

Survey briefing: Life with a neurological condition during COVID-19

Between 9 – 20 June 2020, the Neurological Alliance asked people affected by neurological conditions to respond to a short survey about how the pandemic had impacted them.

The survey was developed in-house by the Neurological Alliance. A small group of Neurological Alliance members were asked to review the draft questions prior to promotion.

The survey was promoted on the Neurological Alliance Twitter and Facebook accounts, and sent to more than 1000 people with a neurological condition who indicated they would like to hear more about our work during the 2018/19 National Neurological Patient Experience survey.

Our members also promoted the survey via email and social media, as did the Cymru Neurological Alliance, the Neurological Alliance of Scotland and Northern Ireland Neurological Charities Alliance.

Who responded?

1672 people responded to the survey across the UK. Further information about who responded is provided below.

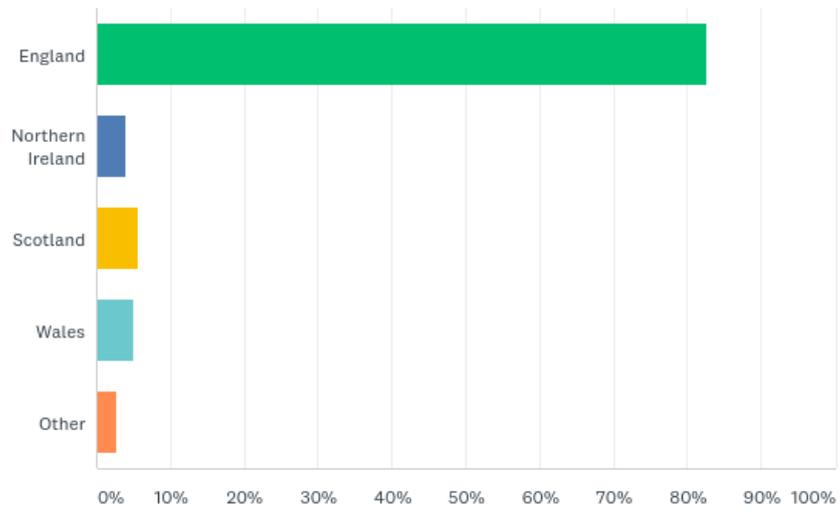


Figure 1: % of respondents by location

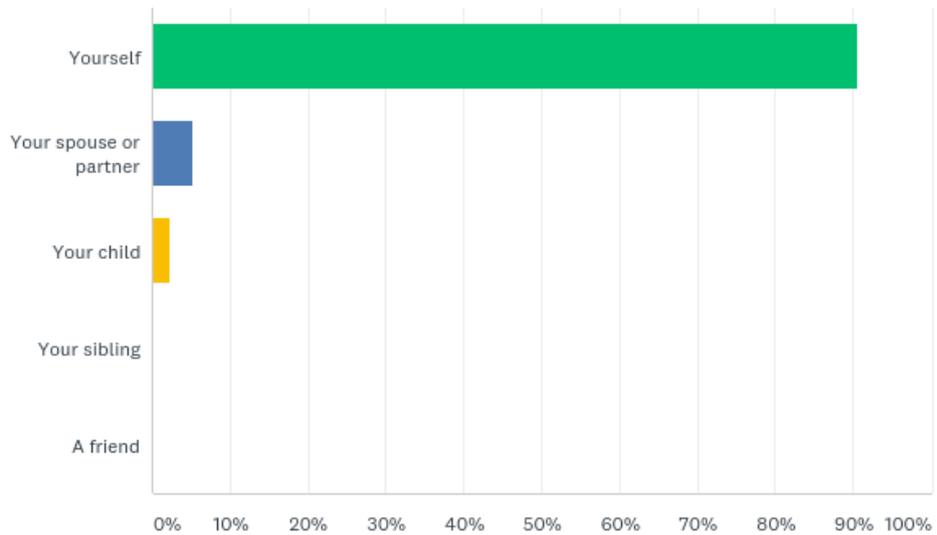


Figure 2: Responses to "Who are you filling in this questionnaire for?"

