

# SCOTTISH PAEDIATRIC EPILEPSY NETWORK (SPEN)

## Joint Clinic Guidance

### 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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## Background

In cases where children or young people with epilepsy require tertiary specialist input, joint clinics delivered in local children's services with input from a visiting tertiary neurologist are a highly effective mechanism for providing that level of input to the child or young person's care. However, it is important to note that joint clinics are not the only way of accessing specialist input. Some areas have managed service networks and utilise regional expertise via virtual clinics where complex patients are presented and discussed by a multidisciplinary team.

Joint clinics already exist in many local non-tertiary paediatric epilepsy services. These are largely based on informal arrangements and often lack an explicit agreement between the respective health boards to provide protected time in job plans and ensure appropriate governance arrangements are in place. There is also currently no agreed standardised set of principles that joint clinics should adhere to. This document is intended to provide such guidance and facilitate discussions between tertiary centres and local services about creating more formal arrangements for joint paediatric epilepsy clinics.

## Benefits of joint clinics

Joint clinics provide tangible benefits to both patients and families and the clinical services that provide their epilepsy care.

- patients and families have a reduced need to travel and receive tertiary specialist input to their care in a familiar hospital environment close to home
- it is reassuring for patients and their families to see effective links between their local epilepsy team and the tertiary specialists
- joint clinics also allow a learning opportunity for the local multi-disciplinary teams (including general paediatric staff who may not be routinely involved in epilepsy care)
- joint clinics minimise the need to refer patients to tertiary centres and allow the tertiary centres to focus more efficiently on cases where attendance at a tertiary centre is necessary
- joint clinics help to build better working relationships between secondary and tertiary epilepsy clinicians
- local clinicians benefit from peer review

## Guidance for joint paediatric epilepsy clinics

The following guidance is intended to describe the key aspects of effective joint clinic organisation and delivery that should be considered. These are presented in four stages: the general framework around the joint clinic, preparing for a clinic, holding a clinic and actions to be followed up after a clinic.

### 1. General requirements for a joint epilepsy clinic:

1. Clinic frequency/ duration:
  - Clinics tend to operate more effectively as all day clinics, making efficient use of clinical staff time and opening opportunities for education and networking.
  - Clinics should ideally be arranged 6 months in advance.
2. Duration of clinic appointments: at least 30 minutes for new referrals and 15 to 30 minutes for follow-up patients.
3. Number of patients on clinic list to be agreed locally – need to agree clinic template locally.
4. Establish local MDT referral criteria in line with SPEN [pathways](#)

5. Agreed process for tertiary centres referring patients back to local children's services for follow up at joint clinic where appropriate.
6. Visiting tertiary specialists should have local IT access and honorary contract with the health board that hosts the joint clinic.
7. Secretarial support is required locally for collation of results/ letters.
8. Local access is required to height/ weight/ BP measurement, urine sampling, phlebotomy, lab results, PACS and pharmacy.

## **2. Preparation before local joint epilepsy clinics:**

1. Local process in place for referring and adding patients to joint clinic list. Clinic list to be coordinated by local 'link' clinician & admin support.
2. Clinic list to be shared with tertiary specialist at least 4 weeks prior to clinic. Final list to be agreed jointly by local and tertiary clinicians.
3. Clinical information on new referral copied in advance (with the clinic list) to visiting neurologists & their admin staff. Tertiary consultants to review patient records at tertiary centres before joint clinics to pick up on any investigations etc that may have been undertaken at the tertiary centre.
4. Relevant imaging to be available for review by national PACS: visiting clinician needs to have access to local IT systems.

## **3. The clinic:**

1. Local consultant paediatrician, visiting paediatric neurologist and local epilepsy specialist nurse conduct patient consultations together.
2. Information recorded in local case notes and shared appropriately.
3. Check patient/ family information needs and issue relevant information materials.
4. Recommendations made by the visiting neurologist and further treatment and management plans agreed by visiting neurologist, local MDT and patient/ family.
5. Responsibility for dictation of clinic visit to be decided by attending doctors. Letters to be typed and mailed by local admin staff.

6. Clinic letters to include agreed investigation, management & follow up action plans.
7. Copies of letters sent to referring local paediatrician(s), neurologists, parents, carers, families, other MDT members and GPs.
8. Time should be allocated for local and tertiary doctors to review cases of patients not seen at clinic where possible and organise dates for future clinics.

#### **4. After clinic:**

1. Letter turnaround within two weeks after clinic where possible.
2. Agreed investigations in action plan to be organised locally by local clinical MDT. Specialist investigations requiring tertiary centre to be organised by neurologists.
3. Local post-clinic MDT meeting to discuss care plan and ensure recommendations are actioned.

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