NEUROLOGICAL ALLIANCE OF SCOTLAND

A REVIEW OF VIRTUAL CONSULTATIONS IN SCOTLAND

SEPTEMBER 2021

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Introduction from the Chair of the Neurological Alliance of Scotland

The Neurological Alliance of Scotland is an umbrella organisation of over 50 neurological charities operating in Scotland. 1 in every 5 people in Scotland lives with a neurological condition that affects their day-to-day life, equivalent to around one million people. For many individuals and families, the impact of a brain, spine or nervous system condition is enormous and life changing. The neurological condition landscape is complex and the challenges that people live with can vary considerably between, and within, conditions.

The COVID-19 pandemic has made life much harder for everyone, but particularly for those living with neurological conditions. Services have been reduced and restricted, vital lifelines including access to specialist nurses have been cut and an already vulnerable and isolated community have been forced to manage their conditions largely online.

As an alliance of neurological charities, we have had plenty of anecdotal evidence from our members that people were not getting the access to their healthcare that they needed. The most common theme was that most virtual consultations were being handled via telephone calls rather than through the more sophisticated and immersive video consultation technology.

When the roll out of video consultations accelerated at the start of the COVID-19 pandemic in 2020, the Scottish Government conducted research into the use and perception of video consultations from both the end-user perspective as well as the clinical perspective in secondary care. However, this public engagement exercise did not necessarily focus on people living with neurological conditions who have greater barriers to using technology and who are less likely to be online.

We wanted to do a quick temperature check with people living with neurological conditions and their carers to see how they are managing with virtual consultations through the pandemic. We are conscious that our survey was only offered online because of time constraints. This means that the experiences of people who are digitally excluded have not been represented in this work.

As the NHS is remobilised, the Neurological Alliance of Scotland wants to ensure any changes to the delivery of health and social care considers the experiences and needs of those living with neurological conditions.

Our survey asks about all primary and secondary care and other healthcare appointments that people have received through the pandemic. The results of our survey reflect the lives of people with neurological conditions who receive their care across settings in the NHS in Scotland.

Tanith Muller

Chair, Neurological Alliance of Scotland

Executive Summary

Telephone and video appointments have been key throughout the COVID-19 pandemic to ensuring that people continue to get access to healthcare. The Neurological Alliance of Scotland wanted to understand the experiences people with neurological conditions have had with telephone and video appointments to feed into NHS guidance on virtual appointments.

We conducted a brief online survey, reaching people with neurological conditions through social media and via our member organisations. We received responses from 267 people across more than 25 different neurological conditions; 81% were people living with a neurological condition and 18% were unpaid carers supporting someone with a neurological condition. The demographic breakdown of our survey respondents can be found in Appendix A.

The majority of respondents (57%) reported that they had not been able access a face-to-face appointment since the pandemic began in March 2020, and nearly two thirds (65%) had not had a video appointment. Telephone appointments were the most common way to access care, with 88% of respondents accessing telephone appointments in this period.

Most people with neurological conditions and unpaid carers believe that there is a place for virtual appointments, for instance where a condition is stable, for clarification of symptoms or for general advice. However, for the majority, some face-to-face contact with clinicians is an essential aspect to their care. Fewer than 2% of respondents wanted all of their appointments to be delivered by video or telephone. About 1 in 7 people (15%) wanted most of their appointments by video, with around 1 in 8 (12%) wanting most of their appointments by phone.

It is also important to note that a significant minority of people rejected virtual appointments altogether. Over one fifth of respondents said that they felt that telephone appointments should never be offered (23%) and a similar proportion said the same about video appointments (21%). As previously noted, our online survey methods are likely to under-represent people who are digitally excluded.

Experience across all appointments has been very varied. Respondents reported both positive and negative experiences of virtual appointments.

The neurological community who responded to our survey are clear that there is a place for virtual appointments, with video being preferred. However, for the majority, face to face contact is a necessary component to their care to support them to better manage their condition.

Personal choice and person-centred care are at the core of maximising best use of existing NHS virtual technology going forward. People want access to good quality and personalised healthcare, they want to feel listened to and cared for, and they want to feel part of their own care team.

We hope that this report will help guide NHS Scotland to make the right decisions about using virtual appointments to provide care and support for people with neurological conditions and their families, friends and carers as the NHS remobilises.