Table 1: Respondents self-reported diagnosis

ANSWER CHOICES	RESPONSES	ANSWER CHOICES	RESPONSES
Acoustic neuroma	0.12%	Motor neurone disease	9.59%
Acquired brain injury	1.74%	Multiple sclerosis	9.59%
Ataxia	1.62%	Multiple system atrophy	0.42%
Autism (neurodevelopmental)	0.78%	Muscular dystrophy	0.24%
Autoimmune encephalitis	0.00%	Myalgic encephalomyelitis/ chronic fatigue syndrome	3.65%
Batten disease	0.00%	Myasthenia	1.68%
Brain tumour	1.20%	Myelopathy	0.24%
Carpel tunnel syndrome	1.20%	Myositis	0.12%
Cavernoma	0.48%	Myotonic disorders	0.24%
Cerebral palsy	1.08%	Narcolepsy	0.24%
Charcot-Marie-Tooth disease	0.48%	Neurodegeneration with brain iron accumulation	0.06%
Chiari malformation	2.22%	Neurofibromatosis	0.12%
Chronic inflammatory demyelinating polyneuropathy	0.66%	Neuromyelitis optica	0.12%
Cluster headache	1.56%	Parkinson's	3.54%
Congenital hemiplegia	0.18%	Poliomyelitis	0.84%
Dementia - Alzheimer's	0.30%	Post-Polio syndrome	1.26%
Dementia - frontotemporal	0.24%	Progressive supranuclear palsy	0.06%
Dementia - Lewy body	0.12%	Radiculopathy	0.36%
Dementia - vascular	0.18%	Refsum's disease	0.00%
Dementia - other	0.00%	Restless leg syndrome	3.71%
Dystonia	42.54%	Somatiform disorders	0.12%
Encephalitis	0.24%	Spina bifida	0.24%
Epilepsy	4.97%	Spinal muscular atrophy	0.12%
Essential tremor	2.40%	Spinal condition	3.30%
Functional neurological disorder	7.61%	Spinal tumour	0.12%
Guillain-Barre syndrome	0.84%	Spondylosis	2.16%
Haemorrhagic leukoencephalitis	0.00%	Stroke - cerebral vascular attack	1.20%
Hemifacial spasm	1.02%	Stoke - transient ischemic attack	1.02%
Huntingdon's disease	0.06%	Tourette syndrome	0.42%
Hydrocephalus	0.54%	Transverse myelitis	1.02%
Idiopathic intracranial hypertension	0.90%	Traumatic brain injury	0.84%
Kennedy's disease/SBMA	0.12%	Traumatic spinal injury	0.72%
Malignant neuroleptic syndrome	0.00%	Trigeminal neuralgia	1.80%
Meningitis	0.24%	Tuberous neuralgia	0.00%
Migraine	8.15%	I'm waiting for a diagnosis	1.26%
		Other (please specify)	7.43%

Key findings

We found that people with neurological conditions had been profoundly impacted by the pandemic, with many reporting disruptions to their treatment, care and support.

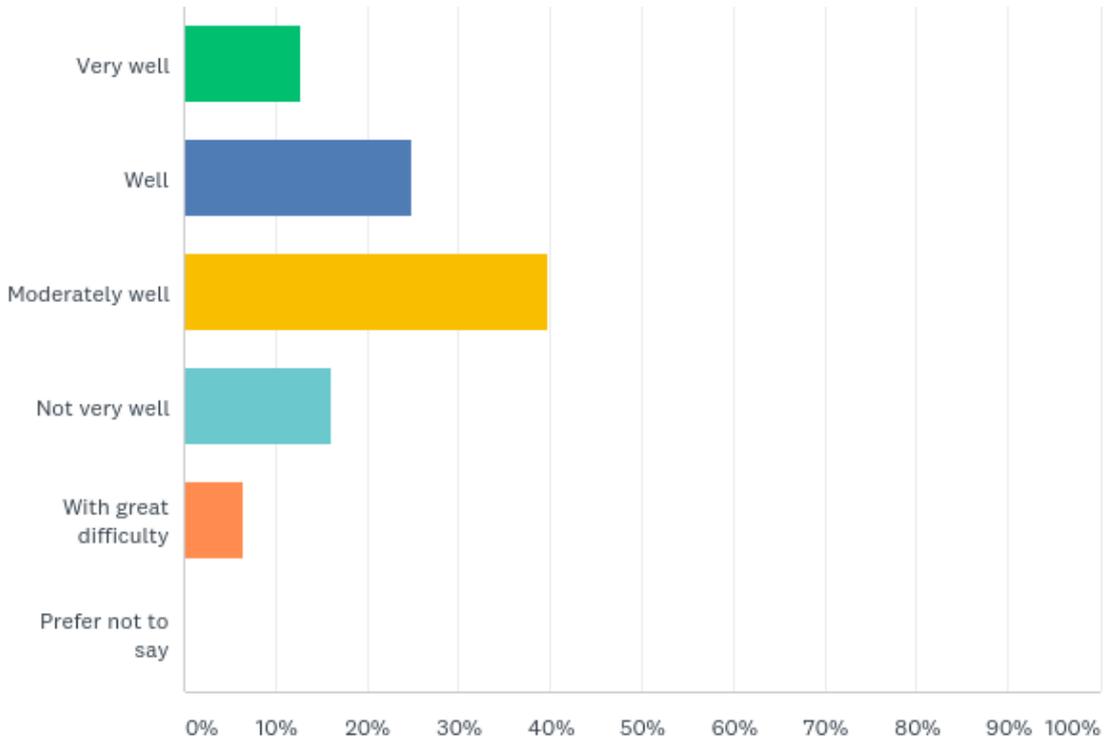


Figure 3: Response to the question "How have you been coping during the pandemic?"

