



2023

**Specialist
Epilepsy
Appointments**

 **Epilepsy
Consortium
Scotland**

Introduction

Epilepsy is one of the most common neurological conditions in the world. An estimated 58,000 people live with the condition in Scotland.

For people with epilepsy, accurate and timely diagnosis and effective treatment and management of the condition are essential to living full and healthy lives. However, in the wake of the COVID-19 pandemic, the format of specialist medical appointments has shifted with the growing use of remote appointments replacing in-person care. In many cases, telephone and video appointments are being used as default.

As an association of organisations representing the epilepsy community in Scotland, Epilepsy Consortium Scotland sought to better understand how this paradigm shift is affecting people with epilepsy.

With a better understanding of the experiences of people with epilepsy, we can better advocate for the best interests of the community, to ensure people with epilepsy are receiving the best possible care. This report seeks to ensure the voices and needs of people with epilepsy are heard in the decisions about their care.

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The Survey

Methodology

Epilepsy Consortium Scotland set out the aim of better understanding the views of people with epilepsy on remote and in-person appointments.

To do so, the Consortium conducted an online survey, receiving 115 responses from people with experience of specialist epilepsy care in Scotland. The survey was open for six weeks and promoted by member organisations.

The Respondents

Of the 115 respondents, 76% were people with epilepsy and 23% were the parents or carers of a person with epilepsy. The remaining 1% were from someone who works with people with epilepsy. This breakdown is displayed in figure one.

12% of respondents were aged between 0-17, 26% 18-30, 55% 31-64, and 7% aged over 65. This breakdown is displayed in figure two.

Respondent Experience

Since the beginning of the COVID-19 pandemic (March 2020), 45% of respondents have attended a mixture of face-to-face, virtual and telephone epilepsy appointments. 40% of respondents had only attended telephone appointments. 9% had only attended face-to-face appointments. A further 4% report having had no appointments during this time. This breakdown is displayed in figure three.