Section 1: Face to face appointments

As expected, the majority of our respondents to our survey (57%) have not been able to access a face-to-face appointment since the pandemic began in March 2020. Several respondents commented that this negatively impacted their mental health and they felt that a face-to-face appointment was what they needed, one respondent commented that they felt that they had "*been abandoned*". Several respondents received their diagnosis over the phone during the pandemic, all commented that this was frustrating and upsetting. One survey respondent commented:

> *"Call lasted 4 minutes in total and decided I did not have epilepsy, how can you decide if someone has possible new onset epilepsy via a 4 minute call is astounding. No EEG completed, no bloods checked. Very poor service."*

Of the 41% of respondents who had been able to access a face-to-face appointment since the pandemic began, several commented that this was only after having to fight and advocate to be seen in person:

> *"Only after placing a complaint and threatening to take it further."*

> *"This was after various phone calls and emails from my GP requesting I was seen in person."*

The majority of respondents understood the need for virtual appointments during the pandemic, especially to protect their own health. However, there is a strong feeling that face-to-face appointments are a vital aspect of their care. This is particularly true at diagnosis, medication changes and for those with progressive conditions.

> *"My neurologist brought me in for an appointment so that he could observe my symptoms and then diagnosed me with Tourette's. If I hadn't gone in to the hospital for a face to face appointment I don't believe that I would have been diagnosed."*

It is clear, from our survey respondents, people with neurological conditions need to be seen face to face at diagnosis and at important points throughout the management of their condition. Neurological conditions are complex and often difficult to manage, people need face to face contact to support them throughout their journey of living with a neurological condition.

> *“How a GP can diagnose a condition without actually seeing or examining the patient, or asking any diagnostic questions, or ordering any diagnostic tests to be carried out is beyond me. Five months later and I am still trying to have the condition addressed/properly diagnosed; meanwhile, the GP continues to prescribe more and more antibiotics, which are causing their own new set of problems.”*

Section 2: About Telephone Consultations

The majority of respondents to our survey (88%) have accessed healthcare over the phone since the pandemic began in March 2020. 32% had an average experience, 22% had an excellent experience whilst 10% had a very poor experience.

Those who had a positive experience cited reasons like convenience, it was appropriate for their needs at the time, that they felt listened to, it was a productive appointment, and they had confidence in the person they were talking to.

> *“Not needing to travel makes a huge difference as it is exhausting, brings in fatigue and makes me physically ill.”*

> *“This was far better for me. I was able to remain lying down while talking on the phone, conserving energy. I didn’t have to get to the GP practice & cope with sensory overload from lights, folk chatting etc.”*

> *“Telephone reviews with my epilepsy nurse specialist have been all I’ve had, he is brilliant though and don’t know what I’d do without him. Medication issues have been resolved quickly during the pandemic and he is always available for ongoing support.”*

Some respondents suggested occasions where telephone appointments might be appropriate and these include:

- Check-ups/reviews or follow ups
- Clarification of symptoms
- Where conditions are well controlled and/or the person is stable
- Where there is a pre-existing relationship with the care team
- For general advice
- To confirm a result
- If the condition is non-urgent
- Where people can adequately describe their condition

> *“For me, a telephone appointment is the most appropriate contact with a doctor most of the time. It is very exhausting to have to travel to and sit in a surgery and not always necessary. I am confident that the doctor and I will know when a face-to-face appointment is necessary.”*

However, everyone is different, and it would be wrong to assume these occasions work for everyone.

Unfortunately, many respondents to our survey only managed to access a telephone appointment, and this type of appointment was not appropriate for their needs at the time. The most common themes for difficulties arising from telephone appointments include:

1. Frustration at having to describe symptoms which would normally be visible to the clinician. People described this as complex and confusing.

   “The Dr couldn't see my physical movements, nor my emotional distress at our discussion. More questions needed to be asked and I became flustered at trying to explain my condition in words, especially when my condition caused my words to slur.”

   “Did the best they could but one look at me would have told them all they needed to know. Trying to explain changes in symptoms over the phone was very difficult, not really a positive experience.”

   “It was very difficult for a neuro physiotherapist to understand my difficulties with my balance on a phone call.”

