NATIONAL INSTITUTE FOR HEALTH AND
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Quality standards

Briefing paper: Epilepsy (update)

**Quality Standards Advisory Committee meeting**: 11 October 2022

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas to update the epilepsy quality standard. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

Recommendations selected from the key development source are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development source referenced in this briefing paper is:

[Epilepsies in children, young people and adults. NICE guideline NG217](https://www.nice.org.uk/guidance/ng217) (2022).

1. Overview
	1. Focus of quality standard

This quality standard will cover diagnosing and managing epilepsy in children, young people and adults in primary and secondary care, and referral to tertiary services. It will update and replace the existing NICE quality standards on [Epilepsy in children and young people](https://www.nice.org.uk/guidance/qs27) (QS27) and [Epilepsy in adults](https://www.nice.org.uk/guidance/qs26) (QS26) which published in 2013.

The topic was identified for update because the key development source, NICE’s guideline on Epilepsies: Diagnosis and management (CG137), has been updated and replaced by [Epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) (NG217).

* 1. Definition

Epilepsy is a neurological disorder in which a person experiences recurring seizures. The [International League Against Epilepsy](https://www.ilae.org/guidelines/definition-and-classification/definition-of-epilepsy-2014) describes epilepsy as a disease of the brain defined by any of the following conditions:

* At least two unprovoked seizures occurring more than 24 hours apart.
* One unprovoked seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
* Diagnosis of an epilepsy syndrome: a characteristic cluster of clinical and electroencephalogram (EEG) features, often supported by specific etiological findings (structural, genetic, metabolic, immune, and infectious).

A seizure is the transient occurrence of signs or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. [Epilepsy Society web pages](https://epilepsysociety.org.uk/about-epilepsy/epileptic-seizures/seizure-types) describe how seizures are divided into groups depending on:

* where they start in the brain (onset)
* whether or not a person's awareness is affected
* whether or not seizures involve other symptoms, such as movement

Depending on where they start, seizures are described as being focal onset, generalised onset or unknown onset.

* 1. Incidence and prevalence

Epilepsy is one of the most common serious neurological disorders, affecting around 50 million people worldwide and about 533,000 in England and Wales. Of these, around 112,000 are children and young people. The incidence of epilepsy is estimated to be 50 per 100,000 per year and the prevalence of active epilepsy in the UK is estimated to be 5 to 10 people per 1,000. Epilepsy is also a common cause of people attending A&E departments. Epileptic seizures can result in injury, and may also be associated with mortality, for example, because of sudden unexpected death in epilepsy (SUDEP).

* 1. Current service delivery and management

Most people with active epilepsy (60% to 70%) have their seizures satisfactorily controlled with antiseizure medications. Other treatment options may include surgery, vagus nerve stimulation, and psychological and dietary therapies. Optimal management improves health and wellbeing, including reducing the impact of epilepsy on social activities, education and career choices, and reduces the risk of SUDEP.

The original NICE guideline on epilepsy (2004) stated that the annual estimated cost of established epilepsy was £2 billion (direct and indirect costs). However, newer and more expensive antiseizure medications are now being prescribed.

* 1. Resource impact

Resource impact work undertaken to support the clinical guideline concluded that most of the recommendations in the guideline reinforce best practice and do not need any additional resources to implement. However, some of the guideline areas and recommendations may represent a change to current local practice. Where a change is required to current practice, this may require additional resources to implement, which may be significant at a local level. Benefits derived from the change in practice may help mitigate any additional costs.

1. Summary of suggestions
	1. Responses

In total 29 registered stakeholders and specialist committee members responded to the 4-week engagement exercise.

* 19 stakeholders suggested areas
* 2 stakeholders had no comments

8 specialist committee members suggested areas

The responses have been summarised in table 1 for further consideration by the committee.

NHS England’s patient safety team submitted a response suggesting an area for quality improvement during stakeholder engagement. It is included in the summary in this paper and can be found in full in appendix 1.

Table 1 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders  |
| --- | --- |
| **Diagnosis & assessment** |  |
| * Referral for assessment
 | Ep Action, Glut 1 Def, SCM5 |
| * Specialist assessment and diagnosis
 | ABN, Kent CHF NHST, LivaNova, NHSE- CYPTP, Ring20, SCM1, SCM4, SCM5, SCM6, SCM 7 |
| Referral to tertiary specialist services | Ang Pharma, Ep Action, Glut1 Def, Intractable Ep, LivaNova, NHSE, NHSE - CYPTP, Ring20, SCM1, SCM3, SCM5, SCM7, SCM8 Young Ep, UK Rare Ep |
| Treatment |  |
| * Treating status epilepticus, repeated or cluster seizures, and prolonged seizures
 | Ang Pharma, ABN, Glut1 Def, SCM2, SCM8 |
| * Antiseizure medications for women and girls / preconception care
 | ABN, FSRH CEU, NPPG, NPST, RCPCH, SCM2, SCM5 |
| * Other treatment
 | Intractable Ep, Jazz Pharma |
| Management & service provision |  |
| * Access to an epilepsy specialist nurse
 | Ep Action, Kent CH NHST, LivaNova, NHSE, NHSE - CYPTP, Ring20, SCM1, SCM3, SCM4, SCM6, SCM7, UHB, Young Ep, UK Rare Ep |
| * Comprehensive care plan
 | Ep Action, Glut1 Def, Jazz Pharma, Young Ep, UK Rare Ep |
| * Patient centred care, support and information
 | Kent CH NHST, RCPCH, SCM2, SCM8 |
| * Transition to adult services
 | Ep Action, Glut1 Def, Jazz Pharma, Kent CH NHST, NHSE- CYPT, Programme, Ring20, SCM2, SCM3, SCM8, Young Ep, UK Rare Ep |
| * Other areas of management
 | Ang Pharma, ABN, Ring20, SCM6 |
| Psychological, neurobehavioural, cognitive and developmental comorbidities |  |
| * Screening for mental health problems, referral and support
 | NHSE- CYPTP, SCM1, SCM3, SCM7, Young Ep, UK Rare Ep |
| * Care of people with psychological, neurobehavioural, cognitive and developmental comorbidities
 | NHSE, RCPCH, SCM2, SCM3, SCM4, SCM7, SCM8, UHB |
| Additional areas |  |
| * Audits, registry and national database
 | Jazz Pharmaceuticals, Matthew’s Friends |
| * Research and evidence
 | RCPCH, Matthew’s Friends |
| * Evidence based formularies and prescribing
 | Ang Pharma |
| * Digital and AI technologies
 | NHSE |
| **No comments** | RCGP, RCN |

Abbreviations:

* Ang Pharma, Angelini Pharma UK-I Ltd
* ABN, Association of British Neurologists
* Ep Action, Epilepsy Action
* FSRH CEU, Faculty of Sexual and Reproductive Healthcare Clinical Effectiveness Unit
* Glut1 Def, Glut1 Deficiency UK
* Intractable Ep
* Jazz Pharma, Jazz Pharmaceuticals
* Kent CHF NHST, Kent Community Health Foundation NHS Trust
* LivaNova, LivaNova PLC
* Matthew’s Friends, Matthew’s Friends for Ketogenic Dietary Therapies
* NPPG, Neonatal and Paediatric Pharmacists Group
* NPST, National Patient Safety Team (NHS England)
* NHSE, NHS England
* NHSE CYPTP, NHS England - Children and Young People’s Transformation Programme
* Ring20, Ring20 Research and Support UK CIO
* RCGP, Royal College of General Practitioners
* RCN, Royal College of Nursing
* RCPCH, Royal College of Paediatrics and Child Health
* SCM1 to SCM8, Specialist Committee Members
* UHB, University Hospitals Birmingham
* Young Ep, Young Epilepsy
* UK Rare Ep, UK Rare Epilepsies Together

Full details of all the suggestions provided are given in appendix 1 for information.

1. Suggested improvement areas

Section 4 presents a summary of the suggested improvement areas, with provisional recommendations that may support statement development and information on current UK practice.

* 1. Diagnosis and assessment

### Referral for assessment

Stakeholders suggested that people of all ages with suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

1.1.1 Refer children, young people and adults urgently (for an appointment within 2 weeks) for an assessment after a first suspected seizure:

* For adults, refer to a clinician with expertise in assessing first seizures and diagnosing epilepsy.
* For children and young people, refer to a paediatrician with expertise in assessing first seizures and diagnosing epilepsy.

