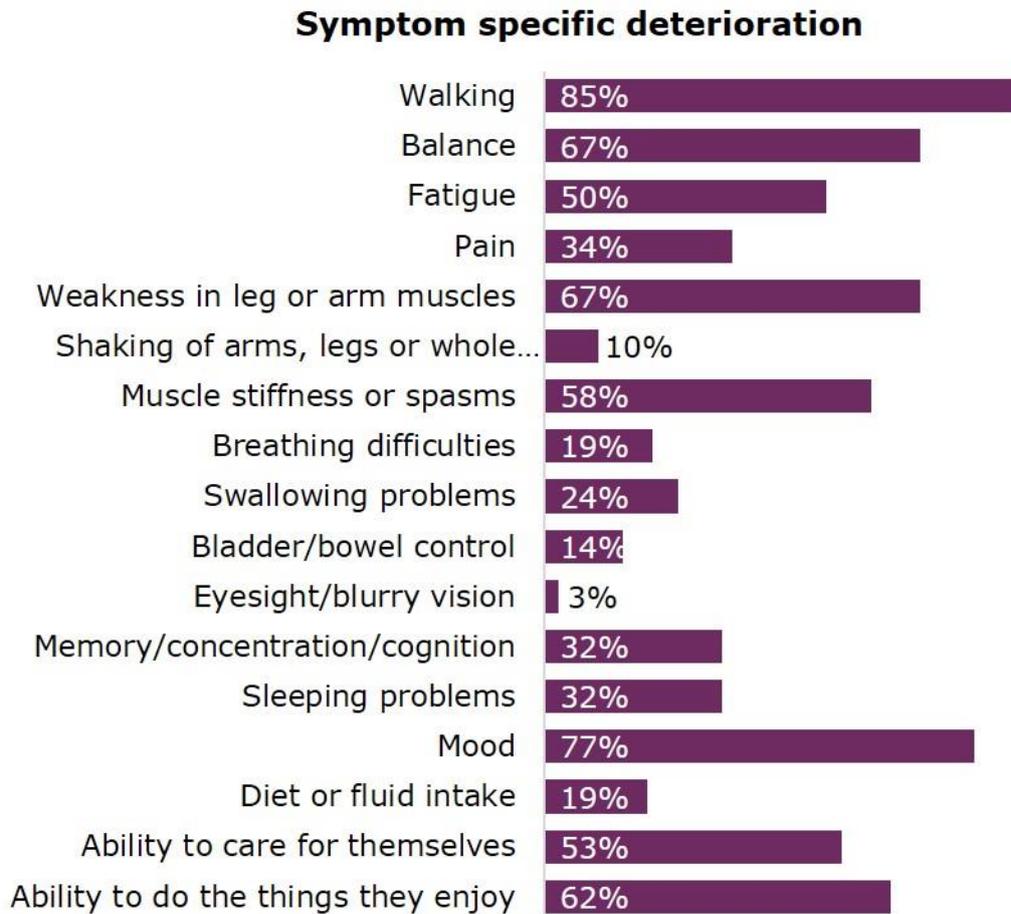
**Figure 9.** In what proportion of your patients are you aware of the following levels of deterioration?

### Severity of deterioration in physical or mental health



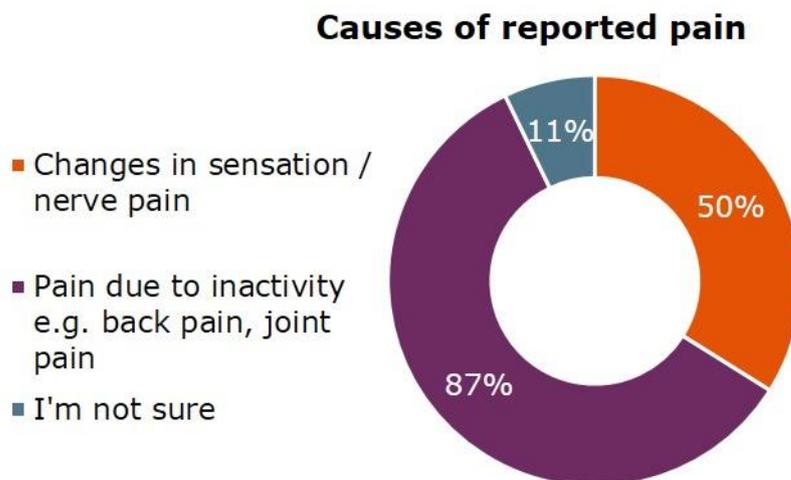
Definitions of severity: **Minimal**=no or minimal deterioration, **Moderate**=moderate deterioration in one or minimal deterioration in several functions, **Significant**=significant deterioration in one or moderate deterioration in several functions, **Severe**=severe deterioration in one or a number of functions  
n=113