2. Telephone calls are too brief. People felt rushed and out of control with their appointment, unable to get through all the questions they intended to ask.

   “Very poor. 5 minute phone call with neurologist, only to be told they need to see me, but it'll be another 3 to 4 months before I get an appointment.”

   “Over the phone you are pushed to be short and sweet and nothing really gets resolved...my condition has been affected.”

3. Communications issues, including not being able to hear each other, speech being negatively impacted by anxiety over having a telephone appointment, and carers not being able to participate in the call, as well as technical issues.

“Epilepsy has caused me to stammer. I find I am spoken over during the call, unable to express myself and it feels like I had the same ineffective conversations several times.”

“At times, there was difficulty between health practitioner and myself hearing each other clearly, leading to misunderstandings.”

“The phone connection kept going down at the hospital end and I had to be connected again on three occasions.”

4. Telephone calls are not person-centred and that the choice of appointment format needs to be a joint decision by the person and their healthcare professional.

   Consider the nature of the call. Consider the health and well-being of the recipient and how the impact of the [appointment] might affect these.

   Services need to offer choice of using face to face, or attend anywhere, so much information is lost in telephone calls.

   I don’t feel like I am at the centre of care as a patient

5. Finally, several respondents reported that they did not feel listened to or believed when they had telephone appointments. This led to greater anxiety and in some cases, mistakes being made with medication, delays made to reviews and a number of other avoidable setbacks.

“I spoke to a nurse practitioner, who gave me an antibiotic that I told her didn’t work for me. She was following the pathway not listening to me. I ended up in hospital because of it.”

“I informed them my Seizures seemed to be increasing and they didn’t seem all that concerned, they just upped my Medication. It would have been useful for them to explain or ask me Questions about it.”

It is clear from our survey respondents that experiences of telephone appointments have been varied with both positive and negative experiences reported. Those who felt positive about their telephone appointment felt listened to, appreciated the convenience and the appointment was appropriate for their needs at the time. Those who had a negative experience struggled to verbally explain their symptoms, felt there was not enough time, struggled with communication issues both relating to their condition and technical issues, and finally several felt not listened to on the phone.

There is clearly a place for telephone appointments in the delivery of health and social care. 64% of respondents to our survey felt that telephone appointments should be used some of the time, whilst 22% said none of the time. No respondent said that telephone appointments should be used all of the time.

As the NHS remobilises, it is imperative that care is delivered in a person-centred way. This means that telephone appointments should be provided for those who prefer them and whose clinical needs can be met in this way. People should also be able to access face-to-face appointments if they need them for personal or clinical reasons.

Section 3: About video (NearMe / Attend Anywhere) consultations

Where people had experience of video appointments, they were often highly rated by respondents. Video appointments were valued because they allow people to develop a rapport with their clinician, observe facial expressions, and allow people to show the clinician their symptoms. For many people with neurological conditions, visual cues are a particularly important aspect of communication because speech can be affected.

Of the respondents who managed to access a video appointment since March 2020, 59% reported a very good or excellent experience.

> *"Video appointments are always better than telephone appointments. It's better to see one another. The NHS Near Me appointments in Scotland usually work really well in our experience."*
>
> *"Easy to connect and it was just like talking to someone in the same room."*
>
> *"It was easier to explain things by video than by telephone. It was good not to have to travel to the appointment. My wife could also participate."*
>
> *"Easier, quicker and cheaper for me than visiting the hospital but still feels personal as you can see the doctor's/nurses face unlike on the phone."*

However, only a third of our survey respondents (32%) had accessed healthcare via video since the start of the pandemic. Some respondents had not been offered a video appointment:

> *"I would really like to have access to healthcare via video! This seems like a happy medium to me between phone and in person."*

Whilst many respondents cited technical issues as their main barrier to accessing a video appointment:

> *“Sometimes the doctor / nurses had to use their own personal mobile because the NHS computers or Wi-Fi weren’t up to scratch. They shouldn’t have to do that.”*

> *“I can’t believe any senior person in the NHS has ever used this system as we experienced it. It’s a disgrace and needs to be completely rethought. Not fit for purpose.”*

> *“Even I, as a frequent Teams and Zoom user, couldn’t get the video window to open in front of the NHS page.”*

The reluctance to use any other form of video software other than Near Me resulted in some respondents missing out on care:

> *“There was no way for me to download the software (and I did ask) and they wouldn't use Zoom or Skype. I declined having telephone counselling calls, as I feel that is one situation where we need to be able to see each other. So I didn't have the counselling.”*

People with neurological conditions often experience issues with movement and cognition that can make it difficult to use technical solutions.