#### Current quality statements

Epilepsy in adults (QS26) statement 1: Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Epilepsy in children and young people (QS27) statement 1: Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

#### Current UK practice

[Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) is a national clinical audit of seizures and epilepsies for children and young people commissioned by Healthcare Quality Improvement Partnership (HQIP). Round 3 of the audit began 2017. It follows a cohort of children and young people for 12 months of care following a first paediatric assessment for a seizure. The 2022 report covers cohort 3; those who had an assessment for a suspected seizure between 1 December 2019 and 30 November 2020. Epilepsy 12 2022 also includes an organisational audit of paediatric epilepsy services as they were in November 2021.

The clinical audit reported that 23% (457/1974) of children and young people diagnosed with epilepsy were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral. Note that 22% of the 1974 records did not have a ‘valid date’ entered for referral.

Although the proportion seen within 2 weeks is low, it has increased compared to previous cohorts: from 16% in cohort 1 and from 19% in cohort 2. Cohort 1 covered children and young people assessed 12 July 2018 – 30 November 2018; cohort 2 covered those assessed 1 December 2018 and 30 November 2019.

The [National Audit of Seizure management in Hospitals third report](https://www.nashstudy.org.uk/Newsletters.aspx) presents data on adults that presented with a seizure to Type 1 emergency departments (EDs) from 1 June 2018 to 30 June 2019. Data was collected for 4,132 patients presenting to 137 EDs.

For adults presenting with a first suspected seizure, onward referral was made for 63.6% of patients. Referral was either direct from the ED, or via a request to the GP to arrange it. For those referred, the median time to an appointment was over 5 weeks (39 days). The report commented ‘Disappointingly, over one third of patients were not put on a pathway to see a seizure specialist’.

### Specialist assessment and diagnosis

Stakeholders suggested investigations as an area for quality improvement to help ensure correct diagnosis and appropriate and timely management. Some suggestions referenced specific tests including EEG, EEG telemetry, electrocardiogram (ECG), magnetic resonance imaging (MRI), antibody testing, genetic testing and whole genome sequencing. Some stakeholders focussed on access and wait times, suggesting tests within 4 weeks, EEGs within 4 weeks, and MRI scans within 6 weeks.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

1.2.2 Evaluate people after a first suspected seizure with a 12-lead ECG to help identify cardiac-related conditions that could mimic an epileptic seizure.

1.2.5 If the person's history and examination suggests an epileptic seizure, and a diagnosis of epilepsy is suspected, consider a routine EEG carried out while awake to support diagnosis and provide information about seizure type or epilepsy syndrome.

1.2.7 If an EEG is requested after a first seizure, perform it as soon as possible (ideally within 72 hours after the seizure).

1.2.10 If routine and sleep-deprived EEG results are normal and diagnostic uncertainty persists, consider ambulatory EEG (for up to 48 hours).

1.3.1 Offer an MRI scan to children, young people and adults diagnosed with epilepsy, unless they have idiopathic generalised epilepsy or self-limited epilepsy with centrotemporal spikes. The MRI should be carried out:

* within 6 weeks of the MRI referral and
* following regionally agreed epilepsy MRI protocols.

1.4.1 Discuss with a neurologist or geneticist any uncertainties about whether to offer genetic testing or which tests to offer to a person with epilepsy.

1.4.2 When making decisions about which tests to offer, refer to the NHS National Genomic Test Directory for rare and inherited disease for information on genetic tests commissioned by the NHS in England.

1.4.3 Before carrying out genetic tests:

* discuss the purpose of testing and the possible implications of the results with the person with epilepsy, and their family and carers if appropriate
* obtain informed consent with appropriate genetic counselling in line with the NHS Genomic Medicine Service.

#### Current quality statements

Epilepsy in adults (QS26) statement 2: Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Epilepsy in children and young people (QS27) statement 2: Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Note that the 4-week timeframe is no longer supported by NICE’s guideline on epilepsy (NG217).

Epilepsy in adults (QS26) statement 3: Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Epilepsy in children and young people (QS27) statement 3: Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

#### Current UK practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical audit reported that for cohort 3, 54% (1058/1974) of children and young people diagnosed with epilepsy had their initial EEG within four weeks of request. 10% of children and young people waited more than 16 weeks for their first EEG.

During their first year of care:

* 98% (1931/1974) of children and young people with epilepsy received an EEG.
* An MRI was achieved for 71% (328/459) of the patients meeting the defined indications for an MRI.
* 69% (840/1218) of children and young people diagnosed with epilepsy and had convulsive seizures, obtained a 12 lead ECG by the first year in England and Wales.
* 5% (101/1974) of children and young people diagnosed with epilepsy had input from a genetics service.

No current practice information was identified for adults.

### Resource impact

No resource impact is anticipated from these recommendations. These recommendations in the epilepsies guideline reinforce best practice and do not need any additional resources to implement.

### Issues for consideration

**For discussion:**

* What is the priority for quality improvement?
* What are the key actions that will lead to improvement?
* Out of the tests suggested such as ECG, EEG, MRI and genetic testing, which are the priority for quality improvement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
	1. Referral to tertiary specialist services

Improved access to tertiary services was raised as a key area for quality improvement by stakeholders. Comments stated that people are struggling to get appointments with long waits experienced and not all those meeting the criteria for tertiary services are being referred. Some stakeholders suggested that referral for tertiary services should be within specified timescales if referral criteria set out in NG217 are met. The criteria aim to ensure that people with epilepsy that is difficult to diagnose or manage, and particular groups of children, receive the specialist care and treatment they need including consideration for clinical trials. It was recognised that there are different criteria and timescales for children and adults. Some described this key area as important as tertiary services provide access to specialists, medicines, emerging treatments and non-pharmacological treatments including surgery, vagus nerve stimulation and a ketogenic diet.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

3.1.1 Ensure that all children, young people and adults with suspected or confirmed epilepsy have access to a tertiary epilepsy service, if needed, via their specialist.

3.1.3 Refer people with epilepsy to a tertiary epilepsy service, to be seen within 4 weeks, if any of the following apply:

* uncertainty about the diagnosis or cause of epilepsy, the seizure type or epilepsy syndrome
* the person has an epilepsy syndrome likely to be drug resistant, their seizures are drug resistant or their treatment is associated with intolerable side effects
* further assessment and treatment approaches are indicated, such as: video electroencephalogram (EEG) telemetry, neuropsychology or neuropsychiatry, specialised neuroimaging, specialised treatments (for example, medication that can only be prescribed by a tertiary epilepsy serice or a ketogenic diet), epilepsy surgery or vagus nerve stimulation
* the person is eligible for and wishes to participate in a clinical trial or research study.

3.1.4 Refer children with suspected or confirmed epilepsy to a tertiary paediatric epilepsy service to be seen within 2 weeks, if they:

* are aged under 3 years
* are aged under 4 years and have myoclonic seizures (see recommendation 5.4.1 in the section on myoclonic seizures)
* have a unilateral structural lesion
* are showing deterioration in their behaviour, speech or learning.

8.2.2 Refer people with drug-resistant epilepsy, including those without identified MRI abnormalities, for consideration of assessment for resective epilepsy surgery:

* For adults, this should be to a tertiary epilepsy service.
* For children and young people, this should be to a tertiary paediatric neurology service for consideration of referral to a children's epilepsy service surgery centre.

8.2.3 For people with MRI abnormalities that indicate a high risk of drug-resistant epilepsy, consider early referral to a tertiary epilepsy service for assessment, including an evaluation for resective epilepsy surgery if appropriate. Examples of specific lesions seen on MRI may include, but are not limited to, the following:

* hippocampal sclerosis
* malformations of cortical development
* epilepsy-associated low-grade tumours
* hypothalamic hamartomas
* neuronal migrational disorders
* tuberous sclerosis complex
* vascular malformations, including Sturge–Weber syndrome
* cerebral contusions from previous head injury.

8.2.4 Do not exclude people with learning disabilities or underlying genetic abnormalities from referral for resective epilepsy surgery assessment if it is indicated.

#### Current quality statements

Epilepsy in adults (QS26) statement7: Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Epilepsy in children and young people (QS27) statement 7: Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

The criteria and timescales for referral are different to those in NICEs current guideline on epilepsy (NG217) as they are based on the old version of the guideline.

#### Current UK practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical audit reported that:

* 67% (195/290) of children and young people who met the criteria for referral to a paediatric neurologist, were seen within four weeks of referral in England and Wales.
* 64% (305/480) of children and young people who met paediatric neurology referral criteria received tertiary input during their first year of care, i.e. had either paediatric neurologist input or had been referred to Children’s Epilepsy Surgery Service (CESS).
* 7% (135/1974) of children and young people diagnosed with epilepsy, met one or more of the CESS referral criteria in England and Wales in Cohort 3. Of these, 28% (38/135) had a referral for surgical evaluation during their first year of care.

