



EPILEPSY CONSORTIUM SCOTLAND

Qualitative Research:
Epilepsy Specialist Nurse services
during the Covid-19 Pandemic



RESEARCH SCOTLAND

May 2022

1. Introduction

About this report

This report summarises findings from qualitative research exploring experiences of Epilepsy Specialist Nurse services in Scotland during the Covid-19 pandemic. It is based on six discussions with Epilepsy Specialist Nurses and six discussions with individuals who had received support from an Epilepsy Specialist Nurse. The research was undertaken by Research Scotland in spring 2022.

Method

Our approach to this qualitative research involved:

- **Permissions** – We worked with Epilepsy Scotland to apply for ethical approval to undertake the research as it involved contact with NHS staff. After an initial application, it was confirmed that the research could go ahead without detailed ethical assessment and approval.
- **Research tool design** – We developed semi-structured discussion guides for the interviews. This set out key questions and themes but allowed the interviewer scope to probe and facilitate discussion around topics important to the participants.
- **Epilepsy Specialist Nurse interviews** – We held six individual interviews with Epilepsy Specialist Nurses. The participants were identified by Epilepsy Consortium Scotland. Interviews took place either over the phone or online as preferred by the participant and lasted 60 minutes.
- **Individual interviews** – We held six interviews with individuals who had received support from Epilepsy Specialist Nurses. The participants were identified by Epilepsy Consortium Scotland. Interviews took place over the phone and lasted 30-60 minutes. Participants received a £25 voucher to thank them for their time.
- **Reporting** – We produced this short report summarising findings along key themes. The report includes anonymised quotes from the interviews.

2. Individual experiences

Introduction

This chapter explores the experiences of Epilepsy Specialist Nurse (ESN) support from the perspective of six individuals. The individuals had experience of ESN services, but not all currently had access to active support through an ESN.

Support from ESNs

Overall, participants were very positive about the support offered by their ESN with some participants describing their ESN support as a 'lifeline'.

Quality of support

Participants with ESN support were positive about the quality of the support they received. They expressed appreciation for the respectful and patient-centred approach taken by their ESNs.

Participants spoke about how their ESNs were approachable, often highlighting the importance of their ESN having time to talk. Participants appreciated their ESNs using simple language and felt comfortable asking them questions.

“ Pre-pandemic, I'd stay in touch with him. I trusted him. You know that they're stretched but you'd still feel able to call up. It felt like he had the time to talk to you. He had the biggest impact on me. Just having the relationship with him. Having someone who knew me and knew my history.”

Some participants described their ESN as providing a bridge between themselves and their neurologist. A few mentioned that they could ask their ESN about things that they wouldn't ask their neurologist, and that their ESN helped to explain things in a different way than their neurologist.

“ My neurologist uses big words that I don't always understand! My ESN helps explain things to me in a way that I understand.”

“ I wouldn't ask my neurologist questions that I would ask my ESN. He's a consultant and busy. As she's a middle person I feel more comfortable asking her questions that I wouldn't ask him.”

Participants spoke about the importance of the relationship that they have with their ESN. Participants appreciated the person-centred approach.

“ I always had a really good relationship with my ESNs. My very first nurse said to keep in touch, to never think that you're bothering us. Sometimes just a 2-minute conversation puts your mind at rest.”

Some noted the value of having someone who understands them and their symptoms, increasing the quality of the advice they receive, their medical notes and ultimately the quality of care they receive from their consultant.

“ Having that relationship with your ESN is so important. Just them having your notes is so valuable. It means a consultant is reading the notes 10 mins before your appointment and it's not all on you to remember.”

Participants highlighted how their ESNs have had a positive impact on their mental health and helps to reduce anxiety, particularly around potential changes to medication.

“ It makes me feel calmer because I have someone I can get to, even if I've just got a couple of questions.”

“ She's been really good at explaining the consequences of changing medication, I'm really hesitant of medication change, so she's helped talk me through it.”

“ Everyone's epilepsy is different. Their level of knowledge of the condition is such that they can provide the advice you need.”

One participant felt that their ESN introduced them to a new way of thinking about and managing their health.

“ It was the first time that I'd ever gone to a medical professional either for my diabetes or my epilepsy and they had asked me what I think. I was completely taken aback by that. These decisions are normally taken for you. That changed my whole ethos on health management. I've seen so many medical professionals and I've never been asked what I think. It gave me choices.”

Accessibility of support

All participants who had an ESN spoke positively about accessibility, noting that whenever they left an answerphone message on the helplines their calls were returned within a couple of days.