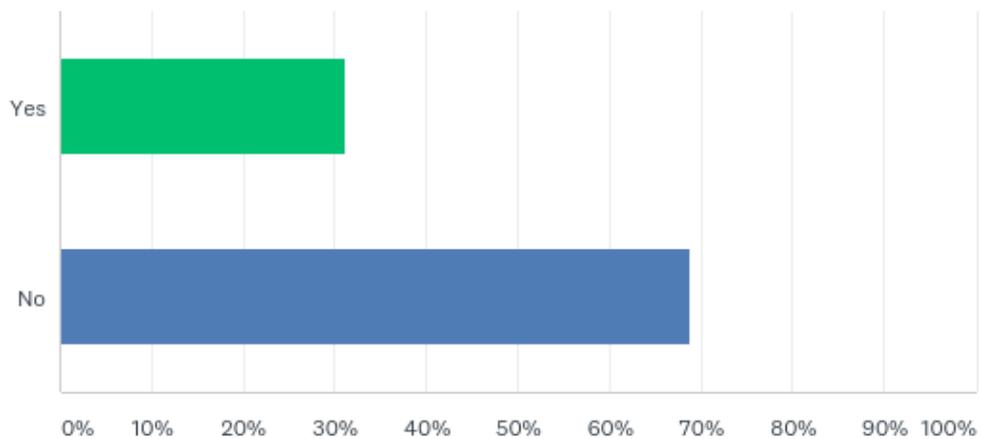


Figure 4: Response to the question "Have you had any problems accessing your normal food supplies during the pandemic?"

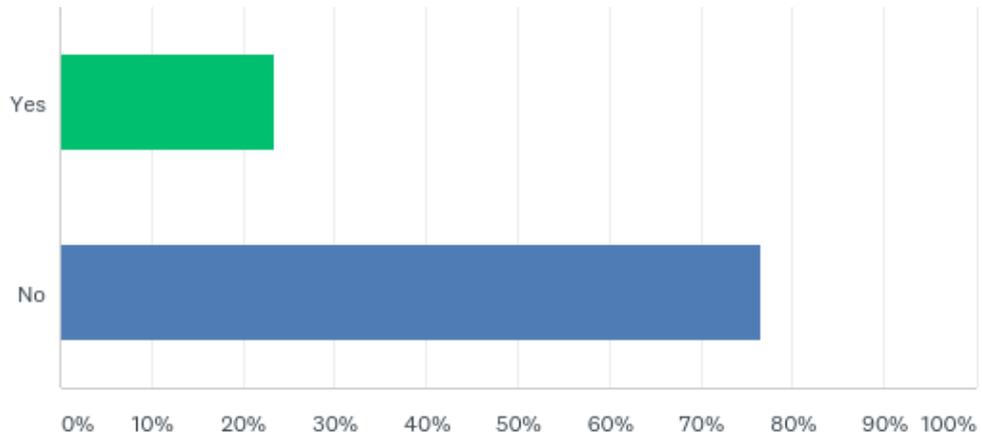


Figure 5: Responses to the question "Have you had any difficulty accessing your regular medication during the pandemic?"

In particular, people reported high levels of cancellation or delays to their treatment, care and support. A high number of people reported not knowing when their treatments had been delayed until.

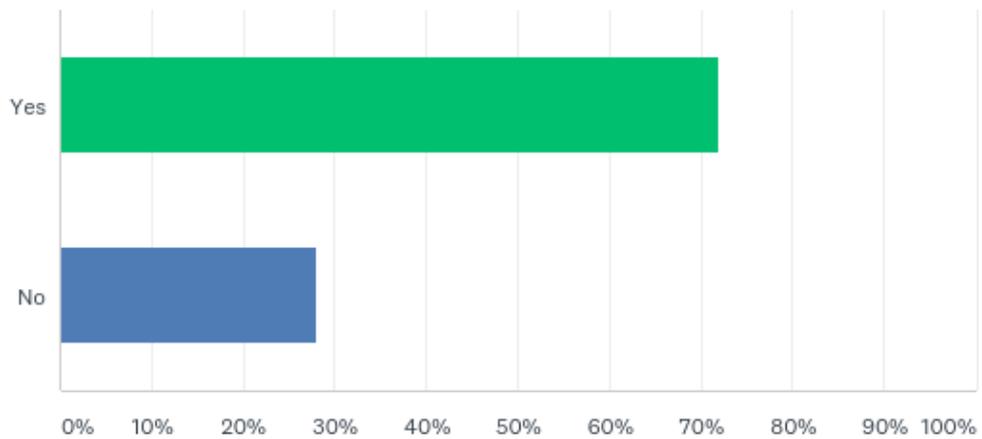


Figure 6: Response to the question "Have you had any medical appointments delayed during the pandemic?"