One respondent said,

> *“This form of communication (video) should be carefully considered when more vulnerable, less computer literate people are concerned.”*

Lack of privacy online was also mentioned a number of times by respondents, which caused anxiety and stress for some people.

> *“I also doubted the privacy of my call as I could hear other people in the background and wondered if the person was working from home. It caused me some paranoia.”*

> *“People do not like medical issues being discussed on the internet due to the lack the of 100 % privacy”*

It is clear, when they work, video appointments are the preferred method of accessing healthcare virtually compared to telephone. 62% of respondents said video appointments should be used some of the time, whilst 21% of respondents said they should never be used.

Technical issues are a significant barrier to accessing video appointments and partly explains why only third of our survey respondents have accessed healthcare via video. We were surprised that most people appeared not to have been offered this, suggesting that many health professionals were not using Near Me at all. Technical issues must be addressed first before it is used as a standard appointment option. This includes better investment in software to ensure it works 100% of the time, and more training for staff to use it properly.

> *“They are a useful tool but without more investment, better technical support and proper leadership that tirelessly works to improve the service, then they can do more harm than good”*

> *“Sometimes the doctor / nurses had to use their own personal mobile because the NHS computers or wifi weren’t up to scratch. They shouldn’t have to do that.”*

However, like telephone appointments, video appointments will never replace face to face methods of accessing healthcare. Particularly for people with neurological conditions, who often suffer from motor, cognitive and or communication issues, using video technology is more difficult than for the general population. Additionally, not every individual has the means to access technology or pay for data to access video appointments. Disabled people are overrepresented amongst those living on the lowest incomes. Reliance on video appointments must not widen health inequalities by providing another barrier to accessing healthcare. Any guidance on the use of video appointments must recognise and address the complexities of access for many people with neurological conditions.

> *“Virtual appointments make life a bit easier. but also harder as it’s not always easy explaining what’s happening.”*

Some respondents suggested occasions where video appointments might be appropriate, and these include occasions when:

- Someone can't travel
- The person's condition is stable
- The person is comfortable with this sort of appointment
- The person already knows their medical team and has a bond with them
- Where attendance is not required; no physical assessment or tests are needed
- Where there is no other way of seeing that person
- Where it is accessible to the person
- For follow up appointments

Again, it must not be assumed that one size fits all. Decisions about the format of appointments must be made jointly between the individual and their health professional, and take into account personal circumstances as well as clinical issues.

Section 4: Conclusions

The COVID-19 pandemic has undoubtedly shifted the world as we knew it in 2019. The effects of the pandemic will be felt for decades to come, particularly in the health service. Investment in technology meant that healthcare could continue during the pandemic virtually, via phone and video.

The Neurological Alliance of Scotland's survey on virtual appointments has demonstrated that the neurological community in Scotland has had a varied experience of phone and video appointments since the pandemic began in March 2020.

The majority of people in our survey were not able to access healthcare face to face or via video. Most respondents have only been able to access healthcare via phone. There is a growing number of people who have been diagnosed virtually with a life-changing condition, and who have had to make do without the normal levels of support that they would otherwise have received.

Most respondents felt that there is a place for the continued use of virtual appointments, with a preference for video over phone. Some have enjoyed the convenience of accessing healthcare virtually and it has been appropriate for their needs at the time. However, a significant number of respondents felt that virtual appointments have been used inappropriately including at the point of diagnosis, for medication changes and at any time for all those living with a progressive condition.

There is plenty of evidence to show that the experience of diagnosis needs to be properly managed, with the result that more burden is placed on the NHS if it isn't. The experience of diagnosis is a critical part of acceptance of the diagnosis, and no-one should ever receive a life-changing diagnosis or suspected diagnosis over the telephone.

Ultimately, people told us that they want to have a choice about how they receive healthcare. Decisions about the format of appointments should be part of joint decision making between the person receiving care and the clinician providing it.