Resource impact

Depending on current local practice, referral of all people with drug-resistant epilepsy to surgical centres (as per NG217 recommendation 8.2.2) will probably lead to an increase in presurgical investigations and surgical procedures. This may necessitate the need for more epilepsy surgical training and a greater investment in epilepsy surgery programmes.

Issues for consideration

**For discussion:**

* Is the priority for improvement access to all tertiary services or is it a specific service such as surgery?
* Is the timescale for referral an important focus?
* Is a statement on this more important for adults or children; or is it equally important for both?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
	1. Treatment

### Treating status epilepticus, repeated or cluster seizures, and prolonged seizures

Stakeholders said that people with a history of prolonged or repeated seizures should have an agreed written emergency care plan. Status epilepticus was also suggested as a key area because it is a life and brain threatening condition requiring rapid and appropriate treatment. Comments highlighted that definitions of prolonged and status epilepticus have changed in NICE’s guideline on epilepsies (NG217); all seizures lasting longer than 5 minutes now constitute status epilepticus.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

7.1.1 Provide resuscitation and immediate emergency treatment for children, young people and adults who have convulsive status epilepticus (seizures lasting 5 minutes or more).

7.1.2 If the person with convulsive status epilepticus has an individualised emergency management plan that is immediately available, administer medication as detailed in the plan.

7.1.3 If the person with convulsive status epilepticus does not have an individualised emergency management plan immediately available:

* give a benzodiazepine (buccal midazolam or rectal diazepam) immediately as first-line treatment in the community or
* use intravenous lorazepam if intravenous access and resuscitation facilities are immediately available.

7.1.12 After an episode of convulsive status epilepticus, agree an emergency management plan with the person if they do not already have one and there is concern that status epilepticus may recur.

7.2.2 If a person has repeated or cluster seizures:

* follow their individualised emergency management plan, if this is immediately available or
* consider giving a benzodiazepine, such as clobazam or midazolam, immediately if they do not have an individualised emergency management plan immediately available.

7.2.4 Agree an individualised emergency management plan with the person after repeated or cluster seizures if they do not have one already and there is concern that repeated or cluster seizures may recur.

7.3.2 If a person has a prolonged convulsive seizure:

* follow their individualised emergency management plan if this is immediately available or
* consider giving a benzodiazepine, such as midazolam or clobazam, immediately if they do not have an individualised emergency management plan immediately available.

7.3.3 After a prolonged convulsive seizure, agree an emergency management plan with the person if they do not already have one and there is concern that prolonged convulsive seizures may recur.

7.3.4 After a prolonged non-convulsive seizure (a non-convulsive seizure that continues for more than 2 minutes longer than a person's usual seizure), agree an emergency management plan with the person if they do not already have one and there is concern that prolonged non-convulsive seizures may recur.

#### Current quality statements

Epilepsy in adults (QS26) statement 6: Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Epilepsy in children and young people (QS27) statement 6: Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Some stakeholders said these statements remain important.

#### Current UK practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical audit reported that 22% (439/1974) of the children and young people diagnosed with epilepsy, had rescue medication prescribed in England and Wales in Cohort 3. Rescue medication is mediation given to a person when they are having prolonged or repeated seizures to stop status epilepticus from happening. It is usually either rectal diazepam or buccal midazolam.

The report also showed that 92% (406/431) of children and young people diagnosed with epilepsy and on rescue medication, had a parental prolonged seizure care plan.

### Antiseizure medications for women and girls / preconception care

Stakeholders said that many women are not aware of the risks to an unborn child of taking antiseizure medications during pregnancy (such as congenital malformations and neurodevelopmental impairments) or how they interact with oral contraceptives. Valproate was specifically identified by some with comments stating that a ‘concerning’ number of pregnancies are still exposed to valproate despite MHRA safety advice and the pregnancy prevention programme (valproate must not be prescribed to women or girls of childbearing potential unless they are on the programme). Suggested actions to address these areas included making women and girls aware of the risks, assessing and reviewing risks, and reducing or avoiding antiseizure medication risk.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

4.4.2 Discuss with women and girls with epilepsy who are able to have children (including young girls who are likely to need treatment when they are able to have children), and their families or carers if appropriate, the risks to an unborn child of taking antiseizure medications during pregnancy, such as congenital malformations, neurodevelopmental impairments and fetal growth restriction.

4.4.3 Assess the risks and benefits of treatment with individual antiseizure medications when prescribing antiseizure medications for women and girls who are able to have children, now or in the future. Take into account the latest data on the risks to the unborn child and be aware that there are important uncertainties about the risks, particularly with newer drugs. Follow the MHRA safety advice on antiepileptic drugs in pregnancy.

4.4.4Specifically, discuss the risks to the unborn child of using sodium valproate during pregnancy, including the increased risk with higher doses and polytherapy. Follow the MHRA safety advice on valproate use by women and girls.

#### Current Practice

[Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) report noted that all females able to have children must be enrolled in a pregnancy prevention programme to be prescribed sodium valproate, but found there were a small number of patients in Cohort 3 where this was not recorded.

The clinical audit reported a much smaller proportion of female children and young people were on valproate compared to males: 21% (120/584) of children and young people receiving it were female.

40% of children and young women aged 9 and above prescribed sodium valproate had evidence of discussion of risk regarding the risks of birth defects and/or neurodevelopmental outcomes. Further breakdown by age is not available to protect patient confidentiality as the numbers involved are small.

The [Community Pharmacy Quality Scheme 2019/20 Valproate Audit Report](https://www.england.nhs.uk/wp-content/uploads/2022/07/B1504_Community-Pharmacy-Quality-Scheme-2019-20-valproate-audit-report-July-2022.pdf) presents information from a national community pharmacy audit of patients who could get pregnant and were prescribed valproate. The audit covered all female patients of childbearing age dispensed valproate once in three consecutive months in 2019/20. 10,293 community pharmacies (almost 90% of pharmacies) conducted the audit and 12,068 patients / patient representatives agreed to take part. Women of childbearing age treated with valproate must be reviewed at least annually by the specialist or GP prescribing this medicine, but 17.7% of participants in this audit reported that they had not had a review with their specialist or GP in the last 12 months to discuss valproate and the need for appropriate contraception.

[Epilepsy Action worked with Epilepsy Society and Young Epilepsy to conduct a survey of women](https://www.epilepsy.org.uk/involved/campaigns/sodium-valproate/survey) who have taken or who are taking valproate, since the introduction of the pregnancy prevention programme. They surveyed women between October 2019 and January 2020 who had taken valproate since the introduction of the PPP in August 2018. 751 responses were received, of which 519 were taking valproate at the time of the survey. Of these:

* 11% of respondents were unaware that taking valproate in pregnancy can, in some cases, cause serious birth defects
* 55% had had a discussion with a health professional about valproate since 1 August 2018
* Of the women who saw a healthcare professional in the last year, 25% reported that their GP did not discuss valproate, 21% said their paediatrician or neurologist did not discuss valproate, and 16% said their epilepsy specialist nurse did not discuss valproate.

### Other treatment

Other key areas for quality improvement suggested by stakeholders included ‘cannabis oils’ for medical use with comments suggesting that these are being made available to those being treated privately, but not to those treated through the NHS. Access to Epidyolex, a cannabidiol, was specifically described as difficult to obtain via the NHS. Another area for quality improvement suggested were treatment protocols for complex epilepsy.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

6.1.5 If triple therapy is unsuccessful for Dravet syndrome and the child is over 2 years, consider cannabidiol in combination with clobazam as a second-line add-on treatment option in line with [NICE's technology appraisal guidance on cannabidiol with clobazam for treating seizures associated with Dravet syndrome](https://www.nice.org.uk/guidance/ta614).

6.2.5 If second-line treatment is unsuccessful, consider the following as third-line add-on treatment options for people with Lennox–Gastaut syndrome:

* cannabidiol in combination with clobazam if the child is over 2 years, in line with [NICE's technology appraisal guidance on cannabidiol with clobazam for treating seizures associated with Lennox–Gastaut syndrome](https://www.nice.org.uk/guidance/ta615)
* clobazam
* rufinamide
* topiramate.

In April 2022, these were off-label uses of clobazam as add-on therapy in children under 6 months, rufinamide in children under 1 year, and topiramate in children under 2 years. See NICE's information on prescribing medicines.

Research recommendation 2: Complex epilepsy syndromes

What antiseizure therapies (alternative or add-on) are effective in the treatment of complex epilepsy syndromes (that is, Dravet syndrome, Lennox–Gastaut syndrome, infantile spams syndrome and epilepsy with myoclonic-atonic seizures [Doose syndrome]) when first-line therapy is unsuccessful or not tolerated?