For those who experienced a delay, we asked them to state which appointments had been impacted:

- 15% reported this being in relation to a drug therapy treatment
- 9% reported delays to a scan
- 47% reported it was an appointment with a neurologist
- 17% said this was an appointment with their specialist nurse
- 15% said their physiotherapy appointment had been delayed
- 6% had experienced delays to their appointment with a psychologist or psychiatrist
- 8% experience delays to an appointment for surgery

43% of all people who had experienced delays, didn't know when their appointment had been delayed until. For those who have experienced a delay in seeing a neurologist 39% don't know when it has been delayed until. 7% of people have experienced delays of more than 6 months, 20% 3-6 months, 24% 2-3 months and 6% experienced delays of less than a month.

Over 1 in 2 people said they had had appointments cancelled. We asked people what had been cancelled:

- 12% said a drug therapy treatment
- 5% said a scan
- 31% had their neurologist appointment cancelled
- 13% said an appointment with their specialist nurse
- 9% said a physiotherapy appointment
- 3% said an appointment with a psychologist or psychiatrist
- 6% said an appointment for surgery

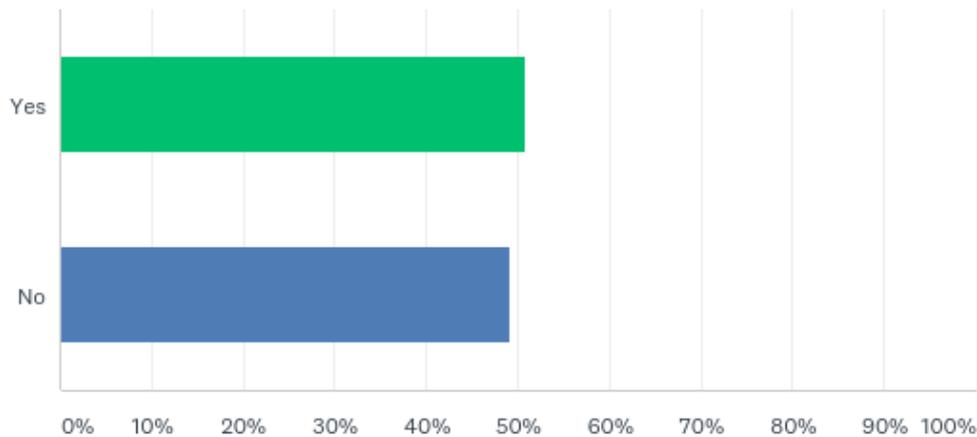


Figure 7: Response to the question "Have you had any medical appointments cancelled during the pandemic?"

Many people had accessed a 'virtual appointment', either by phone or videoconference: 4% of these virtual appointments had been a first meeting with a neurologist, 27% a routine meeting with a neurologist, 12% a routine check-up with a specialist nurse, 5% a rehab appointment, 4% a psychiatric appointment and 27% an appointment with their GP.

Out of all respondents who had accessed a 'virtual' appointment, more than 80% had done so by phone.