Our survey shows that clinicians and people needing care should consider a wide range of factors when considering the format of appointments. This might include:

- The ability of each individual to manage a virtual appointment physically, cognitively and technically
- Difficulties carers may have in speaking freely of the person they support, in front of them
- Anxieties about privacy
- The need for compassionate care to enable participants to relate to each other - express emotion and empathise

All these need to be weighed against other aspects such as clinical considerations, the convenience of a telephone or video call, or the journey saved.

Everyone should have the choice of having a face-to-face appointment if that is what they want, and everyone should have the choice of having a telephone or video appointment if that is what they want.

Being diagnosed and living with a neurological condition is extremely difficult and there should be touch points throughout a person's journey living with a neurological condition to ensure they are receiving the right treatment for their needs.

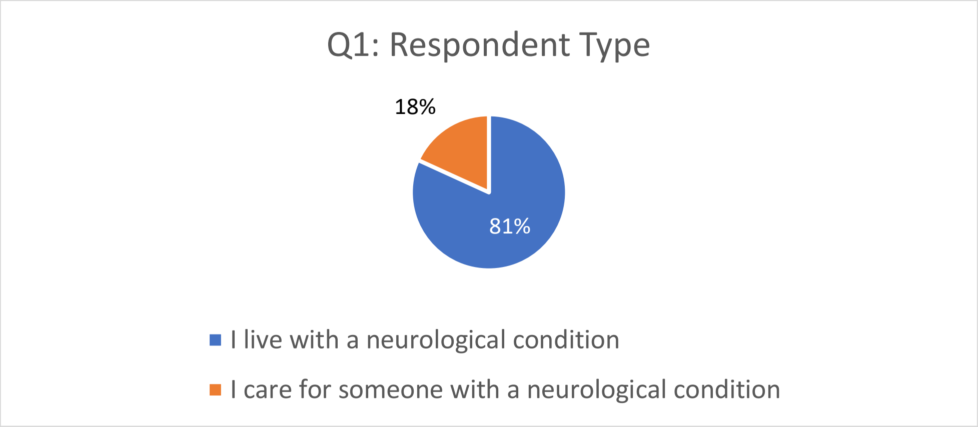
Section 5: Recommendations

In light of this research, the Neurological Alliance of Scotland have the following recommendations concerning the further use of phone and video appointments for people with neurological conditions:

- People should be able to receive the appointment type that's appropriate for their needs at the time
- Nobody should receive a life-changing diagnosis over the phone
- Further investment needs to be made into NearMe/Attend Anywhere Video Technology including staff training, so that technical faults are minimised, and more people can benefit from productive appointments where appropriate

Appendix A: Demographic Information

To keep the research simple and as easy for people to complete all the way through as possible, we only asked the essential demographic information: respondent type, and neurological condition.



Q2 - your condition or the condition of the person you care for:

Condition name/s	**TOTAL**
ADHD	**1**
Ataxia	**6**
Ataxia- Cerebellar	**1**
Ataxia - Friedricks	**3**
Ataxia and Dystonia	**1**
Ataxia and Heriditary Spastic Paraplegia	**2**
Autism	**3**
Brain tumour. Epilepsy.	**1**
Brain injury, epilepsy, chronic migraine	**1**
Cerebral Palsy	**3**
Cervical dystonia	**2**
Chronic Migraine	**5**
Dissociative seizures, PTSD, Depression & Anxiety	**1**
Epilepsy	**59**
Epilepsy - DNET	**1**
Epilepsy - drug resistant	**1**
Epilepsy & Fnd	**1**
Epilepsy - focal aware	**1**
Epilepsy and Chiari Malformation	**1**

