

Paediatric Epilepsy Quality Standard

This quality standard covers the diagnosis and management of the epilepsies in children and young people (aged up to 18 years). It was adapted from [NICE Quality Standard 27: Epilepsy in children and young people](#) with some modifications to reflect the specific circumstances in Scotland.

Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. It is estimated that there are around 4,000 children and young people with a diagnosis of epilepsy in Scotland (Scottish Paediatric Epilepsy Network GP Audit, 2005), with between 800 and 1,000 new diagnoses each year. There are more than 40 different types of epilepsy, with 40 different associated seizure types (link to classification papers). The nature of epilepsy means that it can be difficult to diagnose accurately. [NICE clinical guideline 137](#) estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect. The [Joint Epilepsy Council](#) (2011) reported that up to 40% of children referred to tertiary epilepsy clinics do not have epilepsy. A diagnosis of epilepsy can have a wide ranging impact on a child or young person's health and lifestyle. A key part of this quality standard is therefore focused on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are confirmed and reviewed as necessary.

For many children and young people diagnosed with epilepsy the seizures can be controlled through treatment with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activity. This quality standard therefore includes a focus on tailoring treatment to the individual circumstances and needs of children and young people with epilepsy so that they are offered the most suitable treatment.

Overview

This quality standard describes the main priorities for high quality paediatric epilepsy care that children and young people, and their families, should be able to expect. The intention is that the standard provides a framework for quality improvement of epilepsy services for children and young people across Scotland. It consists of eleven specific, concise and measurable statements and draws on existing guidance, which provides an underpinning, comprehensive set of recommendations, and is designed to support the measurement of improvement. The quality standard, in conjunction with the guidance on which it is based, is anticipated to contribute to the delivery of the key strategic aims of person-centred, safe and effective care as outlined in Scottish health policy:

- [The Healthcare Quality Strategy for NHSScotland](#) (2010)
- [The 2020 Vision for Health and Social Care](#) (2011)
- [A National Clinical Strategy for Scotland](#) (2016)

It is also expected to assist in the delivery of [Getting It Right For Every Child \(GIRFEC\)](#), the Scottish national approach to improving outcomes and supporting the wellbeing of children and young people.

The [NICE quality standard for epilepsy in children and young people](#) stresses that an integrated approach to the provision of services is fundamental to the delivery of high-quality care to children and young people with epilepsy, and that care should be delivered by multidisciplinary teams through a local epilepsy clinical network. Within the Scottish context of a much smaller, more dispersed population, and different organisational structures and commissioning and service delivery arrangements in the NHS, this integrated approach to service provision is best delivered through a mix of secondary and tertiary services at local and regional levels, supported and coordinated by a national epilepsy clinical network.

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating children and young people with epilepsy should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

Overview of Quality Statements

Statement 1. Children and young people presenting with a suspected epileptic seizure are seen by, or discussed with, a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Statement 2. Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested, the results of which should be available (electronically) to the clinician reviewing them.

Statement 3. Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Statement 4. Children and young people with epilepsy are provided with age appropriate information specific to their diagnosis and have an agreed and comprehensive written epilepsy care plan.

Statement 5. Children and young people with epilepsy are seen by, or have contact with, an epilepsy specialist nurse within 1 month of diagnosis.

Statement 6. Children and young people with epilepsy, and their families, can contact an epilepsy specialist nurse between scheduled reviews.

Statement 7. Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan, which is updated annually.

Statement 8. Children and young people who meet the criteria for tertiary care input are seen by, or discussed with, a tertiary care specialist within 4 weeks.

Statement 9. Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Statement 10. Young people with epilepsy have an agreed transition period where review accommodates the needs of teenagers culminating in a formal joint handover to adult services.

Statement 11. Children and young people with epilepsy have their mental health and wellbeing needs assessed and have access to appropriate psychological support to meet their identified needs.

Detailed Description of Quality Statements

Statement 1

Children and young people presenting with a suspected epileptic seizure are seen by, or discussed with, a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Rationale and Discussion

Diagnosing epilepsy can be complex, and it has been estimated that misdiagnosis occurs in 5–30% of people. It is therefore crucial that specialists are involved early in diagnosing epilepsy and that they take great care to establish the correct diagnosis.

It is appreciated that for some clinics waiting times may be longer than two weeks. There may be practical benefit from organising children and young people with a suspected first epileptic seizure to be seen in a dedicated first seizure clinic but such an arrangement is not considered a necessary prerequisite for meeting this standard.

The standard would be considered met if an appropriate specialist (paediatrician with expertise in epilepsy or paediatric neurologist) had triaged the referral within two weeks, giving due consideration to the urgency of the case to ensure that the case would be reviewed by an appropriate specialist in line with the SPEN first seizure pathway.

A suspected epileptic seizure is a reported acute episode of altered functioning, presumed to be the direct result of a change in electrical activity in the brain, the nature of which raises concerns that an epileptic seizure has occurred.

A specialist in the diagnosis and management of the epilepsies in children and young people is a paediatrician with training and expertise in epilepsy and demonstrable ongoing commitment to peer review and continuing professional development in relation to epilepsy care.