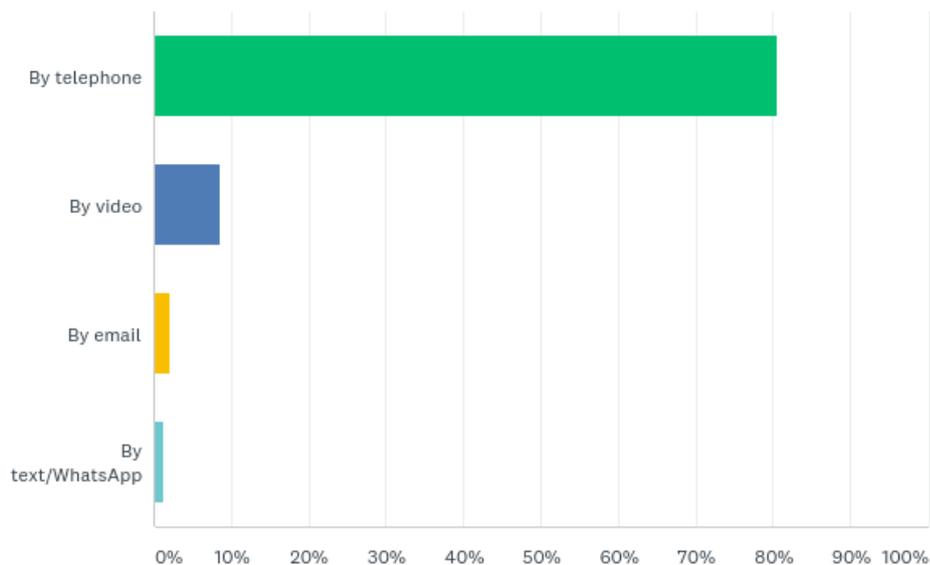


Figure 8: Response to the question 'How were these consultations delivered (please tick all the methods that apply)?'

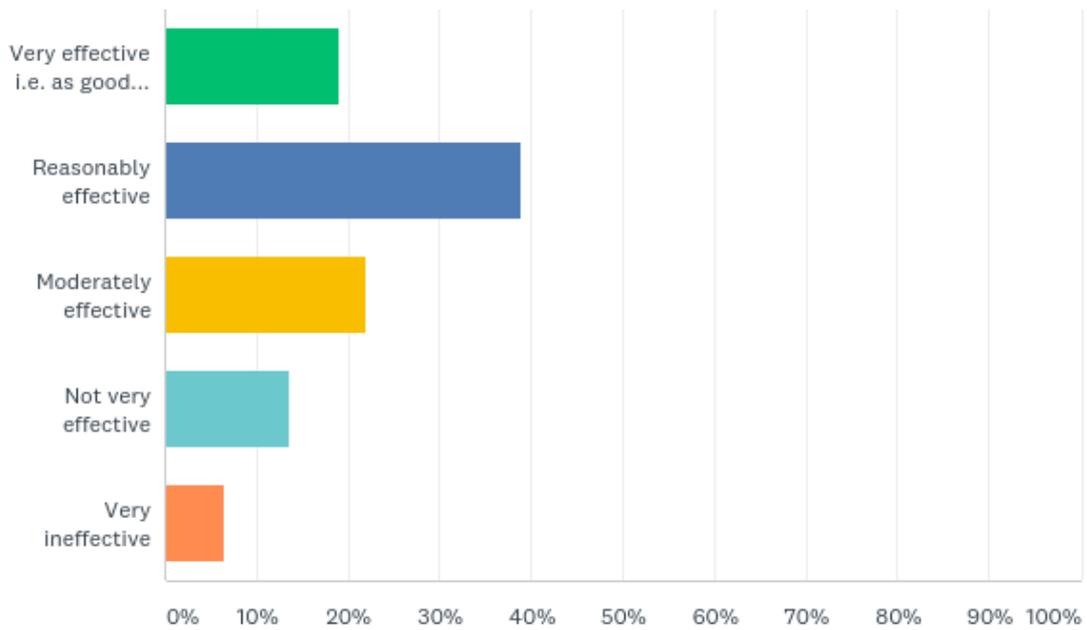


Figure 9: Response to the question 'On average, how do you feel these virtual consultations went?'

In the future however, 39% would prefer their appointments to be face to face, compared to 8% who would prefer a virtual appointment. 54% said that it would depend what the appointment was about.

We also asked people if they had accessed emergency care during the pandemic.

Table 2: Response to the question "Have you accessed emergency care during the pandemic?"