“I’ve never not heard back when I’ve left message.”

“She’s always there. She is there if you have anything that takes place. She’s always been there.”

Participants spoke about the value of being able to contact their ESN directly. Participants valued the ability to have a direct dial number and an answerphone – which normally resulted in a swift response.

“Even if they’re in clinic and it goes to answerphone, they always respond. Usually, you’d call your GP but they’re difficult to get hold of and don’t have the specialist knowledge. And I can’t contact my neurologist, so they’re the accessible support.”

Some participants felt that the ESN service needed more visibility to improve awareness and facilitate people accessing the service.

“Advertising it better. I didn’t even know one existed to begin with. Even neurologists don’t tell you about it. I was left to myself to find all that out. But when I did receive support, it was great; I couldn’t fault it.”

Some participants had difficulty initially accessing ESN support. Participants expressed frustration that there isn’t an automatic referral to the ESN services in their area, suggesting that had they known that this support was available, they would have accessed it sooner.

“I had to go looking for it [support]. It was quite stressful at the time. When I contacted my consultant, I felt that this support should have been on offer. Nobody told me that there were epilepsy nurses, if I’d known that I’d have been using their support.”

“And even when there is an ESN, so many patients don’t have their ESN nurses’ numbers. It should be a matter of course that when you see the neurologist you get introduced to the ESN but that doesn’t automatically happen at the moment.”

A few participants did not have an ESN, but noted that they would access this support if it were available.

“I’m not receiving any support as there are none in the area, but I would be using the service if it was available.”

I'd call them to discuss side effects of medications and my mental health. I've had problems with my mental health, and I wondered if it was a side effect from the medication. You don't need to see them face to face, it's just someone to speak to over the phone."

All of the participants were aware of the pressures on the NHS and their ESNs, noting that problems with short-staffing were already an issue prior to the pandemic.

“Both the nurses retired before the pandemic, so this was a problem even before then.”

“I know that they are short staffed. The last time I saw my ESN, there was one covering the whole area, so I've not had a great deal of meetings with her.”

Impact of the pandemic

Impact on managing health conditions

Some participants described changes in their epilepsy during the pandemic, with most stating that they had experienced an increase in seizures and feel that their epilepsy is not as well-managed now.

“It's not very well managed at the moment. It has been better but not in the last year or two.”

“My epilepsy changed during pandemic. For me, one of my triggers is stress and anxiety, so I was on the phone more. Being in the house on my own was different. Constantly being on my own in the house, working from home. My work colleagues provide a lot of support for me, so working from home was hard.”

In contrast, one participant felt that her seizures had reduced due to being on furlough.

Impact on access to support

Most participants reported that they felt that the quantity of contact with their ESN hadn't changed during the pandemic, in terms of assessments and reviews.

“...the nurses still emphasised that we should keep in touch. The quantity of contact didn't change.”

However, some participants noted that the level of informal support had changed, with a reduced level of contact. This had impacted negatively on their wellbeing.

“The lack of contact with my ESN has set me back. I'm quite anxious now.”

Some participants felt that the lack of contact meant that they didn't feel that they had an ongoing supportive relationship with their ESN service.

“Currently, there's a lack of contact, and a lack of continuity that affects me going forward.”

Some participants stated that they felt that their care had become less patient-centred as a result of the pandemic.

“Personally, I'd like to have back a more patient centred approach. Whether that be telephone or face to face, there just needs to be more discussions about what I can do to help you manage your condition.”

Participants expressed awareness of the pressures on the ESN service, with many talking about staffing pressures and the resulting change in their experience of the service. Some had tried not to get in touch unless it was urgent, to reduce pressure on ESNs. Some had gone to others for support instead.

A few mentioned that the number of ESNs providing support had decreased, and the geographical areas covered by the ESNs had increased. A few said that ESNs had been shifted to provide support in other areas, reducing the level of support available to them.

“There was only one ESN for the full area, but I think they left, so they've been a bit short staffed.”

“...So sometimes it took 4-5 days to call you back and that never happened before.”

“I think during the pandemic, I knew personally not to get in touch unless it was a crisis. I avoided ringing him.”

Impact on type of support

All participants spoke about a shift from face to face support to telephone and video calls. Although this provided flexibility and the opportunity to have appointments during working hours, all participants expressed a desire to return to face-to-face contact. Participants felt it was easier to understand information when face to face, easier to remember, easier to show people issues, easier to ask questions and easier to chat.