#### Current Practice

An [answer to a written parliamentary question submitted by Lord Field of Birkenhead](https://members.parliament.uk/member/478/writtenquestions#expand-1487674) showed the number of items for licensed cannabis-based medicines prescribed on a National Health Service prescription, dispensed in the community and submitted to the NHS Business Services Authority since 2018. The figures show that the number has increased from 2,591 items in 2018 to 2,981 items in 2021. The information also shows the number of items for licensed and unlicensed cannabis-based medicines prescribed on a private prescription. In 2021 there were 28 private prescription items dispensed for licensed cannabis-based medicines and 42,393 private prescription items dispensed for unlicensed cannabis-based medicines.

Resource impact

Depending on current local practice, the provision of reviews and support for women and girls with epilepsy varies at the present time and so the recommendations are likely to have an impact on practice with an increase in regular reviews (NG217 recommendations 4.4.1 to 4.4.8).

Issues for consideration

**For discussion:**

* What is the priority for improvement?
* What is the key action that will lead to improvement?
* Can we develop a measurable statement for that action? Note that the only recommendations for cannabidiol are ‘consider’ statements so cannot be measured.

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
	1. Management and service provision

### Access to an epilepsy specialist nurse

Stakeholders suggested access to an epilepsy specialist nurse as an area for a quality statement. Comments suggested a specialist nurse can provide education and support; be point of contact, especially between scheduled reviews; support continuity of care; enable access to other services; support self-management; and play a key role in transition to adult services. Providing access to epilepsy specialist nurses can reduce emergency admissions, generate cost savings and improve quality of life. Some stakeholders described problems with existing access: not everyone with epilepsy has access to a specialist nurse; provision is fragmented; there is variation in the nurse’s role; and not everyone is getting appointments after A&E visits. An open access model was also suggested to provide a more responsive service, where patients contact an epilepsy specialist nurse who will then assess if an appointment is needed or provide advice and treatment over the telephone.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

11.1.1 Ensure that all children, young people and adults with epilepsy have access to an epilepsy specialist nurse who:

* has a central role in providing information, education and support (see box 1 for information that should be covered)
* supports epilepsy specialists and healthcare professionals in primary and secondary care, and in educational, respite and social care settings
* is a point of contact for, and facilitates access to, other community and multi-agency services.

11.1.2 Offer people with epilepsy an information and care-planning session with an epilepsy specialist nurse that includes emotional wellbeing and self-management strategies promoting inclusion and participation.

11.1.3 For people with epilepsy who continue to have seizures, offer epilepsy specialist nurse sessions:

* at least twice a year and
* after A&E department visits.

#### Current quality statements

Epilepsy in adults (QS26) statement 5: Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Epilepsy in children and young people (QS27) statement 5: Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

#### Current Practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical and organisational audits identified that:

* 72% (1420/1974) of children and young people diagnosed with epilepsy had input from an epilepsy specialist nurse in their first year of care.
* 80% (1579/1974) of children and young people diagnosed with epilepsy had an input from an epilepsy specialist nurse.
* 89% (102/115) of Health Boards and Trusts employed some epilepsy specialist nurse provision within their paediatric service.

Young Epilepsy’s [young people’s changing experiences of epilepsy care survey](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) gathered information from people with epilepsy aged 11 to 25. The survey looked at how their experience of epilepsy care changed as they grew older and transitioned to adult services. There were 207 survey responses from young people with epilepsy across the UK, between 27 November 2020 and 18 January 2021. The survey results showed that more young people had contact with an epilepsy specialist nurse in children’s services (79.4%) compared to adult epilepsy care (73.1%).

The [National Audit of Seizure management in Hospitals third report](https://www.nashstudy.org.uk/Newsletters.aspx) identified that only 15% of adults with an existing epilepsy diagnosis who presented with a seizure to emergency departments between June 2018 and 30 June 2019 had seen an epilepsy specialist nurse in the previous year.

The [Neurology GIRFT Programme National Specialty Report 2021](https://future.nhs.uk/GIRFTNational/view?objectId=30318096) identified that there are 172 epilepsy specialist nurses working in England based on the results from a questionnaire. At 57 sites of 210 sites with neurological services, there were no hospital or community-based specialist nurses. The report recognised the nature of the role varies and said there is no clear-cut route of entry and no single qualification required to become an epilepsy nurse. It noted that hospital-based specialist nurses are usually linked closely to the neurology team and provide services to patients who attend the hospital whereas specialist nurses working in the community tend to be locality based, providing services to patients within the boundaries of one CCG.

### Comprehensive care plan

Stakeholders suggested that people with epilepsy should have an agreed and comprehensive written epilepsy care plan. Some comments suggested what the plan should include and how it should be developed such as, discussions on risks of valproate, SUDEP, and information for families. The benefits of a plan identified included ensuring continuity of support across settings and between professionals. According to comments, not all children with epilepsy have a care plan.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

2.1.7 Provide the person with epilepsy, and their family or carers if appropriate, with a copy of their care plan, which includes details of their care and support as discussed and agreed with the person, and their family or carers if appropriate.

#### Current quality statements

Epilepsy in adults (QS26) statement 4: Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

Epilepsy in children and young people (QS27) statement 4: Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.

#### Current UK practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical audit reported that:

* 70% (1379/1974) of children and young people diagnosed with epilepsy, had evidence of a comprehensive care plan that had been updated where necessary and agreed between the child, their family and their primary and secondary care provider for the first year of care.
* 75% (1487/1974) of children and young people diagnosed with epilepsy had documented evidence of communication regarding core elements of care planning.
* 47% (925/1974) of children and young people diagnosed with epilepsy did not have evidence of SUDEP information being provided in Cohort 3.

The organisational audit reported:

* 89% of Health Boards and Trusts said they that routinely undertake comprehensive care planning for children and young people with epilepsy in November 2021.

The [National Neuro Patient Experience Survey 2021/22](https://www.neural.org.uk/togetherforthe1in6/) (‘My Neuro Survey’) provides information on the experiences of people living with a neurological condition in the UK. The most recent survey was conducted in clinics and using an online survey. Data were collected from 25 October 2021 to 6 February 2022. There were 7,881 responses from adults and 629 responses from children. Of these, 1006 adults and 179 children had epilepsy. The technical report presents information for specific neurological conditions, including epilepsy. The survey identified that:

* 31% (273/889) of adult respondents with epilepsy had been offered a care and support plan to help them manage their neurological condition.
* 51% (80/156) of paediatric respondents with epilepsy had been offered a care and support plan to help them manage their neurological condition.

### Patient centred care, support and information

Stakeholders suggested a range of key areas for quality improvement including patient centred care to improve outcomes and treating people with compassion, dignity, and respect. Some comments focussed on information and communication; giving people information to promote active participation in their care and self-management, communicating complex information to people with epilepsy, and discussing risk of epilepsy-related death, including SUDEP.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

2.1.2 Provide tailored information and support to people with epilepsy, and their families or carers if appropriate, according to their individual needs and circumstances.

2.1.6 Support people to self-manage their epilepsy and make informed choices by discussing the following issues with them during their first appointment:

* triggers that may provoke seizures
* medications for epilepsy, the importance of adherence to medication and possible side effects
* reducing epilepsy-related risks, including sudden unexpected death in epilepsy (SUDEP)
* impact on daily activities, including driving
* their epilepsy syndrome or seizure types.

The discussion may be reiterated at an information and care-planning session with an epilepsy specialist nurse (see also the section on epilepsy specialist nurses).

2.1.11 Offer people with epilepsy, and their families and carers if appropriate, opportunities at each appointment to discuss issues that concern them including, but not limited to, the topics in box 1.

[Box 1 lists topics to discuss with people with epilepsy and their families and carers and includes activities of daily living, carers, cognition, medication, mental health, reproductive health and pregnancy and SUDEP.]

10.1.4 Discuss with people with epilepsy, and their families and carers if appropriate, their individual risk of epilepsy-related death, including SUDEP, from the time of diagnosis onwards. For young children, this discussion should be with the child's parents or carers. Discussion should include:

* supporting them to understand the risks of epilepsy-related death, including SUDEP
* exploring and agreeing ways to reduce the risks.

10.1.5 Discuss the risk of SUDEP with people who have seizures during sleep and, if appropriate, include their families and carers. Provide information on minimising risks, including taking their medication as prescribed.

#### Current Practice

The [National Neuro Patient Experience Survey 2021/22](https://www.neural.org.uk/togetherforthe1in6/) found that:

* 38% of adult respondents with epilepsy considered their health and care to be joined up and centred on their priorities.
* 45% of adult respondents with epilepsy said information about their condition is effectively passed between the people that care for them (such as my specialists, GP, family carer).
* 83% (145/174) of paediatric respondents felt fully involved in making choices about their health care (for younger children this might be the extent to which the parent is included to make decisions).