ANSWER CHOICES	% OF RESPONSES
YES	11.12%
NO BUT I HAVE NOT NEEDED TO	81.33%
NO BUT I PROBABLY NEEDED TO	7.56%

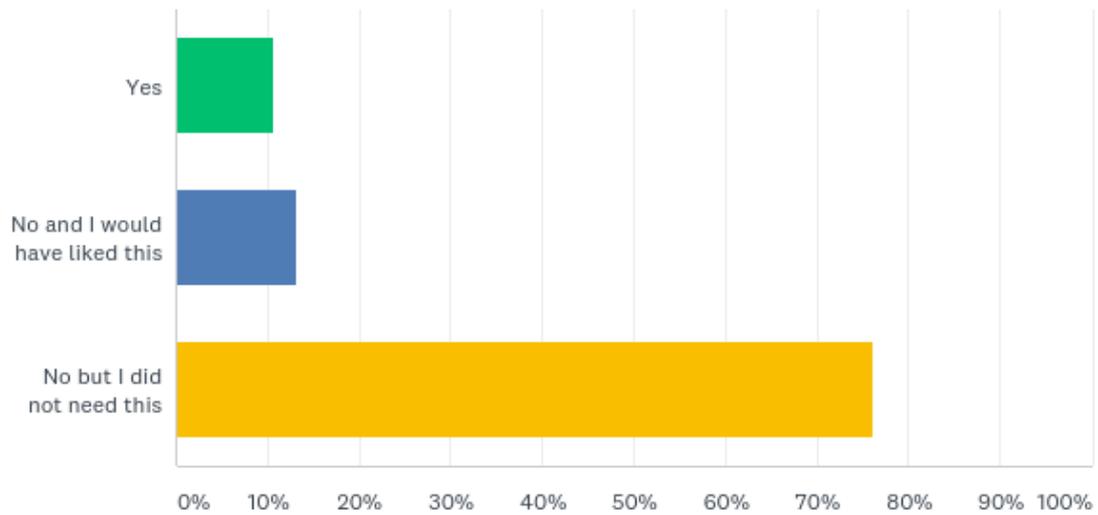


Figure 10: Response to the question "If you have accessed emergency care, was your carer, friend or family member allowed to go with you?"

The majority of people who responded to our survey had not experienced interruptions to their social care, although 4% had experienced a reduction in their care package. A further 4% had reduced or cancelled their care and support due to concerns about infection.

Overwhelmingly, support is being provided by informal carers – 30% of respondents said the support they needed to maintain their independence was provided by friends or family.

'Shielding' has had a huge impact on people with neurological conditions, and many people reported issues with Government communication and guidance on this.

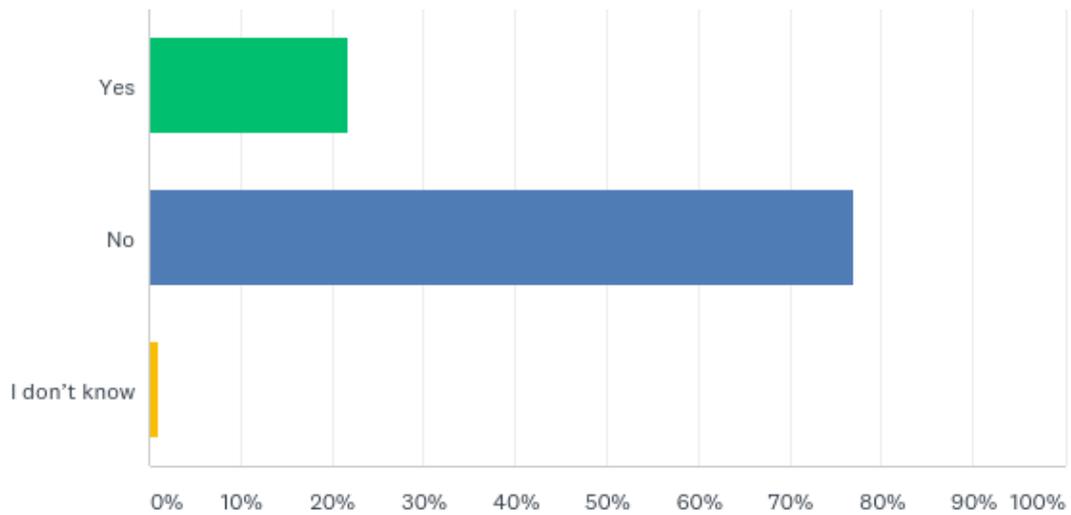


Figure 11: Response to the question "Did you receive a letter or a text from the NHS or your healthcare professional asking you to shield?"

49% of respondents felt that the official communications on whether they needed to shield were not clear; 28% felt that communications were quite clear and 23% of people felt that communications were very clear. Amongst those who were asked to shield, 15% of people felt that communications were not clear.

Many respondents reported that their neurological condition had been impacted by the COVID -19 crisis, as shown in figure 12.