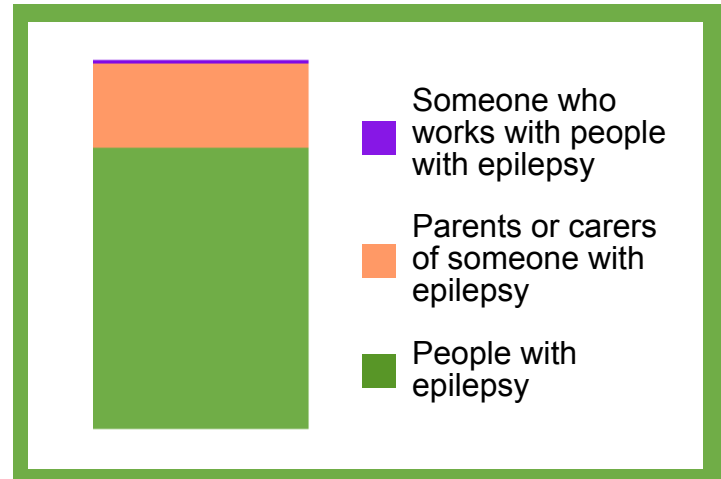


Fig 1. Respondents' relationship to epilepsy

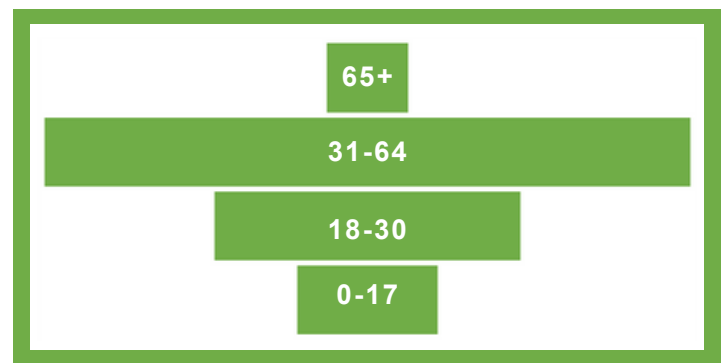


Fig 2. Age breakdown of survey respondents

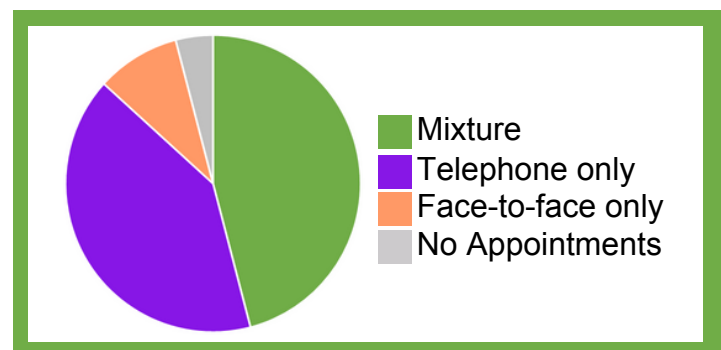


Fig 3. Appointment format

Communication

To communicate is to exchange information. This extends beyond verbal communication, to behaviour. Many respondents commented on how they feel more comfortable and relaxed during in-person appointments. Respondents said they found it easier to articulate their needs, ask questions, and understand specialists. Epilepsy is a complex condition and clear communication between patients and specialists is vital.

"It is easier to explain what I mean in person. The conversation can flow more naturally."

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"I have issues with expressing myself over the phone and understanding when it is my turn to speak. This causes me anxiety which means I never get to discuss all of my concerns as I start to forget things when I get anxious. I also have trouble focussing when I am speaking on the phone and struggle to understand tone of voice alone without the context of body language."

Respondents highlighted the importance of observations. Many commented on how by meeting in person, the epilepsy specialist can better understand the nuances of their condition, using body language to better understand true feelings. This is also reflected in figure four.

"The move to Hybrid or telephone prevents the doctor from having the power of observation of their patient and runs the risk of the patient presenting a false representation of their actual wellbeing."

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"I think facial expressions are a key factor, as it can be easy to hide emotion during a telephone appointment."

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"I have found video and phone appointments to be difficult for my mental health. I have found it hard to feel fully understood and am of the opinion that I have, at times, been misunderstood and have, in turn, misunderstood my specialist."

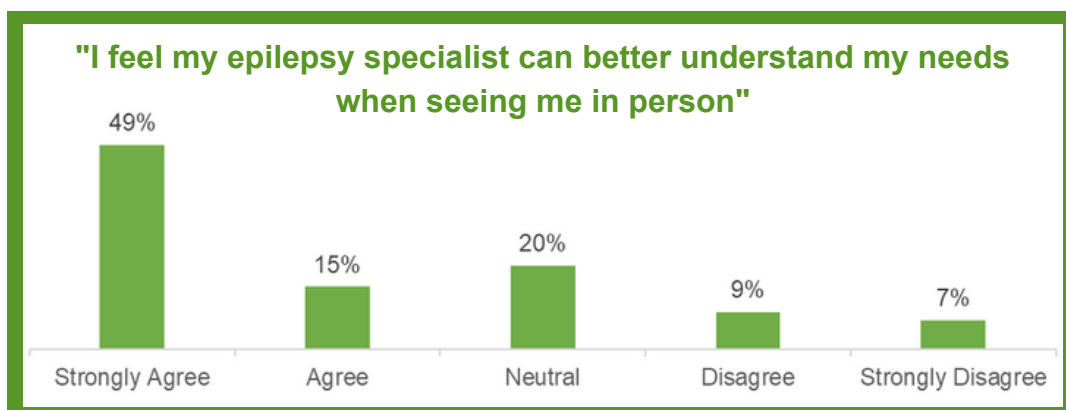


Fig 4. Face-to-face appointments and understanding needs

Engagement

Themes of engagement emerged throughout the survey. Building a foundation of trust is essential to people engaging fully with their care. In this respect, many commented on the importance of the personal nature of face-to-face appointments.

"More personal, felt able to ask more questions. Did feel like I was cut off on video call as I was upset and couldn't get asked what I wanted to ask. I cried the whole video appointment basically but face to face I did not shed one tear!"

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"I feel that my Neurologist has to see me face to face to understand my situation and to make decisions based on that meeting. Particularly, if it comes to a medication change or any other changes to my treatment. Phone appointments are impersonal, brief and never at the time they are scheduled for."