Statement 2

Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested, the results of which should be available (electronically) to the clinician reviewing them.

Rationale and Discussion

The period between a suspected epileptic seizure occurring and diagnosis can be a particularly anxious time for patients and families and it is therefore important that investigations are conducted in a timely manner. The earlier a correct diagnosis of epilepsy is made, the sooner tailored therapy can be initiated. Delays caused by a lack of available diagnostic equipment can lead to distress and impact negatively on the everyday lives of patients.

Initial investigations for epilepsy include electroencephalogram (EEG) and magnetic resonance imaging (MRI), as appropriate. Tests such as long-term video or ambulatory EEG, which might be used in the assessment of children and young people in whom there are difficulties with diagnosis after clinical assessment and standard EEG, might not be possible within this timeframe.

Test results should be interpreted by practitioners who have the necessary competencies.

Information should be provided to children and young people, and their families and/or carers as appropriate, on the reasons for the tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them.

Given the cross boundary nature of paediatric epilepsy services in Scotland, in particular tertiary neurology services, timely and reliable access to test results is not without challenge, especially in relation to IT systems that frequently do not adequately support working across health board boundaries.

Statement 3

Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Rationale and Discussion

Magnetic resonance imaging (MRI) is shown by evidence to be the most sensitive and specific neuroimaging option in terms of identifying structural abnormalities in the brain, but access to MRI scanning and reporting facilities varies across the country.

Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. People diagnosed with genetic generalised epilepsy or benign epilepsy with centrottemporal spikes (BCECTS) are unlikely to have any aetiologically relevant structural abnormalities and therefore do not require neuroimaging.

The criteria for MRI in children and young people are newly diagnosed epilepsy in a child aged under 2 years, epilepsy with focal onset (unless there is evidence of benign epilepsy with centrotemporal spikes) and failure of first-line medication.

In acute situations computed tomography may be used to determine whether a seizure has been caused by an acute neurological lesion or illness.

Statement 4

Children and young people with epilepsy are provided with age appropriate information specific to their diagnosis and have an agreed and comprehensive written epilepsy care plan.

Rationale and Discussion

There are a number of potential lifestyle, health and wellbeing implications directly related to epilepsy. Timely and appropriate information giving and a care plan are essential elements of high quality care and support for children and young people with epilepsy and their families, ensuring that all aspects of a person's life that could be affected by their epilepsy syndrome and the treatment they are receiving are considered and addressed.

(a) Information giving

All children and young people with epilepsy and their families should be given age appropriate information, both verbally and in written or recorded form (e.g. information videos), on the following topics:

- epilepsy in general
- the child's or young person's specific epilepsy syndrome
- risk management
- first aid, safety and injury prevention at home and at school or work
- social security benefits and social services
- insurance issues
- education and healthcare at school
- importance of disclosing epilepsy in college or at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted)
- road safety and driving
- sudden unexpected death in epilepsy (SUDEP)
- status epilepticus
- lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation)
- family planning and pregnancy
- voluntary organisations, such as support groups and charitable organisations, and how to contact them

(b) Care planning

In addition to the above generic information, it is essential that each person is given a care plan with tailored information about their specific diagnosis, treatment options, prognosis and personal circumstances. This should address:

- diagnosis and treatment options
- medication (including drug titration) and side effects
- seizure type(s), triggers and seizure control
- management and self-care
- prognosis
- psychological issues

It is important to recognise that the emphasis in care planning is not on the product of a 'care plan' per se but on the process of discussing and agreeing with children/young people and their families a range of pertinent issues that will impact on their health and wellbeing. This process needs to be documented in a way that reflects discussion and that is shared with the child/young person and their family. There will be flexibility with regards to the specific mechanisms or tools that are used locally to achieve this.

Statement 5

Children and young people with epilepsy are seen by, or have contact with, an epilepsy specialist nurse within 1 month of diagnosis.

Rationale and Discussion

Epilepsy specialist nurses play a key role in supporting people with epilepsy and early involvement of epilepsy specialist nurses is crucial. They support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and wellbeing. There is some evidence that epilepsy specialist nurses improve clinically important outcomes such as knowledge, anxiety and depression for people with epilepsy in secondary and tertiary care. In the Epilepsy 12 audit ease of access to epilepsy specialist nurses was strongly correlated with a positive patient experience.

Statement 6

Children and young people with epilepsy, and their families, can contact an epilepsy specialist nurse between scheduled reviews.

Rationale and Discussion

Epilepsy specialist nurses play a key role in supporting people with epilepsy and their families. They support both epilepsy specialists and generalists, to

ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and wellbeing. There is some evidence that epilepsy specialist nurses improve clinically important outcomes such as knowledge, anxiety and depression for people with epilepsy in secondary and tertiary care. In the Epilepsy 12 audit ease of access to epilepsy specialist nurses was strongly correlated with a positive patient experience.

Ongoing access to epilepsy specialist nurse is an important factor in ensuring care for people with epilepsy is well coordinated.

Statement 7

Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan, which is updated annually.