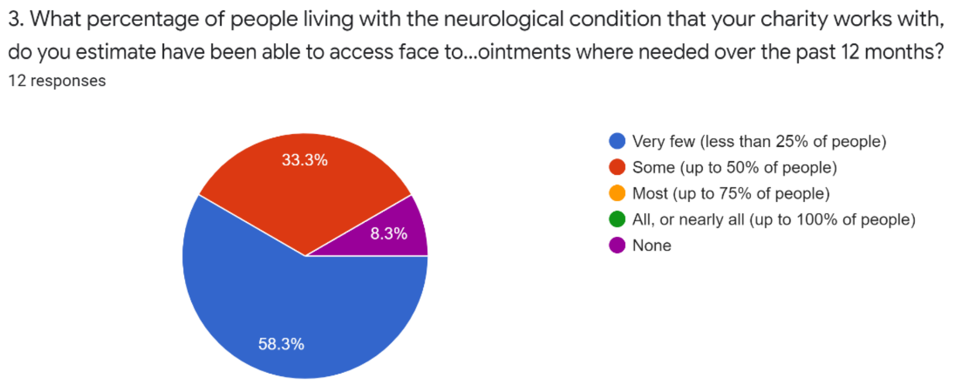
Epilepsy and low grade tumour	1
Epilepsy and benign brain tumours	1
Epilepsy and AVM	1
Epilepsy and right mesial temporal lobe sclerosis	1
Epilepsy - myoclonic	4
Epilepsy - juvenile myoclonic	1
Epilepsy temporal lobe	1
Essential tremor	2
FND	14
FND, neurological pain, & migraines	1
FND and depression	1
Functional Neurological Disorder, and Depression	1
Headache disorders.	2
Hemorrhagic stroke with epilepsy and migraine	1
Huntington's Disease	6
M a	1
ME	10
ME/CFS	8
Migraine & Spinal problems	1
MS	31
Primary Progressive MS	2
MS, Parkinson's, anxiety	1
MS, Parkinson's	1
Multiple Sclerosis. Functional Neurological Disorder	1
Myasthenia Gravis	15
Neurosarcoidosis	4
Parkinson's	35
Parkinson's plus syndrome	1
Progressive Supranuclear Palsy	2
Seizures (not epilepsy) and migraine	1
Seizures under investigation	1
Severe brain injury after contracting meningitis at 8 days old.	1
Subarachnoid haemorrhage	1
Traumatic Brain Injury	1
Tourette's	4
Tourette’s, Autism	1
Tourette's non epileptic seizures	2
Tourette's, ADHD	2
Trigeminal Neuralgia	1
Undiagnosed	2
Left blank	2
Other (husband died/name)	3
TOTAL NUMBER OF RESPONSES:	**267**

Appendix B: Neurological Charities' Experience

In addition to the survey for people living with or caring for people with neurological conditions, we issued a second survey over the same fieldwork period, to neurological charities. We received responses from 12 charities, covering 21 neurological conditions:

Acquired brain injury	1
All neuromuscular conditions	1
Ataxia	1
Autism	1
Cerebral Palsy	1
Dementia	1
Dystonia	1
Epilepsy	1
Essential tremor	1
Fibromyalgia	1
Huntington's	1
ME/CFS	1
MND	1
MS	3
Parkinsons	3
Post stroke	1
Stroke	1
Tourette	1
Total	21

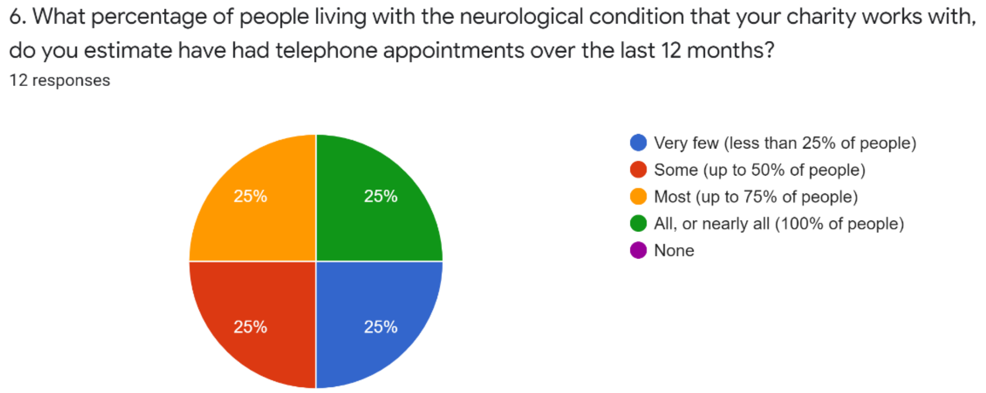
The majority of third sector colleagues (58%) correctly estimated that very few people living with neurological conditions had been able to access face to face appointments through the pandemic.[1]



3. What percentage of people living with the neurological condition that your charity works with, do you estimate have been able to access face to...ointments where needed over the past 12 months?