“Video calls even if not face to face. Just once in a while. If that was possible, it would be nice. I want to meet my ESN! I communicate better when I can see the person. I get tongue-tied on the phone, I get anxious, particularly about medical stuff and it helps me stay calmer if I can see the other person's face.”

“For example, if my hand is shaking during a seizure, I can show them what it looks like. I can't always explain that well over the phone.”

Future priorities

Participants spoke about their desire for everyone to have access to ESN support. They expressed awareness of how stretched current services are but also noted how crucial this is to their care. In particular, participants felt that people living in rural areas may face barriers to accessing ESN support.

“I'd want anyone with epilepsy to have access to a medical professional. To a specialist, not a GP. Because if there's ever anything your ESN can't do because they're usually based in the same place as the neurologist, they can have a quick word with the neurologist and you can get an answer.”

Participants spoke of the impact that epilepsy has had on their lives, with some expressing a desire for more holistic support. Some participants felt that the support they currently receive focuses on medication rather than lifestyle issues and expressed a desire to spend time with other people with epilepsy through support groups.

“The support I get is mainly around medication but there's no quick fix. There's a lot of benefits to be had by meeting up with people in similar situations though.”

“I'd like more formalised ways of pulling people together. It's beneficial speaking to people and getting their experiences. You don't know what's normal, what's an average seizure, what's a normal amount to have. So it might help give you a frame of reference for what's normal.”

3. Experiences of Epilepsy Specialist Nurses

Introduction

This chapter explores the experiences of six Epilepsy Specialist Nurses of delivering support, both before and during the pandemic.

Becoming an Epilepsy Specialist Nurse

All the participants were highly experienced with between seven and seventeen years' experience working as an ESN.

All the ESNs interviewed had worked in the field of neurology prior to their decision to specialise, including working as charge nurses on neurology wards and gaining specialist qualifications in neuroscience. Two participants had worked in academia and research prior to specialising.

There were four key motivating factors for the decision to become a specialist nurse: a desire to remain patient-focused, diversity of patients, the complexity of the condition and career progression.

- **Patient-Focused** – All participants spoke of their desire to remain working directly with patients. Participants demonstrated a clear passion for the work and a desire to improve the situations and challenges faced by epilepsy patients.

“I knew I didn't want to follow the traditional charge nurse management route, I wanted to stay patient focused, so speciality nursing was a good choice for career progression.”

- **Diversity of Patients** – Participants emphasised the variety presented by this patient group as being a key motivating factor for their decision to specialise in epilepsy. They spoke of the breadth of specialisms within their work, including working across obstetrics, addiction, learning disability and pharmacology, but also how the condition includes working with the social and environmental conditions of the patient.

“I'd always wanted to be a specialist in an area and get to know one area well. And epilepsy is not just one condition, there are lots of different epilepsy's and you end up looking after patients with lots of different conditions. I've never had two days the same.”

- **Complexity of the Condition** – Participants spoke of the significant and complex impacts that an epilepsy diagnosis can have on patients' lives. They highlighted that this complexity and the needs of this patient group informed

their decision to specialise, noting that the potential to be able to support a patient through their diagnosis and various life stages is incredibly rewarding.

“It’s very rewarding to see someone reach seizure freedom or guide someone through diagnosis. You get to see good outcomes.”

- **Career progression** – Participants viewed specialist nursing as an attractive option for career progression. Factors mentioned include not wanting to move into a management role, autonomy, responsibility and the ability to respond to patient need.

“It was for career progression. I was band E on the ward so still one of the junior nurses but heading towards senior level. But I didn’t want to do senior management, managing people on the ward.”

Typical Work

All the participants highlighted the breadth of their work and their ensuing depth of knowledge and expertise. Participants stated that their work involved clinical work, including provision of regular and specialist clinics, visiting patients on wards, provision of assessments and reviews, provision of a responsive telephone helpline service and crisis prevention. Participants also noted that increasingly they were being asked to provide pharmacological advice to GPs and other medical professionals.

- **Clinical Work** – Participants described how they provide regular clinics and travel to see patients on wards in hospitals located anywhere within their region, noting that this often requires extensive travel.

“Much of my work is clinic based, seeing patients in wards if they’ve presented seizures for first time or are having unusual seizures.”