**Figure 10.** In what areas have your patients reported deterioration?

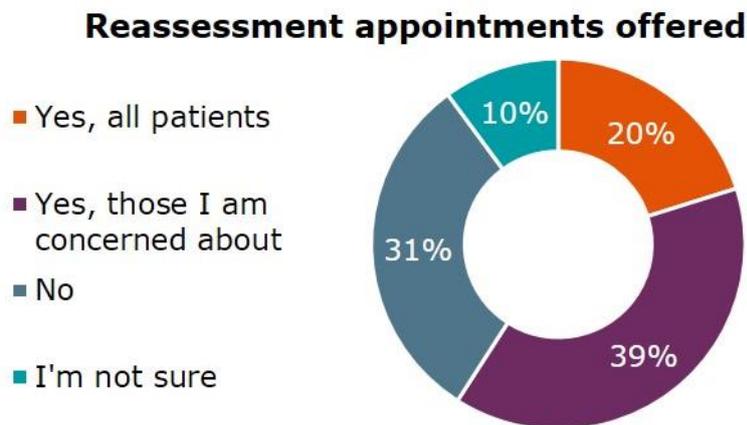


Other=12%, n=113

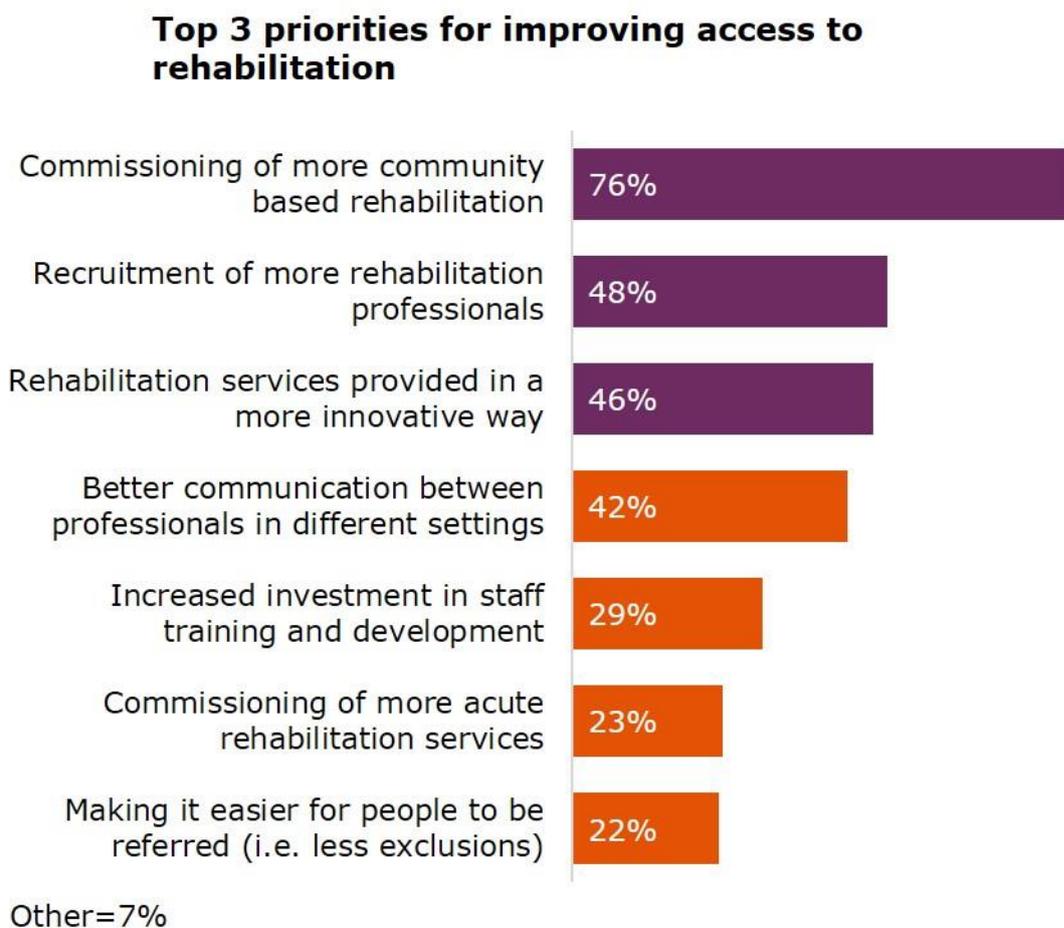
**Figure 11.** Was the pain reported due to (select from the following)



**Figure 12.** To date have you offered a reassessment appointment to those patients with progressive neurological conditions that were discharged from neuro-rehabilitation services at the start of lockdown?