Several commented on how their telephone appointments have felt rushed, with general feelings of detachment between patients and specialists.

"I don't think you get the same care over the phone, its like a rush to get you off the phone and you don't get everything you needed to say out."

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"I feel disconnected, isolated and dismissed by the health professionals that I have trusted to support me. My phone appointments never take place on time, always early when I am not prepared. I have a list of my concerns, symptoms and worries and I do not feel heard."

Engagement was also a theme in terms of patients engaging with their own care.

"It becomes a distraction rather than an important exchange of information."

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"While video and phone appointments might work for some people, I absolutely hate them, they stress me out and it feels like my job, I can't separate it like I can physically going to an appointment with my attention focused on what I need to discuss"



Unpaid Carers

It is important to consider unpaid carers. 23% of respondents were parents or carers of a person with epilepsy. Many people with epilepsy rely on the support of unpaid carers, whether it be a spouse, parents, children or close friends.

Responses from both carers and people with epilepsy made clear the difficulties of including carers in remote appointments.

"My partner and I attend with our son. The 3 of us are involved in the appointment which is harder if on loud speaker on the phone."

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"With face to face appointments I am more likely to explain how the side effects of seizures/meds are affecting my life. My partner or mother can explain in depth how each of my seizures have happened and also have the ability to have their say on how the disability impacts day to day life."

People with epilepsy often face issues with their memory. Seizures can affect a person's ability to process information and their awareness meaning some may have little or no recollection of their seizures. Epilepsy medication may also be a factor, with the side effects of some medication (for example poor concentration and drowsiness) affecting memory. Some people have epilepsy as a result of damage to the brain which may also impact memory. Such issues can be more difficult to identify over the phone and make it more challenging for people with epilepsy to fully explain any issues they are facing. This is reflected in responses, with some commenting on the importance of having someone with them at appointments due to issues they face with their memory.

"With face to face, my husband is there to support me and take part in any discussions about my condition. I don't have that advantage during a phone call and my concern is that I may not remember things discussed, so having my husband with me helps to make sure I have all the information I need."

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"Telephone appointments make it difficult for a family member/partner who is present during most seizures to explain in full what's been happening as more likely to take the phone call alone. This limits what information can be passed on to specialists."



Patient Choice

In recent epilepsy appointments, 79% of respondents had not been given the option of choosing between face-to-face, telephone or video appointments. 16% of respondents had. 5% did not answer.

If given the option to choose, 62% of respondents would prefer to attend appointments with their epilepsy specialist in person. 24% would prefer to attend a mixture. 9% would prefer telephone appointments and 5% video appointments (see figure five).

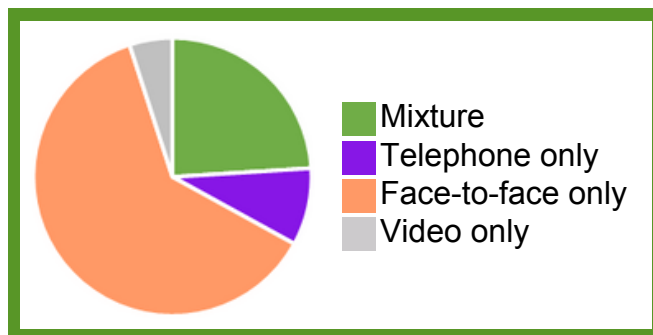


Fig 5. Preferred appointment format

Respondents highlighted the benefit of having flexibility with regards to caring responsibilities, securing transport, employment and education.

"While I prefer face to face appointments so I can understand and read the doctor's body language better when explaining things, often times I have difficulty finding a ride to appointments during normal business hours."

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"Sometimes a face to face appointment is better and if things are stable and settled a video call is enough, means less time out of school for my son."

Others commented on how this flexibility would help due to the changing nature of their epilepsy. Many suggested that for some appointments a phone call would be sufficient, while for others, face-to-face appointments are necessary.

"I would choose a face to face if I needed a lengthy discussion about my epilepsy... I would choose a phone call if I needed to do my annual epilepsy review and I had had no differences in seizures."