- **Assessments and Reviews** – Participants described how the provision of initial assessments and regular 3-, 6- and 12-monthly reviews either in-person, over the telephone or via video conferencing, forms a large part of their workload.
- **Helpline** – All participants stated that they run a responsive telephone helpline service. This service is run by the ESNs and covers all patients within their geographical regions. All participants stated that this is covered by one or two nurses. Patients are encouraged to call the helpline for any difficulties that they may have, from changes in seizure activity, difficulties with medication, to wider issues. Participants described how one call has the potential to change their whole working day.
- **Specialist Services** – All participants had specialised areas of interest for which they ran dedicated clinics. This included working in areas such as

epilepsy and learning disability, antenatal epilepsy, and addiction. Participants described the challenges across each of these fields of work, noting the depth of knowledge and demands that these place on their workloads.

- **Training** – Some participants regularly deliver training to the community and other professionals, including ward staff. Participants noted that this work has increased over the last two years due to the need to deliver to smaller groups through video conferencing rather than in-person.

“We also provide a significant amount of epilepsy training to community, things like epilepsy awareness.”

- **Pharmacological Advice** – Participants described their responsibilities as prescribers, with the majority of participants noting that they are qualified to dispense medication. Some participants noted that they are increasingly providing pharmacological advice to GPs and other medical practitioners. They stated that this is in part due to current supply issues, resulting in GPs needing to change to generic brand drugs and who are therefore seeking advice on potential side effects.

“We deal with both acute side effects and chronic side effects, so there’s a lot of pharmacology in our work too.”

- **Crisis Prevention** – Importantly, all participants highlighted the centrality of crisis prevention within their roles. They spoke of the importance of prevention as an essential part of epilepsy nursing, noting the importance of getting to know the social and environmental conditions surrounding their patients. Participants noted the bidirectional relationship between mood and epilepsy, highlighting how changes in patients’ lives can affect seizures. They spoke of the importance of mental health, noting the higher suicide rate among people with epilepsy. Participants described how part of their role is therefore to work at the interface between clinical care and listening to people’s lived experiences.

“We know there is a relationship between mood and anxiety and epilepsy, so I see a role for caring for people’s mood and emotional health as part of their care.”

“You need to look at the social conditions surrounding the patient. If there’s a deterioration in social conditions, it will affect the patient’s epilepsy.”

Workload

Participants described an extremely busy and varied workload involving a high level of responsibility. Most participants noted that their current workloads feel potentially unmanageable and that they do not feel like they are constantly in control of their work.

“It’s the closest to being unmanageable as it’s ever been.”

One participant stated that she felt that her workload had remained manageable, although she noted that this was due to neither her nor her colleague being redeployed, meaning that they had been able to maintain their service throughout the pandemic.

Participants described large caseloads of up to 3,500 patients for one or two nurses. They all stated that due to the numbers, it is impossible to have individualised patient care and that they have waiting lists for their service.

“Trying to manage that workload is really difficult. You never really feel on top of it.”

Participants described the demands of their specialist provision, noting the complexities for different patients. This includes issues with cognitive capacity, chaotic lifestyles, and more active seizure patterns.

Despite the size of workloads, all participants talked about their focus on patient care and emphasised the importance of accessibility. Participants remain committed to providing quality of service, reiterating the importance of prevention within epilepsy support.

“You need to focus on patient care. The patient in front of you, they need to take all your energy and thought.”

All participants stated that they regularly work beyond their contracted hours. Participants noted that this was already an issue prior to the pandemic but has further increased over the past two years.

“I tend to do a couple of hours above my hours every day.”

Some participants spoke of the need to balance accessibility with patient responsibility, noting that their accessibility can sometimes promote dependence among their patients.

Impact of the pandemic

Redeployment

All participants spoke about the impact of redeployment on their service, with some highlighting that they worked extra hours to maintain their service despite being redeployed elsewhere.

“I was redeployed three times. It was the same for most of colleagues.”

“We were redeployed for a short time to cover shortages on neurological wards but even then, we worked extra hours. We didn't charge for it, but we'd work 8 hours in clinic and then come in and answer calls.”

Three participants expressed gratitude that they were not redeployed throughout the pandemic, noting how much they appreciated the value placed on specialist nurses by their managers and health boards.

“We've been allowed to be epilepsy nurses throughout the pandemic. Our health board has seen the value of specialist nurses, we haven't been seen as just a nurse.”

“I haven't been redeployed, so I feel quite lucky in that respect. It comes from my boss being very supportive and so she didn't put me under any pressure.”

Impact on patients

Participants felt they were able to continue delivering their services throughout the pandemic and minimise impact on patients, despite redeployment. They noted however that this was due to their own commitment to their patients and willingness to work beyond their remits.

“I'm really proud that not a single nurse-led clinic was cancelled.”