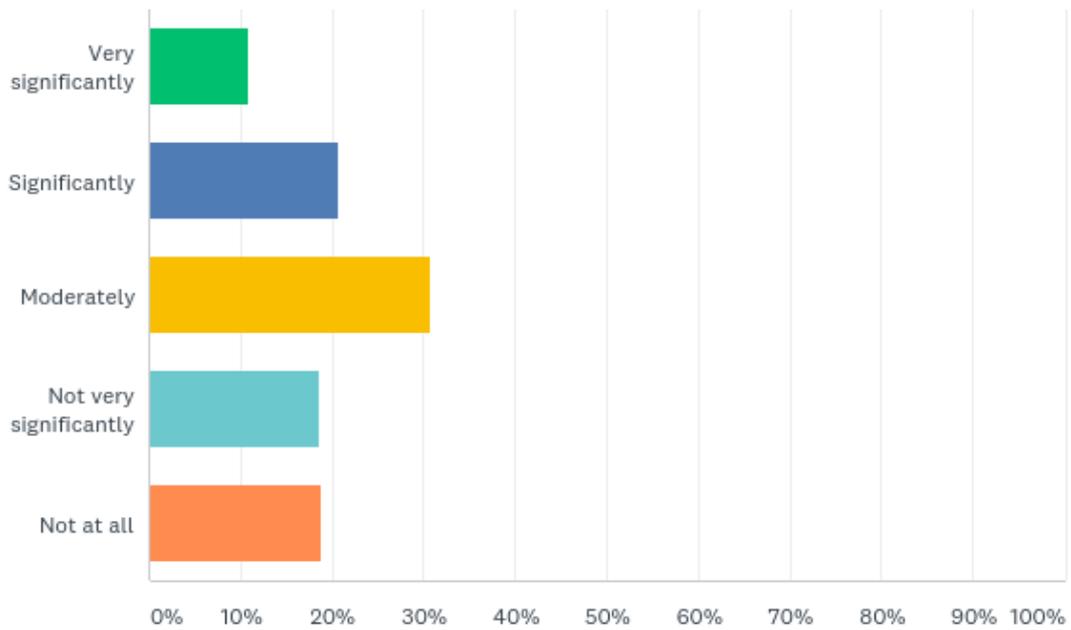


Figure 12: Response to the question "Do you feel your neurological health condition has been affected by the COVID-19 crisis?"

Of those who felt their health had been impacted:

- 3% reported that this was because they had had COVID-19
- 49% felt that this was because of delays and/or cancellations to their treatment and support
- 44% said that not being able to access services had caused increased stress and anxiety
- 50% said that it was because they had not been able to see friends and family

Finally, we asked people to tell us which words described how they were feeling at the moment. 19% of respondents reported feeling lonely, and one in ten felt hopeless.

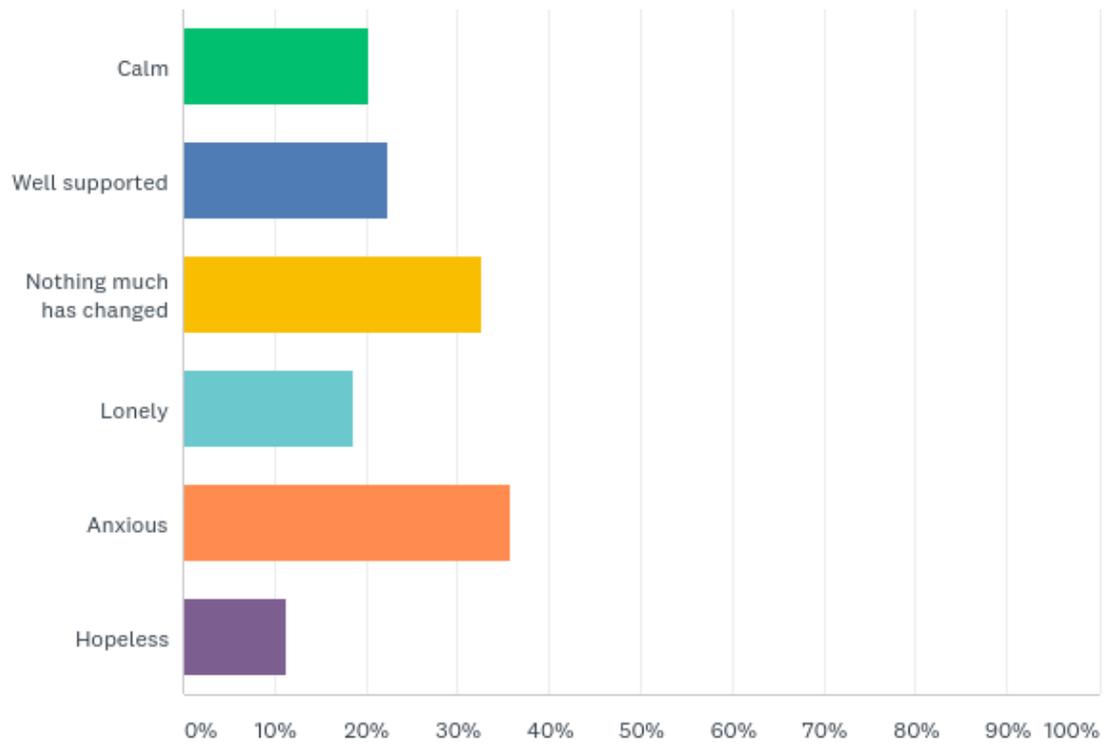


Figure 13: Response to the question "Finally (if you are happy to share this with us) which of the following describes how do you feel at the moment? Select all that apply"