12 responses

Opinion was equally divided when it came to guessing the volume of people accessing telephone appointments.



6. What percentage of people living with the neurological condition that your charity works with, do you estimate have had telephone appointments over the last 12 months?

12 responses

Only 8% of charities thought most people would have had access to video appointments through the pandemic

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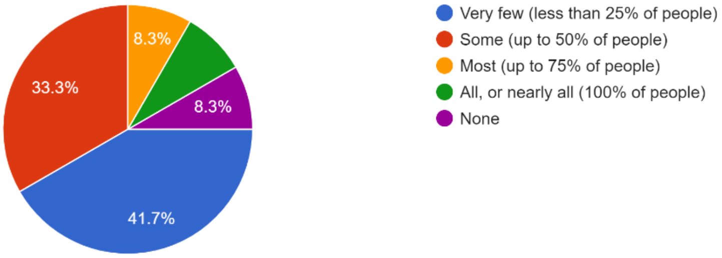
[1] 3. What percentage of people living with the neurological condition that your charity works with, do you estimate have been able to access face to face in person appointments where needed over the past 12 months?

10. What percentage of people living with the neurological condition that your charity works with, do you estimate have had a video appointment over the last 12 months?

12 responses



Some comments from our member charities:

Virtual appointments work well for those that have good technology available and have the skills and confidence to use it, but for many people with Parkinson's who are older and more impaired, the ability and confidence to use the tech has been a barrier to its use. Video appointments have huge potential for supporting people in more remote and rural settings, or who find it very difficult to travel to clinic appointments because of their symptoms. And we would like to see services embracing the potential of video appointments to improve the care and support offered to people who live in care homes in particular. Many people do not even have the technology needed to manage virtual appointments effectively. For some appointments - especially where physical or other assessments are key - virtual appointments are not appropriate. Virtual appointments should only be offered where both the person and the clinician feel it is appropriate and are content with this format. (012)

Once we get back to face-to-face contact with clients, and we can work with them on using devices to attend virtual appointments, it will be an extremely useful tool for them to have. It's just a shame that it took a total lockdown to start the widespread use of the technology, because our vulnerable clients did not have the equipment, the skills or the confidence to use them effectively. (007)

Virtual appointments have their place, but they are no subsitute for in person therapy. (How can you have a successful physiotherapy appointment to relieve your pain from an online appointment? You can make suggestions - eg stretching exercises, seating adjustments, but it is not the same as a physio getting their hands on you!) (004)

Good to have the option of offering this as a way of having appointments. I think they will remain part of the service we offer. For some client who found it difficult to travel it is a bonus. (010)

They have made a massive difference to the amount of people we have been able to reach and support. (009)

A list of our members

Action for ME	MS Trust
Ataxia UK	MSA Trust
Brain Tumour Action	Multiple Sclerosis National Therapy Centres (MSNTC)
Brainstrust	Muscular Dystrophy
Cavernoma UK	My aware
Cerebal Palsy Scotland	Neuro Central
Child Brain Injury Trust	Parkinson's UK
Dochas Fund	PSP Association
Dystonia UK	QNIS
Epilepsy Connections	Revive MS Support
Epilepsy Scotland	Sarcoidosis UK
FND Hope UK	Scottish Centre for children with motor impairments
Funding neuro	Scottish Huntington’s Association
GAIN	Scottish Head Injury Forum
Headway Dundee and Angus	Scottish Post Polio Network
Headway Edinburgh	Scottish Tremor Society
Headway Glasgow	Spina Bifida Hydrocephalus Scotland
Lanarkshire Epilepsy	Sue Ryder Care
ME Action	The Oxygen Works
ME Association	The Migraine Trust
MND Scotland	The Stroke Association
MS Society	Thistle Foundation
MS Therapy Centre Lothian	Tourette Scotland
MS Therapy Centre, Tayside	Transverse Myelitis Scotland Support Group
MS Therapy Centre, Mid Argyll	William Quarriers Epilepsy Centre