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical audit reported that:

* 47% (925/1974) of children and young people diagnosed with epilepsy did not have evidence of SUDEP information being provided in Cohort 3.
* 85% (1686/1974) of children diagnosed with epilepsy had evidence of discussion regarding general participation and risk.
* 93% (1827/1974) of children diagnosed with epilepsy had evidence of discussion of service contact details.

### Transition to adult services

Stakeholders suggested transition to adult services as a key area for improvement with several highlighting the importance of the process involving a joint review by paediatric and adult services. Comments noted there have been some improvements in transition over recent years, but there still variation across the country; sometimes there is no joint involvement prior to transfer to adult services and some groups of young people are missing out on transition. Transition was described as important to ensure continuing epilepsy care and it provides an opportunity to review the diagnosis, classification, cause and management. Some stakeholders identified specific groups transition is important for including young people who have complex or additional health and social care needs, and those affected by rare and complex epilepsies.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

11.2.2 Ensure transition from children's to adults' epilepsy services is individually tailored to the young person with epilepsy.

11.2.3 Begin planning transition early for young people who have complex or additional health and social care needs, for example young people whose seizures are not yet controlled or those with learning disabilities.

11.2.4 During transition of young people with epilepsy to adult services, the paediatric and adult multidisciplinary teams should jointly review the person's diagnosis and management plan, taking a person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their care.

11.2.5 Ensure that information about the young person's management plan and support for transition to adult services is discussed with the young person with epilepsy and shared in an accessible format that meets their needs and uses language they understand. Repeat this information at different time points to establish that the young person understands their care plan and the support that will be provided.

11.2.6 When discussing transition to adult epilepsy services with the young person, cover any issues of concern to the person, including, but not limited to, the following:

* activities of daily living, including driving and sports
* adherence to antiseizure medication
* comorbidities, such as low mood or impaired memory
* continuing in education or work
* emotional health and psychological wellbeing
* living independently
* possible effects of epilepsy and antiseizure medication on neurodevelopment, cognition and behaviour
* risks associated with alcohol and illicit drugs
* safety and risk (including sudden unexpected death in epilepsy [SUDEP])
* reproductive health, including contraception, pregnancy and teratogenicity
* sleep disturbance
* social aspects of epilepsy, including considering if or when to disclose epilepsy status and managing the impact of possible assumed limitations
* stigmatisation of epilepsy.

#### Current quality statements

Epilepsy in adults (QS26) statement 9: Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Epilepsy in children and young people (QS27) statement 9: Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Transition from children’s to adults’ services (QS140) has 5 statements covering planning, annual meeting, named worker, meeting a practitioner from adult services and missed first adult service appointment.

#### Current Practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) report identified:

* 87% (100/115) Trusts and Health Boards had an agreed referral pathway for young people to transition to adult care.
* 62% (71/115) of Health Boards and Trusts, used structured resources (for example ‘Ready, Steady, Go’) to support patients’ transition to adult services. ‘Ready, Steady, Go’ is a programme to improve the transition to adult care developed by Southampton Children’s Hospital.
* 65% (75/115) of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals.
* 86% (99/115) of Health Boards and Trusts reported that adult neurologists were routinely involved in transition to adult services.
* 65% (75/115) of Health Boards and Trusts reported that adult epilepsy specialist nurses were routinely involved in transition to adult services.

Young Epilepsy’s [young people’s changing experiences of epilepsy care survey](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) based on responses between November 2020 and January 2021 reported that:

* 39.5% of young people said they had no joint appointments with children’s and adults’ epilepsy services as part of the transitions process.
* 32.3% of young people said their experience of moving from children’s to adults’ epilepsy services had a negative impact on their mental health; 52.1% said that the process had no impact on their mental health.

### Other areas of management

Other key areas for quality improvement suggested include:

* Communication between services that see people with epilepsy, as systems used in one setting are often inaccessible in another and it is not always known if a person has been seen by another specialist, attended and emergency department or been seen for a comorbidity.
* Providing multi-disciplinary team care for people with rare and complex epilepsies to ensure coordination across specialisms.
* Children and young people with epilepsy should have a review with a specialist at a frequency which takes account of the nature of their epilepsy.

Continuation of prescribing and ongoing management in primary care for stable patients was also suggested as a key area. This would be achieved through pathways and transition of care protocols. However, there are no recommendations within the source guideline to support a quality statement on this.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

9.1.3 Be aware that children and young people with a complex childhood epilepsy syndrome can have developmental difficulties and cognitive impairment, and may need additional support from a multidisciplinary team.

9.1.4 Ensure effective communication and liaison between healthcare professionals across the relevant services involved in the care of people with epilepsy and a mental health condition to agree and plan care across services.

4.5.2 Discuss monitoring reviews with children and young people with epilepsy and their families and carers if appropriate, and agree a frequency for regular reviews that is:

* individually tailored to the child or young person's needs, preferences and the nature of their epilepsy and
* at least every 12 months.

#### Current quality statements

Patient experience in adult NHS services (QS15) statement 3: People using adult NHS services experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.

#### Current Practice

No national data sources or large scale published studies on current practice have been identified for this suggested area for quality improvement.

Resource impact

No resource impact is anticipated from the recommendations above. These recommendations in the epilepsies guideline (NG217) reinforce best practice and do not need any additional resources to implement.

Issues for consideration

**For discussion:**

* The Epilepsy 12 2020 audit shows over 70% of children and young people have a care plan and have input from an epilepsy specialist nurse. Are these still priority areas for quality improvement?
* Could the priority areas suggested be covered by a single statement? For example, could a statement on an epilepsy specialist nurse also address care plans, patient centred care, communication and transition?
* If not, what is the priority for improvement?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
	1. Psychological, neurobehavioural, cognitive and developmental comorbidities

### Screening for mental health problems, referral and support

Screening for mental health problems was suggested as a key are for quality improvement, and where there are concerns people should be referred to an appropriate mental health service. Stakeholders said there is a higher prevalence of mental health comorbidities in people with epilepsy. However, only a small proportion of NHS trusts routinely screen for this.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

9.2.2 Review neurodevelopment, cognitive function, mental health, social and emotional wellbeing, and learning disabilities as part of the routine management for people with epilepsy.

9.2.3 Offer assessment and provide mental health support and treatment for people with epilepsy and depression in line with NICE's guidelines on depression in adults with a chronic physical health problem and depression in children and young people.

9.2.4 Be alert to anxiety, other mental health difficulties and the risk of suicide in people diagnosed with epilepsy. If mental health difficulties are suspected, consider referral and follow the recommendations in NICE's guidelines on:

* attention deficit hyperactivity disorder
* autism spectrum disorders in under 19s
* autism spectrum disorder in adults
* common mental health problems
* mental health problems in people with learning disabilities
* generalised anxiety disorder and panic disorder in adults
* psychosis and schizophrenia in adults
* psychosis and schizophrenia in children and young people.

#### Current UK practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) clinical and organisational audits reported that:

* 5% (53/1124) of children and young people between the age of 5-15 years diagnosed with epilepsy had an identified mental health condition.
* 74% (85/115) of Health Boards and Trusts had no formal screening services for Attention Deficit Hyperactivity Disorder, Autistic Spectrum Disorder and mental health disorders.
* 69% (79/115) of Health Boards and Trusts have agreed referral pathways for children with mental health conditions. They referred to clinical psychology, psychiatric, educational psychology, neuropsychology, and formal developmental services.
* 6% (7/115) of Health Boards and Trusts could not refer to mental health assessment services, either in or outside of their Health Board or Trust.

Young Epilepsy’s [young people’s changing experiences of epilepsy care survey](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) found 45% of young people (aged 11 to 25) said their epilepsy doctor or nurse had spoken to them about how epilepsy might impact on their mental health.

No current practice information for adults with epilepsy has been identified.

### Care of people with psychological, neurobehavioural, cognitive and developmental comorbidities

Stakeholders suggested personalised care and support to meet the needs of people who have a learning disability, autism or dementia as key areas for quality improvement. Comments described a higher prevalence of epilepsy for people in these groups, variations in the quality of care they received and suggested services and professionals make adjustments to meet their needs and deliver coordinated care.

Improved access to mental health services such as a psychologist, psychotherapy and Child and Adolescent Mental Health services was also suggested as an area for improvement for people with epilepsy. Specific groups suggested as needing access included people with depression, people who have experienced severe psychological trauma, children who have mental health problems, and children with comorbidities including autism and ADHD.

