

Scottish Paediatric Epilepsy Network (SPEN)

SPEN New Normal Recommendations

NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined based on all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

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1. Executive Summary/Key Recommendations

- New Patients ('first seizure' and new epilepsy diagnosis) should be seen in a face-to-face clinic
- For new epilepsy diagnosis, the opportunity to meet with an Epilepsy Nurse Specialist face-to-face is also recommended
- Where appropriate, patients, parents, and carers should be given the choice over follow-up consultation format (face-to-face or remote)
- In most cases, an annual face-to-face review appointment should still be arranged. This interval can be extended for those with very stable epilepsy
- Additional considerations are warranted for patients in certain special groups, who will require more frequent face to face review
- Ongoing Quality Improvement work on services should be carried out and the training needs of trainees and nurse specialists in clinics should be prioritised
- The working group acknowledge that there may be other considerations when planning appointments, such as for rural and remote patients, and clinical judgement will be needed in these cases

2. Background

The Scottish Paediatric Epilepsy Network (SPEN) is a multiprofessional managed clinical network which seeks to:

- **Promote the delivery of high-quality care** to children and young people (CYP) with epilepsy in Scotland
- Be **patient-centred** and deliver seamless care between organisations and professional groups
- Contribute to the **setting of standards** for epilepsy care and to audit the care provided
- Ensure **equity of services** for all CYP with epilepsy wherever they live in Scotland

In recognition of the rapidly implemented changes to Child Health Services following the COVID-19 pandemic, and the impact this had on paediatric epilepsy care, a short life working group (SLWG) was convened in 2021 to seek stakeholder views and provide recommendations on service provision and planning.

Two national surveys were performed:

- CYP (Children and Young People) and Parent/Carer Views on Epilepsy Clinic Consultations
- SPEN Stakeholders

The views of 77 parents/carers and CYP were gathered and 25 SPEN clinicians. Further views from 50 of SPEN stakeholders were gathered at focus groups. A review of current evidence and literature was performed, and this data was also taken into consideration.

3. Recommendations

Note: 'remote consultations' refer to either telephone or video (Attend Anywhere). Results from patient/parent/carer feedback and clinicians showed that video consultations remain in the minority and are frequently limited by technology.

3.1 New Epilepsy Patients

New Patients ('first seizure' and new epilepsy diagnosis) should be seen in a face-to-face clinic.

Details:

- The recommendation is that all patients referred as 'first seizure'/paroxysmal events or new epilepsy should be seen in a face-to-face clinic
- Telephone triage or 'enhanced referral vetting', including the use of vCreate videos, where appropriate, may be helpful before the clinic
- Where the patient needs to travel a considerable distance for an appointment, an initial remote consultation may be helpful in some cases of suspected epilepsy to plan investigations for the face-to-face appointment
- A diagnosis of epilepsy should be given face-to-face where possible. For new epilepsy diagnosis, the opportunity to meet with an Epilepsy Nurse Specialist (ENS) face-to-face is also recommended

3.2 Follow-up Appointments for Epilepsy Patients (Includes patients under investigation for suspected epilepsy)

- **Where appropriate, patients, parents, and carers should be given the choice over follow-up consultation format (face-to-face or remote)**
- **In most cases, an annual face-to-face review appointment should still be arranged. This interval can be extended for those with very stable epilepsy who are not approaching transition**
- **See also guidance on special groups in section 3.3**

Details:

- There are numerous benefits to remote consultations (reduction in travel and expenses, environmental impact, less time off work/school, efficient use of clinic space etc). It remains a valuable consultation method

- However, there are both good clinical and non-clinical reasons to prefer face-to-face follow-up (monitoring development & growth, joint clinic appointments with ENS, improved involvement of CYP, family/CYP preference)
- For the safe monitoring of epilepsy in a CYP a minimum interval of appointments is recommended in line with SPEN guidance. SPEN Paediatric Epilepsy Quality Standard Statement 9: 'Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually'
- Our work found that approximately half of parents/carers/CYP preferred face-to-face appointments only. The remaining half preferred a mixture of face-to-face and remote follow-up appointments.
- The best modality for follow-up appointments will require clinical judgement. However, where possible, parent/carer/CYP preferences should be sought

3.3 Special Group Considerations (for follow-up appointments)

- For patients with poorly controlled epilepsy and high-risk groups, more frequent face-to-face appointments should be considered
- Children under 2 years old: should be seen face-to-face by default
- Children with active child protection concerns: should be considered for face-to-face by default
- Epilepsy Joint Network Clinic* Patients: should be seen face-to-face by default (for network clinics)
- Teenage patients: should be encouraged to be seen face to face, however, their views on follow-up modality should be actively sought
- CYP with multiple/complex needs:
 - Where possible efforts to reduce appointment burden on families should be made (for example, same day appointments for different specialties, or multi-disciplinary team [MDT] clinics)

Details:

Patients in all these groups will benefit from joint appointments with Epilepsy Nurse Specialists.

Where there are active child protection concerns, it should be strongly considered to arrange the follow-up appointments as face-to-face but it is recognised that clinical judgement is important in these cases and some may be appropriate for remote consultation.

Epilepsy Joint Network Clinics* should be facilitated to run as face-to-face appointments with all professionals present. These more complex patients may be suitable for remote appointments with their local teams at other times.

For CYP with multiple/complex needs a Patient Centred approach should be taken. In some cases, a remote follow-up appointment is preferred by parents/carers especially where travel is difficult or distressing for the CYP. This patient group also often have a high burden of clinic appointments. As such, MDT clinics, or combining dates of face-to-face reviews is recommended, where possible.

3.4 Other recommendations

- Departments should have robust protocols for determining the outcome of patients who are not brought to clinic (DNA/WNB) in line with local policies
- It is recommended that ongoing Quality Improvement work is carried out (reviewing clinic non-attendance rates and feedback from parents/carers/CYP).
- Training needs of clinicians (Medical Trainees and Nurse Specialists) should be prioritised. This requires protected clinic time and space

* 'Epilepsy Joint Network clinics' refer to joint clinics delivered in local children's services with input from a visiting tertiary neurologist.