**Figure 13.** Please select your top 3 priorities for improving access to rehabilitation



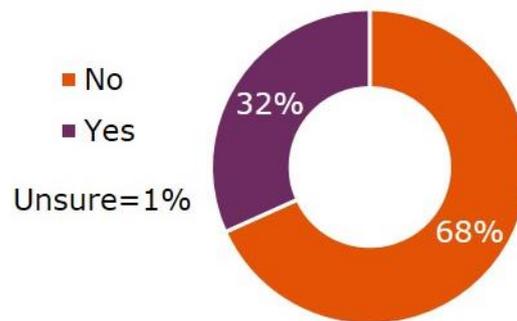
**A selection of free text responses about improving access to rehabilitation**

"We are only just now beginning to contact people whose care was placed 'on hold, due to Covid and staff being redeployed so it is too early to know what the full impact of Covid has been until we review all clients. Additionally, we now have really long waiting lists to get through and were team with insufficient capacity before Covid arrived so this will be a challenge. Our service will be offering a limited service to help clear the waiting lists. We also have a lot of people on our new referral waiting lists who have been referred to us but have not had an initial assessment yet to understand their needs/goals. Rehabilitation was under-resourced prior to Covid and now Covid has made capacity and demand issues even worse."

"I think services will develop and change to support the increased need. Unfortunately acute services are seeing more investment and the need for rehabilitation services for long term neuro patients aren't seen as a priority. I am struggling to develop my service because of this."

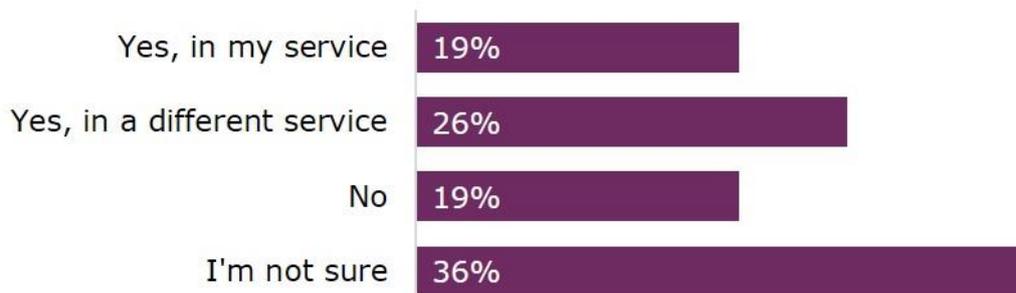
**Figure 14.** Are you aware of any of your existing patients having had COVID-19 symptoms, from mild to critical?

**Patients with COVID-19 symptoms**



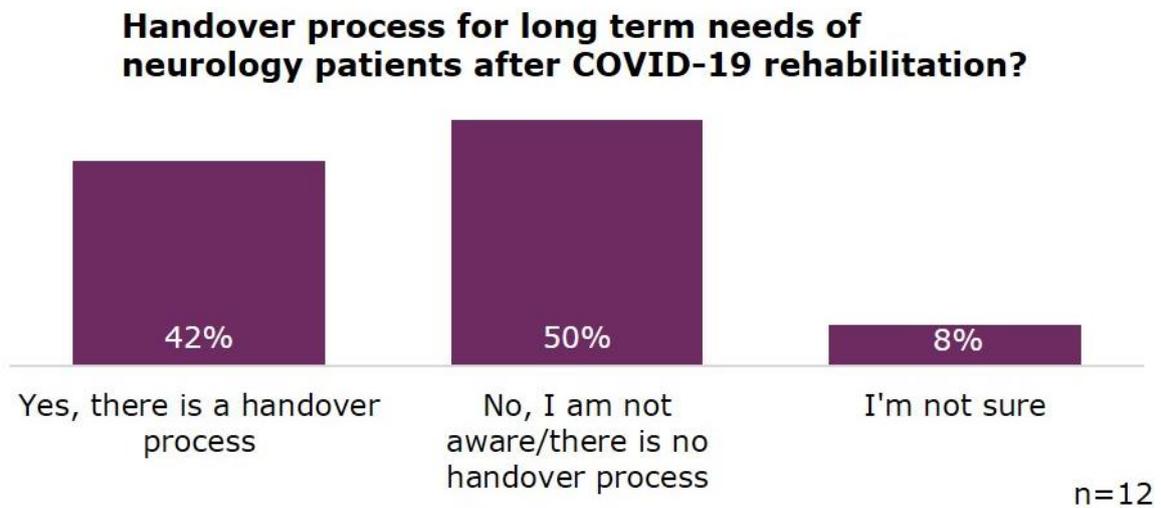
**Figure 15.** Are you aware whether these patients are receiving/have received acute rehabilitation for COVID-19?

**Have these patients been offered acute rehabilitation?**



n=47

**Figure 16.** Have you received/is there a process you are aware of for handover about longer terms needs of neurology patients being referred back to you after COVID-19 rehabilitation?



<sup>i</sup> Data from an online survey of 1,674 people with MS by the MS Society and UK MS Register, 12 – 26 August 2020. See MS Society, Too Much To Lose, September 2020:

<https://www.mssociety.org.uk/what-we-do/our-work/our-evidence/care-and-support>

<sup>ii</sup> Ibid

<sup>iii</sup> Ibid

<sup>iv</sup> Ibid