Rationale and Discussion

An emergency care plan is an important tool in improving the quality of emergency care in the community. It ensures that previous incidents and the agreed treatment strategies are taken into account by healthcare professionals. It also provides guidance for family members or carers who may need to administer emergency treatment. The timely and appropriate management of a prolonged or repeated seizure may significantly reduce the risk of mortality and morbidity (long-term complications) known to be associated with prolonged or repeated seizures.

An agreed written emergency care plan should describe what happens in the event of a prolonged or repeated seizure, including pharmacological treatment that should be given and actions to take, who to contact and when. It should be agreed between the child or young person with epilepsy, their family and/or carers if appropriate and their primary and secondary healthcare professionals. Family members and/or carers of children and young people with epilepsy will need training to initiate treatment at home or in the community when necessary. It is important that the emergency care plan is reviewed regularly – at least annually – which should include a review of emergency medication dosage and the continued need for emergency medication prescriptions.

Prolonged seizures are seizures that last 5 minutes or more.

Repeated seizures are seizures that occur 3 times or more within 1 hour.

Any child or young person with epilepsy who has experienced a prolonged or repeated seizure is considered to have a history of prolonged or repeated seizures.

Statement 8

Children and young people who meet the criteria for tertiary care input are seen by, or discussed with, a tertiary care specialist within 4 weeks.

Rationale and Discussion

Tertiary care input can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on treatment (drug or non drug treatments such as surgery or diet), epilepsy combined with other complicated medical conditions or psychological problems.

Access to a tertiary specialist does not necessarily involve referral to a tertiary service and in many cases it may be more effective and patient-centred to provide tertiary input through case discussion with a tertiary specialist or through locally held joint clinics with input from both the local paediatrician with an interest in epilepsy and a tertiary epilepsy specialist.

Input from tertiary services should be considered when one or more of the following criteria are present:

- There is diagnostic uncertainty as to the nature of the seizures or the seizure syndrome
- The epilepsy is not controlled with two medications after at least 6 months of treatment.
- The child is under two years of age.
- The child or young person experiences, or is at risk of, unacceptable side effects from medication.
- There is a unilateral structural lesion.
- There is psychological or psychiatric comorbidity.

A tertiary care specialist in epilepsy is an adult or paediatric neurologist who devotes the majority of their working time to epilepsy, is working in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review.

Statement 9

Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Rationale and Discussion

Reviews are important in ensuring that ongoing interventions are effective in meeting the needs of children and young people and to identify any changes in how their epilepsy is being controlled. They also ensure that epilepsy care plans remain relevant and up-to-date.

A structured review should cover all aspects of the child's or young person's epilepsy care, including medical history and a review of their treatment and

diagnosis. The physical, psychological and social needs of children and young people with epilepsy should always be considered by healthcare professionals. Attention should be paid to their relationships with family and friends, and at school.

For children and young people, the maximum interval between reviews should be one year, but the frequency of reviews should be determined by the child's or young person's epilepsy, their wishes and the wishes of their family and/or carers. The interval between reviews should be agreed between the child or young person, their family and/or carers as appropriate, and the paediatric epilepsy specialist, but is likely to be between three and twelve months.

A person with epilepsy who has been seizure free without medication for six months or more does not require an annual review but needs to be given contact details for the epilepsy service in case their circumstances change and they need to re-engage with epilepsy services. There should be a recall system to ensure that their status can be amended to 'epilepsy resolved' once they meet the ILAE criteria for that (seizure free for ten years and off medication for five years). Anyone who is likely to meet the age threshold for transition to adult services in this time period should be given contact details for adult epilepsy services.

Statement 10. Young people with epilepsy have an agreed transition period where review accommodates the needs of teenagers culminating in a formal joint handover to adult services.

Rationale and Discussion

During the transition from paediatric to adult services it is particularly important for young people managing the physical and mental transition from adolescence to adulthood to have continuity of care. Good management of this transition period by healthcare professionals is vital to develop and maintain the self-esteem and confidence of the adolescent with epilepsy. Managed transition also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood.

Transition needs to be seen as a process over a period of time rather than as an event. During the transition period, teenagers with epilepsy need to be supported, ensuring that they are prepared for the differences in how adult services operate compared to children's services. The transition process should lead to a joint handover with input from both paediatric and adult services (which may include a range of adult destination services, e.g. primary care, learning disabilities, adult neurology etc).

Statement 11. Children and young people with epilepsy have their mental health and wellbeing needs assessed and have access to appropriate psychological support to meet their identified needs.

Rationale and Discussion

Long term conditions in general, and epilepsy in particular, are associated with significant rates of mental health issues, which may adversely impact on the child's / young person's quality of life, wellbeing, educational attainment and effective self-management. Many epilepsies are also associated with a range of mental health related co-morbidities. It is therefore vital that mental health needs are identified early and addressed appropriately, which may include generic interventions or bespoke solutions tailored to the individual's circumstances.

This care quality standard was produced by the Scottish Paediatric Epilepsy Network. It was adapted from [NICE Quality Standard 27: Epilepsy in children and young people](#) with modifications to reflect the specific circumstances in Scotland.

Final Version (Version 1), March 2018.

Revision date: March 2020.