#### Selected recommendations

NICE’s guideline on epilepsies in children, young people and adults (NG217):

2.1.4 Take into account the information and support needs of people with epilepsy who are older, have a learning disability or have other complex needs, for example:

* give longer appointments to allow more time for discussion
* provide information in different formats, such as easy read, large print or audio versions
* involve family members or carers or an advocate if the person wishes
* share information with those involved in the care of older people or people with learning disabilities if appropriate.

3.1.2 Take into account that people with suspected or confirmed epilepsy and a learning disability, physical disability or mental health problem may need additional specialist support to manage their epilepsy. Support them to access a tertiary epilepsy service if needed.

9.1.2 Provide coordinated care for people with epilepsy who have a mental health condition or learning disability using a multidisciplinary team approach.

9.1.4 Ensure effective communication and liaison between healthcare professionals across the relevant services involved in the care of people with epilepsy and a mental health condition to agree and plan care across services.

9.1.5 For people with epilepsy who have a learning disability, a mental health problem or challenging behaviour, or who have dementia, follow the recommendations on coordinating care in NICE's guidelines on mental health problems in people with learning disabilities, challenging behaviour and learning disabilities and dementia.

9.2.2 Review neurodevelopment, cognitive function, mental health, social and emotional wellbeing, and learning disabilities as part of the routine management for people with epilepsy.

9.2.3 Offer assessment and provide mental health support and treatment for people with epilepsy and depression in line with NICE's guidelines on depression in adults with a chronic physical health problem and depression in children and young people.

9.2.4 Be alert to anxiety, other mental health difficulties and the risk of suicide in people diagnosed with epilepsy. If mental health difficulties are suspected, consider referral and follow the recommendations in NICE's guidelines on:

* attention deficit hyperactivity disorder
* autism spectrum disorders in under 19s
* autism spectrum disorder in adults
* common mental health problems
* mental health problems in people with learning disabilities
* generalised anxiety disorder and panic disorder in adults
* psychosis and schizophrenia in adults
* psychosis and schizophrenia in children and young people.

#### Current Practice

The [Epilepsy 12 2022](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022) organisational audit reported the following proportions of Health Boards and Trusts had agreed referral criteria for children and young people with the neuro-developmental condition services for:

* ADHD: 80%
* ASD: 85%
* Behaviour difficulties: 60%
* Developmental coordination disorder: 62%
* Intellectual disability: 56%

13% of Health Boards and Trusts had no agreed referral criteria for children and young people with neurodevelopmental conditions.

No current practice information has been identified for adults with epilepsy.

Resource impact

No resource impact was anticipated from the recommendations above. These recommendations in the epilepsies guideline (NG217) reinforce best practice and do not need any additional resources to implement.

Issues for consideration

**For discussion:**

* What is the key area for quality improvement?
* If the quality improvement is about caring for people, is there a specific group such as people with a learning disability and what is the key action?
* If it is about caring for people, could this be incorporated into a statement on care planning?

**For decision:**

* Should this area be prioritised for inclusion in the quality standard?
	1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard, or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the Advisory Committee meeting.

Table 2 Summary of information available for additional areas

| Suggested area for improvement | Within remit of NICE QS | In scope | Guideline recs | Relevant existing QS  |
| --- | --- | --- | --- | --- |
| Audits, registry and national database | No | No | No | No |
| Research and evidence | No | No | No | No |
| Evidence based formularies and prescribing | No | No | No | No |
| Digital and AI technologies | Yes | Yes | Yes | No |

### Audits, registry and national database

An audit of specialised service provision, an epilepsy registry and a national database of ketogenic diet therapy were suggested.

These suggestions have not been progressed. Audits, registries and databases collect data and are ways by which quality improvement can be evidenced. However, quality statements focus on actions that demonstrate high quality care or support, not the methods by which evidence is collated.

### Research and evidence

Research to address gaps in epilepsy treatment and knowledge, including ketogenic diet was suggested. Use of the RIGHT (Reporting Items for practice Guidelines in HealThcare) tool was also suggested. This is a tool that can be used to assess the quality of reporting of clinical guidelines These areas have not been progressed because they are outside of the remit of quality standards.

### Evidence based formularies and prescribing

Evidence based formularies were suggested for access to and prescribing of evidence based, cost-effective treatments. This area has not been progressed because there are no guideline recommendations to support it.

### Digital and AI technologies

Improving use of digital and artificial intelligence technologies for diagnosis and management of epilepsies was suggested. The source guideline notes that no evidence was found on using digital health technologies during development. The guideline committee produced a research recommendation to encourage more work in research in this emerging area: What is the clinical and cost effectiveness of digital health technologies in people with epilepsy? This area has not been progressed in the quality standard because there are no recommendations to support it, and a research recommendation has already been published to help address the lack of evidence.

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# Appendix 1: Suggestions from registered stakeholders