The majority of those who prefer telephone or video appointments commented on their well-controlled epilepsy. Others commented on convenience in terms of travel to appointments, caring responsibilities and employment.

"It's convenient to organise around work - don't have to take time off and saves a long distance public transport journey. Perhaps if my epilepsy was much worse I'd prefer face to face for a feeling of relationship and security, which I think is gained face to face better."

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"Its easier for me as a carer to have video call. [It is] sometimes hard to get my son awake for early appointments as his sleeping pattern all over the place. He's more inclined to get up if it's a video call from home and no worry of him taking an episode outside."

The Patient Experience

45% of respondents believe the introduction of remote appointments has made it easier for them. 32% do not. Of those who said it made it easier, many made clear they would still prefer face to face appointments. 19% were unsure and the remaining 4% did not answer in full.

"Granted these appointments are so much easier to attend however a face-to-face appointment always seems to get the best result for me. Travelling to and from my appointments is out of town but worth the journey for a better consultation."

When asked why they found it easier, the majority of respondents referred to avoiding disruption to caring responsibilities and employment and the convenience and time saved from avoiding travel to appointments. For people with epilepsy, transport can be challenging. In the UK, you are unable to drive within 12 months of a seizure, and for people who are experiencing regular seizures, accessing public transport unaccompanied can pose risks and cause avoidable anxiety. The cost of travel was also a consideration for some.

"To see a specialist in person I have to travel south to Aberdeen. This means time off work, travel expenses, accommodation expenses."

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"Just getting to hospital is a worry, as don't drive now and live on my own and family are all working."

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"Telephone appointments also help in reducing my anxiety. I get anxious about making sure I'm there on time, worried in social situations so it helps with that aspect a lot... It means the worry of having to put others out to take me to appointments is gone as well."

For those who do not find it easier, some commented on technical difficulties and the challenges of finding a stable internet connection or phone signal. Others commented on the lack of reliability in the service.

"It is cheaper because of less travel but it's not always convenient – I often get called earlier or on the wrong numbers."

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"It isn't convenient as if it's late no one lets you know. Have you been forgotten etc? All adds to stress of appointment. I have felt hurried when speaking and have no info as to how long the appointment is."



Conclusion

This report makes evident the need for patient choice. The impact of the epilepsy is unique to each individual and so every person with the condition has different experiences and needs.

The 115 survey respondents used their lived experience to emphasise the importance of communication and engagement with healthcare professionals as well as the significance of including unpaid carers in appointments. This clearly illustrates the need for patient choice.

This report emphasises the significance of face-to-face care. 62% of survey respondents would prefer to attend their appointments in person, while a further 24% would like a mix of in-person and remote. However, thus far, only 16% of respondents to this survey have been allowed the opportunity to choose the format of their recent epilepsy appointments. Furthermore, while 40% of respondents had only attended their specialist epilepsy appointments via telephone since March 2020, only 9% would prefer to attend telephone appointments if given the choice.

“I just want human contact with someone who cares.”

For many people, meeting with specialists in person is a way of building trust. People find it easier to articulate their needs, ask questions and understand their specialists, helping them better engage with their care. For others, it can be easier to communicate their needs remotely, reducing the stress and anxiety they may experience through attending face-to-face appointments. Many prefer a mix of both in person and remote depending on their needs at that time.

It should be noted this report does not seek to diminish the benefits of remote consultations. For some people, remote consultations provide an important service.

Specialist care must be designed to meet the needs of patients. If care is to be truly person centred, the decision between in person and remote appointments must be the patient's to make. To allow this, flexibility must be built into the systems of care. It is essential actions are taken to enable people with epilepsy to have their voices heard in the decisions made about their care.

Key Messages

People with epilepsy, where possible, must be allowed the opportunity to make informed decisions about their care

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Remote consultations must not become the default format of epilepsy management

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Face-to-face care is critical in providing holistic epilepsy support



Epilepsy Consortium Scotland is the united voice for the wider epilepsy community in Scotland. We aim to drive forward to best outcomes for the estimated one in 97 people living with epilepsy in Scotland. We are an information exchange, informing policy makers, MSPs and the Scottish Government and we back epilepsy awareness campaigns to end discrimination and social stigma.



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