“I don't think it has affected patients because we've overstretched ourselves. We've worked beyond our remit. Patients have been affected by community care, but not our service.”

However, some participants spoke of the inevitable impact of redeployment on their patients, notably that reduced access to their services will have resulted in more seizures and increased hospital admissions.

“If you’d spoken to that patient earlier on it might have been a simple medication change but now they’ve had a seizure and are in A&E. So now they are in hospital and taking up a bed.”

Accessibility

Participants felt that ESN support remained accessible to patients during the pandemic. Most highlighted that they were able to maintain their telephone service throughout the pandemic.

All participants said that the volume of calls to their helplines increased. Some were concerned that as ESNs were accessible when patients continue to encounter difficulties accessing other parts of the NHS, such as GPs, this encouraged more people to come to ESNs first, before they contact their GP. Some participants spoke about the increase in the number of primary care queries, both from patients and from GPs.

“There has been an exponential rise in primary care queries. Not just patients but GPs too. They’re coming to us, and we’re being sent clinical queries about patients we’ve never met. GPs are struggling and they’re reaching out for help.”

One participant noted however that due to all of the ESNs being redeployed, there was a period during the second wave of Covid-19 for about a month when they were unable to provide any specialist service provision.

Timeliness of services

Some participants stated that their services now have a backlog of cases and waiting lists for clinics.

“Initially we maintained the epilepsy service but both me and my colleague were redeployed. He was away, then there was a period when I was away, so a backlog has stemmed from that. There’s now a 5-month waiting list on clinics. So, if you are needing your regular 3-month review, you will need to wait 8 months now.”

Participants noted that it would take a long time to work through the backlog, and longer if there was any further redeployment. Some were concerned that patients were not getting seen in a timely way, negatively impacting work to prevent seizures and manage health conditions proactively.

Telephone and online assessments

All participants spoke about the increased use of telephone appointments and the introduction of video conferencing for consultations. All participants highlighted that telephone work was not new and that it had always been a feature of their work. However, they noted that the proportion of telephone and video conferencing to face-to-face appointments had changed, with the majority of reviews and assessments now being conducted either online or over the phone.

Participants highlighted the positive and negative impacts of this change. Positively, they noted that telephone and online appointments suited some patients, particularly those who are unable to drive, live in rural areas, or who may have more chaotic lifestyles. Participants reported that this change has resulted in a lower 'Did Not Attend' (DNA) rate. Some also felt that telephone appointments could be more efficient, allowing teams to work through backlogs faster and review patients quicker.

However, participants also noted that telephone and online appointments are not always suitable, particularly for initial assessments, for older patients, and for patients with certain cognitive conditions. ESNs emphasised the importance of patient choice.

Some participants cautioned against the assumption that telephone appointments are always more time efficient. They noted the importance of meeting patients face-to-face, without masks, to facilitate a full assessment of the patient and of their situation and to enable early identification of potential medical conditions. Face to face meetings allow ESNs to assess behaviour, spot cognitive defects, pick up on language disturbance, pick up on things in person that they can't over the phone, read emotions and develop a therapeutic relationship more effectively.

Future support needs

Staffing

All participants spoke about issues around staffing in the NHS in relation to ESNs, general nursing roles, and more widely in terms of administrative support. Some participants also felt there was a need for dedicated epilepsy specialist staff across various sectors, including social work and psychology, noting that the prevalence of the condition within society means that there is a need for specialist services.

Participants also noted that the impact of the shortages across the NHS creates a sense of frustration. Some felt very well supported by immediate managers, colleagues and senior management..

“ I feel in our role we are supported. By both clinical and non-clinical. It's very much an autonomous role, we're not micro-managed by anybody. But the support is available if you need it.”

“ There are shortages all over the NHS. I feel supported but frustrated.”

Others felt that senior managers did not fully understand the ESN role. They noted that an improved understanding of their role would support them to effectively develop and deliver their service. Some felt that it would be useful to have more supervision and access to training.

“For managers to have a better understanding of our role would be a good start.”

Participants highlighted the level of responsibility they hold within their services, noting that they independently run clinics, prescribe medication, and make decisions independently from consultants and managers. Some participants felt that this level of responsibility was not accurately reflected by their current banding.

When asked where they see themselves in five years' time, participants all responded in ways that highlighted their passion and dedication for their roles. While some participants acknowledged that retirement is in their near future, they still expressed a desire to remain involved in their work. Some participants however expressed more caution, noting that while they love their work, the pressures they are experiencing have caused them to rethink their future.