#### Diagnosis and assessment

| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
|  | Association of British Neurologists (ABN) | Investigations for new onset epilepsy | People with epilepsy should have investigations appropriate to their presentation as these may influence treatment.At onset – MRI, 12-lead ECG, blood tests and, in many EEG, should be undertaken as these may highlight how high the risk is of recurrence or if there is any underlying disorder requiring separate treatment.If presentation is suspicious for autoimmune encephalitis; antibody testing should be performed to ensure timely treatment (immunosuppressants).If presentation is suspicious for genetic cause (Dravet syndrome, Tuberous sclerosis etc); genetic tests should be performed as specific treatments may be appropriate.If the patient is refractory to medical treatment; additional imaging (high-field MRI using epilepsy specific protocol, PET) should be carried out to assess potential underlying cause that may highlight a surgical target. | For recommended guidance on management of autoimmune encephalitis please see <https://jnnp.bmj.com/content/92/7/757> For recommendations on genetic testing in epilepsy please see <https://www.ilae.org/files/dmfile/Kobow-et-al_Epigenetics_EpilepticDisorders-2020-003.pdf>  |
|  | Epilepsy Action | Adults, children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation. | This current quality statement is supported by the NICE epilepsy guidelines and it is important that this is maintained in the updated quality standard. | Please see the updated Epilepsies in children, young people and adults NICE guideline - [Epilepsies in children, young people and adults (nice.org.uk)](https://www.nice.org.uk/guidance/ng217/resources/epilepsies-in-children-young-people-and-adults-pdf-66143780239813) |
|  | Glut1 Deficiency UK | Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation. | Why is this a key area for quality improvement?Delay in diagnosis is a common theme in Children with rare epilepsies such as Glut1 Deficiency Syndrome. | Supporting information <https://academic.oup.com/brain/article/144/9/2879/6408766>Plus Anecdotal evidence from parents and carers forums |
|  | Kent Community Health Foundation NHS Trust | Genomics | Aim: Improve the diagnosis and health outcomes of patients with rare genetic neurological diseasesFocus: Young adults with complex epilepsies and neuromuscular disorders of all ages.Benefits of Embedding GenomicsEquitable access to genomic testing.Identifying a genetic cause of neurologic disorder may explain the condition and provide a prognosis.Enable the wider family to access clinical genomic services and counselling.Access to community and hospital services as well as clinical research/trials.Reduce loss to follow-up and delay in getting a diagnosisBenefits of Genetic TestingTuberous sclerosisEverolimus therapyCannabidiol HLA Genotyping prior to Carbamazepine to avoid Steven-Johnson syndrome & toxic epidermal necrolysis ([NG217 Evidence review C (nice.org.uk)](https://www.nice.org.uk/guidance/ng217/evidence/c-effectiveness-of-genetic-testing-in-determining-the-aetiology-of-epilepsy-pdf-398366282812)  | South East Genomic Medicine Service Alliance, Guy’s & St Thomas’ NHS Foundation Trust: Inherited Epilepsy N&M Genomics Transformation Project:The aim of the project is to look at the genetic testing pathways for patients with a possible diagnosis of inherited epilepsy, and roles and responsibilities of the Clinical Nurse Specialist in enabling equitable access to genetic testingA scoping survey was completed and clinical staff have been invited to attend online genetics workshops.Outcome: for staff to have an improved awareness ofgenetics and the Neurology-Familial Epilepsy Pathway and a better understanding of genotyping prior to the prescribing of Carbamazepine and medicines with a similar structure (such as Oxcarbazepine and Esclicarbazepine Acetate), and the increased risk of serious skin reactions posed in people of Han Chinese, Thai, European or Japanese family background. To date: staff attended a meeting in July 2022 where a presentation was given by St Georges University Hospital Neurogenetics Clinical Nurse Specialist about the St George’s Nurse-Led Neurogenetics Clinic.LINKS:[Genomics Education Programme](https://www.genomicseducation.hee.nhs.uk/)[International Society of Nurses in Genetics (ISONG)](https://isong.org/page-1325051)[Association of Genetic Nurses and Counsellors (AGNC](https://www.agnc.org.uk/))[NHS South East GLH and NHS South East GMSA](https://southeastgenomics.nhs.uk/)[Genomics England](https://www.genomicsengland.co.uk/) |
|  | LivaNova | Children, young people & adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested. | To ensure that the correct diagnosis and timely management of epilepsy is provided to avoid worsening outcomes  | We propose that statement 2 from the current Epilepsy in children and young people quality standard is included and covers adults as well. ([www.nice.org.uk/guidance/qs27](http://www.nice.org.uk/guidance/qs27)).This is because the period between the suspected 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.  |
|  | NHS England- Children and Young People’s Transformation Programme | EEG Waiting Times  | There is currently significant variation in EEGs being undertaken within 4 weeks as per the current Quality Standard. According to Epilepsy12, 54% of children and young people diagnosed with epilepsy, obtained an EEG within four weeks of request. There was an increase in children and young people waiting more than 16 weeks for an EEG (10% in Cohort 3 compared to 5% in Cohort 2) – this may be due to the impact of COVID-19. The below graph shows variation within NHSE Regions based on Epilepsy12 data:[Chart not included in this table] | NG217 [Epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) The above NICE guidance sets standards relating to EEGs under section 1.2. Part of this includes the standard that ‘if an EEG is requested after a first seizure, perform it as soon as possible (ideally within 72 hours after the seizure)’.Epilepsy12 measures: Time in weeks to when EEG was obtained since EEG request date |
|  | Ring20 Research and Support UK CIO | Strive for more equity in testing for diagnoses for cause of epilepsy, specifically across all the genetic epilepsies. | Current testing is focused and sometimes limited to structural abnormalities, or a specific list of pathogenic genes for epilepsy, or clinical diagnosis.Many chromosome abnormalities are not tested appropriately for and there is an over reliance on Next Generation Sequencing (NGS) techniques for genetic/genomic diagnosis and yet these can be lacking e.g., for ring chromosome disorders. | Updates req’d to the [National genomics test directory for rare and inherited disease.](https://www.england.nhs.uk/publication/national-genomic-test-directories/) to accommodate known epilepsy syndromes that cannot be diagnosed by NGS. |
|  | SCM1 | All CYP and adults who experience a first seizure should have an EEG as soon as possible (ideally within 72 hours after the seizure).  | Epilepsy 12 audit 2019-202054% (1058/1974)of children and young people diagnosed with epilepsy,obtained their EEG within four weeks off request. Pre-treatment EEGs are more helpful for seizure and syndromic classification. Delays in EEG may delay offering treatment and there may be further seizures in the interim with risk of injury | NICE Guideline Epilepsies 2022 |
|  | SCM1 | If an MRI scan is indicated to investigate epilepsy it should be carried out within 6 weeks and reported by a radiologist with expertise in paediatric or adult neuroradiology as appropriate | Waiting lists for MRI scans are long and there appears to be insufficient MRI scanning capacity in the system more generally which delays scans for those diagnosed with epilepsyEpilepsy12 audit showed that only 71% (1202/2106) of those who required an MRI brain scan received one in the first year of care.  | NICE Guideline Epilepsies 2022 |
|  | SCM4 | Access to video EEG telemetry | This is required for assessment of patients where diagnosis is uncertain and also for assessment for surgical support. Provision across the country is patchy. Access to this service as measured by access time would be a marker of quality | Covered by recommendation 1.2.10 and 3.1.3 |
|  | SCM5 | Urgent referral after a first suspected seizure or seizure recurrence after remission | Still wide variations on whether a person is referred **urgently** after a first suspected seizure. Where a person is not referred urgently it may increase risk of SUDEP, status, injuries, and health inequalities.Epilepsy 12 showed only 19% of children presenting with a first suspected seizure saw a specialist within 2 weeks. | NG217Refer children, young people, and adults urgently (for an appointment within 2 weeks) for an assessment after a first suspected seizure or if they have seizure recurrence after remission<https://www.rcpch.ac.uk/sites/default/files/2021-07/Epilepsy12%20summary%20report%203.3_0.pdf> |
|  | SCM5 | Identifying the epilepsy syndrome and using whole-genome sequencing for people with epilepsy and learning disability or autism where there is unknown cause  | Still too many adults, children and young people with epilepsy and learning disability or autism have a generic diagnosis. i.e., Epilepsy and learning disability.A generic diagnosis may result in poor health outcomes for people with epilepsy and learning disability or autism. Whole-genome sequencing may lead to a syndromic diagnosis, and this will have implications for optimal treatment, quality of life and a prognosis. | NG2171.4.4 Consider whole-genome sequencing for people with epilepsy of unknown cause who: were aged under 2 years when epilepsy started or have clinical features suggestive of a specific genetic epilepsy syndrome (for example, Dravet syndrome) or have additional clinical features such as: a learning disability autism spectrum disorder a structural abnormality (for example, dysmorphism or congenital malformation) unexplained cognitive or memory decline. <https://www.ilae.org/guidelines/definition-and-classification/classification-and-definition-of-epilepsy-syndromes> |
|  | SCM6 | Wait times on diagnostic tests – e.g. EEGs | While the current quality statement recommend a time limit (4 weeks) for undergoing the diagnostic tests, it does not specify a timeframe for the results to be reported. I understand there can be long wait times for EEGs to report for example (I recently was given this information by our consultant who said that a while back they were having to wait months for results due to a serious shortage of people who can read EEGs). The quality statement is created to minimise anxiety but if the results are not reported promptly this can undo the benefits to the patient and their family of getting the actual tests done swiftly.  |  |
|  | SCM7  | Timely investigations following first potential seizure. | The guideline makes a number of recommendations (1.1 1.2.5 1.3.1 and 1.4.4) regarding speed of required investigations based on evidence of usefulness in informing diagnosis and treatment. Early diagnosis and treatment reduces mortality and damage to the brain caused by further seizures.  | The NASH report found not all people attending ED with a suspected first seizure were referred to a neurology clinic for assessment some attended several times before being seen by an epilepsy specialist. |

#### Referral to tertiary specialist services

| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
|  | Angelini Pharma UK-I Ltd | Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral. | This remains a critical standard needed from the previous quality standards. Access to tertiary care is limited by the number of centres and clinicians meaning that patients in need can’t access NICE approved medicines and care.  | ABN workforce survey, GIRFT report and NHS rightcare highlight issues in resource and variation in access to care/pathways. <https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf> <https://cdn.ymaws.com/www.theabn.org/resource/resmgr/files/temp/girft_report_2021_-neurology.pdf> <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf>  |
|  | Angelini Pharma UK-I Ltd | Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services | This remains a critical standard needed from the previous quality standards. Re-Access to tertiary or specialist care is limited by the number of centres and clinicians meaning that patients in need can’t re-access care  | ABN workforce survey, GIRFT report and NHS rightcare highlight issues in resource and variation in access to care/pathways. <https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf> <https://cdn.ymaws.com/www.theabn.org/resource/resmgr/files/temp/girft_report_2021_-neurology.pdf> <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf> |
|  | Epilepsy Action | Adults, children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral | It is important that this quality statement is updated to emphasise the need for adults, children and young people to have access to mental health services at pace.People with epilepsy are more likely to experience mental health problems than the general population. | The findings of the Neurological Alliance’s My Neuro Survey highlighted problems many people with epilepsy face accessing mental health services - [Together for the 1 in 6: findings from My Neuro Survey – Neurological Alliance (neural.org.uk)](https://www.neural.org.uk/togetherforthe1in6/)Most people with a neurological condition reported that they are unable to access the mental wellbeing support they need. 40% reported their mental wellbeing needs are not being met at all. |
|  | Glut1 Deficiency UK | Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral. | Early referral to a tertiary care specialist is essential in order that investigations and a diagnosis can be made. This can then inform early initiation of the correct therapy. | <https://www.nice.org.uk/guidance/ng217> |
|  | Intractable Epilepsy  | Young adults are struggling to get an appointment to see a specialist, and are often left waiting a very long time. |  |  |
|  | LivaNova | Children, young people & adults who meet the criteria for referral to a tertiary care specialist are seen within specified time-frames of referral.E.g. Refer people with epilepsy to a tertiary epilepsy service, to be seen within 4 weeks, if the person has an epilepsy syndrome likely to be drug resistant, their seizures are drug resistant OR their treatment is associated with intolerable side effects or further assessment and treatment approaches are indicated, such as: video electroencephalogram (EEG) telemetry, neuropsychology or neuropsychiatry, specialised neuroimaging, specialised treatments (for example, medication that can only be prescribed by a tertiary epilepsy service or a ketogenic diet), epilepsy surgery or vagus nerve stimulation  | In the NG 217 process, it was identified that “the committee agreed that clearer and more specific criteria for referral would help to ensure that people who will benefit most from specialist services are prioritised. The proposed criteria aim to ensure that people with **epilepsy that is difficult to diagnose or manage receive the specialist care and treatment they need,** including consideration for clinical trials.” | NG 217 states to “ensure that all children, young people and adults with suspected or confirmed epilepsy have access to a [tertiary epilepsy service](https://www.nice.org.uk/guidance/ng217/chapter/terms-used-in-this-guideline#tertiary-epilepsy-service), if needed, via their specialist” at specified time points:**Refer people with epilepsy to a tertiary epilepsy service, to be seen within 4 weeks, if any of the following apply**: * uncertainty about the diagnosis or cause of epilepsy, the seizure type or epilepsy syndrome
* **the person has an epilepsy syndrome likely to be drug resistant, their seizures are drug resistant or their treatment is associated with intolerable side effects**
* **further assessment and treatment approaches are indicated, such as: video electroencephalogram (EEG) telemetry, neuropsychology or neuropsychiatry, specialised neuroimaging, specialised treatments (for example, medication that can only be prescribed by a tertiary epilepsy service or a ketogenic diet), epilepsy surgery or vagus nerve stimulation**
* the person is eligible for and wishes to participate in a clinical trial or research study.