Appendix – Survey questions

1. Where do you live?

- England
- Northern Ireland
- Scotland
- Wales
- Other

2. Who are you filling in this questionnaire for?

- Yourself
- Your spouse or partner
- Your child
- Your sibling
- A friend

3. What neurological condition do you have? Please select all that apply

4. How have you been coping during the COVID-19 crisis?

- Very well
- Well
- Moderately well
- Not very well
- With great difficulty
- Prefer not to say

5. Did you receive a letter or a text from the NHS or your healthcare professional asking you to shield?

- Yes

- No
- I don't know

6. How did you feel the communications of whether you should shield were?

- Very clear
- Quite clear
- Not clear

7. Have you had any problems accessing your normal food supplies during the pandemic?

- Yes
- No

8. Have you had any difficulty accessing your regular medication during the pandemic?

- Yes
- No

9. Have you had any medical appointments delayed during the pandemic?

- Yes
- No

10. If you answered YES to the question above, which appointments have been delayed?

Please tick all that apply

- A drug therapy treatment
- A scan
- An appointment with a neurologist
- An appointment with your specialist nurse
- A physiotherapy appointment
- An appointment with a psychologist or psychiatrist
- An appointment for surgery

- Other (please specify)

11. If you answered yes above, how long have your appointments been delayed for?

- Less than 1 month
- 2-3 months
- 3-6 months
- More than 6 months
- I do not know

12. Have you had any medical appointments cancelled during the pandemic?

- Yes
- No
- Other (please specify)

13. If you answered YES to the question above, which appointments were cancelled?

- A drug therapy treatment
- A scan
- An appointment with a neurologist
- An appointment with your specialist nurse
- A physiotherapy appointment
- An appointment with a psychologist or psychiatrist
- An appointment for surgery

14. Have you had any 'virtual' consultations (i.e. by phone or video) to replace your appointments?

- Yes
- No
- Other (please specify)

15. If you answered YES to the question above, was your 'virtual' appointment:

- A first meeting with a neurologist
- A routine meeting with your neurologist
- A routine check-up with a specialist nurse
- A rehabilitation or physiotherapy appointment
- An appointment with a psychiatrist or psychologist
- An appointment with your GP or practice nurse
- Other (please specify)

16. How were these consultations delivered (please tick all the methods that apply):

- By telephone
- By video
- By email
- By text/WhatsApp

17. On average, how did you feel this/these 'virtual' consultations went? Were they:

- Very effective i.e. as good as or better than face to face meetings
- Reasonably effective
- Moderately effective
- Not very effective
- Very ineffective

18. Do you have any other comments about how you felt about having a 'virtual' consultation as opposed to a face to face consultation? Please outline these below

19. In the future what would be your preference for routine – as opposed to emergency - appointments?

- Virtual

- Face to face
- Depends what the appointment was about

20. In the future what services would you prefer to have face to face?

21. Have you accessed emergency care during the pandemic?

- Yes
- No but I have not needed to
- No but I probably needed to

22. If you have access emergency care, was your carer, friend or family member allowed to go with you?

- Yes
- No and I would have liked this
- No but I did not need this

23. How far do you normally have to travel to your local hospital/clinic?

- 1-2 miles
- 3-10 miles
- 11-20 miles
- More than 20 miles

24. If you need outside care and support (e.g. from social services or an agency) to assist with daily living, has the coronavirus outbreak had an impact on the support you get? By care and support we mean help to remain independent and to carry out practical tasks like washing and dressing and preparing meals.

- No impact, I get the same amount care and support as before
- My care and support have been reduced or been cancelled

- I've reduced or cancelled my care and support, due to concerns about COVID-19 infection
- Not applicable - I don't need care and support to assist with daily living
- The support I need is provided by family and friends Other (please specify)

25. Do you feel your neurological health condition has been affected by the COVID-19 crisis?

- Very significantly
- Significantly
- Moderately
- Not very significantly
- Not at all Other (please specify)

26. If you feel your neurological health condition has been significantly affected by the COVID-19 pandemic is this because (tick all that apply)

- You have had COVID-19 delays and/or cancellations to your treatment and support that have affected your health
- Not being able to access services has caused increased stress and anxiety
- You have not been able to see friends and family

27. Do you feel the COVID-19 crisis has affected your mood and sense of wellbeing?

- Very Significantly
- Significantly
- Moderately
- Not very much
- Not at all

28. Please outline below anything else you wish to share about how the COVID-19 pandemic has affected your health, care and treatment that has not already been covered by the above questions

29. Finally (if you are happy to share this with us) which of the following describes how do you feel at the moment? Select all that apply

- Calm
- Well supported
- Nothing much has changed
- Lonely
- Anxious
- Hopeless