“If we continue to be pulled in different directions, I don't know if I can continue.”

“It's a hard time to be a nurse in the NHS. We're caregivers, that's why we do what we do, but we have limits.”

Need and impact

Participants spoke of the need to find ways to demonstrate the need for their work and the impact of their work.

In terms of need, participants felt it was important to evidence the high rates of community prevalence, the hidden nature of the condition and the complex impacts it has on patients' lives – particularly in terms of mental health.

“Poor mental health is a major issue now. In our telephone service people call us not necessarily for epilepsy related illnesses but for advice about other things. And there's a rise in addiction.”

In terms of impact, participants felt it was important to demonstrate the impact of their work in preventing issues and problems. This is a crucial aspect of the work of ESNs, but participants felt it was hard to demonstrate nationally. For example, through providing support at an early stage this may prevent last minute prescriptions, unscheduled visits to the health service, and accident and emergency visits.

“As nurse managers, we need to try to show what it is that we're preventing..”

“It needs to be comprehensive. How many times do they present to their GPs or hospitals? How often do they have a psychiatric crisis? How many are unemployed or not economically active? It’s not just the amount of times they come through the door.”

Some participants felt that people were now experiencing more issues, due to delays in either presentation of an issue or provision of healthcare. This means that when people are being seen, their conditions are more complex.

Participants spoke about the need for fair and effective workforce planning that recognises the positive impacts that prevention of unplanned and unscheduled care has across wider society.

A co-ordinated approach to support

Most ESN participants spoke positively about their relationship with third sector organisations, noting that they provide crucial outreach and day-to-day support for patients. Participants highlighted how they use the literature developed by organisations like Epilepsy Scotland and refer patients to organisations like Epilepsy Connections and Quarriers for support with benefits advice, for home visits, and for support groups.

One ESN highlighted the lack of third sector support within her region, noting the impact that this has on her patients and on the demands for her service.

Participants expressed a desire for more specialised support, including the provision of respite care and employability support, alongside highlighting the need for stable funding to ensure sustainability.

Some participants spoke of the need for a unified, coordinated approach among epilepsy organisations to develop a national policy for epilepsy with a cohesive voice. Participants highlighted the specific difficulties faced by their patient group, noting for example that epilepsy patients tend to be poorer and less economically active due to the condition, and are statistically more likely to have their Personal Independence Payments turned down. Participants emphasised that this increases the need for a coordinated national strategy.

“We need more services to get together and work out a national strategy and put that to the government.”

“We need to agree on national strategy for Scotland. They need to apply a unified pressure together.”

4. Key findings

This report involved discussions with six Epilepsy Specialist Nurses (ESNs) and six people with epilepsy.

Overall, participants with epilepsy were very positive about the support offered by their ESN. Participants felt that they received a high quality, respectful and patient-centred service through ESNs, and valued the relationships they had with their ESNs. The ESN support had a positive impact on their mental health, helped them feel calmer and more relaxed, and helped them to manage their condition more effectively.

Participants valued being able to contact their ESN directly through helplines, but felt that ESN services needed to increase in visibility to ensure everyone could access the service as soon as they were eligible.

Participants felt that they still had contact with their ESN during the pandemic for assessments and reviews, but the level of informal support had reduced. Some felt care became less patient-focused and this impacted on their wellbeing. While participants valued the flexibility of telephone and video calls, they were keen to return to face to face contact.

Participants would like to see everyone with epilepsy have access to ESN support, as well as wider peer support through support groups.

ESNs explained that their work was wide ranging and varied, including providing regular clinics, visiting patients on wards, undertaking assessments and reviews, responding to calls, and undertaking specialist work on topics such as antenatal epilepsy, epilepsy and addiction, and epilepsy and learning disability. Some staff also provide training, dispense medication and provide pharmacological advice to GPs and other medical practitioners.

ESNs were extremely busy, and many noted that their workloads are potentially unmanageable. The pandemic created pressures through backlogs of clients, as ESNs were redeployed and pressure on the health system resulted in an increase in calls to the ESN helpline.

ESN support largely remained available to patients during the pandemic, but there were delays and backlogs and much of the support moved online or over the phone. ESNs highlighted the importance of sometimes seeing patients face to face, to recognise issues more effectively and at an earlier stage.

ESNs felt that it was important to demonstrate the need for and impact of ESN services, so that the value of preventative work could be recognised and effectively resourced and planned for. Some felt there needed to be a unified approach among epilepsy organisations to develop a national policy for epilepsy.