Refer children with suspected or confirmed epilepsy to a tertiary paediatric epilepsy service to be seen within 2 weeks, if they: * are aged under 3 years
* are aged under 4 years and have myoclonic seizures (see recommendation 5.4.1 in the section on myoclonic seizures)
* have a unilateral structural lesion
* are showing deterioration in their behaviour, speech or learning.

The Quality Standard should reflect this updated guidance.This is especially important for people with Drug Resistant Epilepsy (DRE) as, compared with people in the general population and people with epilepsy that responds to treatment, people with DRE experience significantly more comorbidities, including depression, vascular disorders, seizure-related injuries, and neurological deficits (1,2). People with DRE also have a significantly higher mortality risk than those whose epilepsy responds to treatment (3,4). SUDEP, where a person with epilepsy suddenly dies during or following a seizure for no obvious reason, is a major cause of death in people with DRE (5). SUDEP is 40 times more likely to occur in people with epilepsy who continue to experience seizures versus those who are seizure-free (6).People with DRE report significant reductions in health-related quality of life compared with those whose epilepsy responds to treatment, including in measures of physical and social functioning (7-9).Referral to a tertiary epilepsy service within the specified 4-weeks will help facilitate timely assessment, and access to appropriate treatment options1 Strzelczyk A, Griebel C, Lux W, Rosenow F, Reese J-P. The Burden of Severely Drug-Refractory Epilepsy: A Comparative Longitudinal Evaluation of Mortality, Morbidity, Resource Use, and Cost Using German Health Insurance Data. Front Neurol. 2017;8:712-.2 Kantanen AM, Reinikainen M, Parviainen I, Kälviäinen R. Long-term outcome of refractory status epilepticus in adults: A retrospective population-based study. Epilepsy research. 2017;133:13-21.3. Wang T, Wang J, Dou Y, Yan W, Ding D, Lu G, et al. Clinical characteristics and prognosis in a large paediatric cohort with status epilepticus. Seizure. 2020;80:5-11.4. Tian L, Li Y, Xue X, Wu M, Liu F, Hao X, et al. Super-refractory status epilepticus in West China. Acta Neurol Scand. 2015;132(1):1-6.5 Novak JL, Miller PR, Markovic D, Meymandi SK, DeGiorgio CM. Risk Assessment for Sudden Death in Epilepsy: The SUDEP-7 Inventory. Front Neurol. 2015;6(252).6 Tomson T. Mortality in epilepsy. J Neurol. 2000;247(1):15-21.7 Sinoo C, de Lange IM, Westers P, Gunning WB, Jongmans MJ, Brilstra EH. Behavior problems and health-related quality of life in Dravet syndrome. Epilepsy & behavior : E&B. 2019;90:217-27.8 Rassart J, Luyckx K, Verdyck L, Mijnster T, Mark RE. Personality functioning in adults with refractory epilepsy and community adults: Implications for health-related quality of life. Epilepsy research. 2020;159:106251.9 Tritton T, Bennett B, Brohan E, Grant L, Cooper A, Fladrowski C, et al. Health utilities and quality of life in individuals with tuberous sclerosis complex (TSC) who experience epileptic seizures: A web-based survey. Epilepsy & behavior : E&B. 2019;92:213-20. |
|  | LivaNova | Access to resective surgery for eligible patients | NG 217 stated to “discuss the options for assessment for resective epilepsy surgery with people who have drug-resistant epilepsy, and their families or carers if appropriate. Explain what the process of surgical assessment involves as well as the benefits and risks associated with surgical procedures.Refer people with drug-resistant epilepsy, including those without identified MRI abnormalities, for consideration of assessment for resective epilepsy surgery: For adults, this should be to a tertiary epilepsy service. For children and young people, this should be to a tertiary paediatric neurology service for consideration of referral to a children's epilepsy service surgery centre.  | NG 217 states that “The evidence on surgical interventions showed that resective epilepsy surgery is the most clinically effective treatment for children, young people and adults with drug-resistant focal epilepsy. This was based on the evidence showing better quality of life and lower rates of recurrence after surgery compared with medical care”. |
|  | NHS England | Improving access to care and experience of care for people with a learning disability and autistic people  | Improving **access, and experience of epilepsy care and support** for people with a learning disability and autistic people including for Children and Young people and children transitioning to adult services  | Please see the Kings College London LeDeR report which highlights that epilepsy is a significantly occurring condition in people with intellectual disability and a significant cause of premature mortality as identified in the LeDeR annual report 2021 by Kings College London [leder-main-report-hyperlinked.pdf (kcl.ac.uk)](https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf): * Of deaths considered in 2021 by LeDeR 33% people who died had epilepsy – 40% of those in the 50 – 64 age group
* 2.3% of all deaths (all age) were from epilepsy in 2021
* In 4 to 17-year-olds reported to LeDeR between 2018 and 2021 epilepsy and status epilepticus was in the top 5 causes of death
* In adults epilepsy was the most common long-term condition associated with an earlier age at death with a hazard ration of 1.47 95% CI 1.28, 1.69
* KCL also found that having a diagnosis of epilepsy …[was] associated with younger age at death. This suggests that improvements in treatment of these conditions may help to delay age at death.

Diagnostic assessments for intellectual disabilities and / or autism –should be multi-dimensional and should specifically address physical conditions – in particular epilepsy – to enable holistic and comprehensive care, intervention and support (supported by professional opinion on assessment in recent WPA textbook on Intellectual Disability and Autism Spectrum Disorder).  |
|  | NHS England- Children and Young People’s Transformation Programme | Referrals into tertiary services, including epilepsy surgery  | Epilepsy surgery in infancy and early childhood is increasingly recommended because it may prevent many years of unnecessary seizures. Surgery can help prevent or reduce the impaired development and behaviour that is sometimes caused by early onset seizures. Children and adolescents with drug-resistant epilepsy who had undergone epilepsy surgery had a significantly higher rate of freedom from seizures and better scores with respect to behaviour and quality of life than those who continued medical therapy alone at 12 months ([Surgery for Drug-Resistant Epilepsy in Children)](https://pubmed.ncbi.nlm.nih.gov/29069568/).NHS England Specialised Commissioning commissions the Children Epilepsy Surgical Service (CESS) to provide specialist pre-surgical evaluation and surgery for children in specialised CESS centres across England should they meet the acceptance criteria in line with NICE guidelines. It is estimated that in England, 780 children should be evaluated per year and 405 should have a resective surgical procedure. In 2019, the CESS service received 543 referrals and undertook 398 evaluations and 235 surgical procedures. In addition to surgical assessment and referral into CESS, CYP may be referred into tertiary care for assessment for VNS insertion or ketogenic dietary therapy in line with NICE NG217. [Epilepsy12 data](https://www.rcpch.ac.uk/sites/default/files/2022-07/epilepsy12-_main_report_2022.pdf) showed that only 28% of CYP with epilepsy that met the criteria for surgery were referred to the epilepsy surgery service for assessment within the first year of care. In addition, 64% of children and young people who met paediatric neurology referral criteria had either input from a paediatric neurologist, or had been referred to CESS, during their first year of care. The below graph shows variation within NHSE Regions based on Epilepsy12 data:[Chart not included in this table] | NG217 [Epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) The above guidance contains standards relevant to the referral to tertiary specialist services (section 3) and Non-pharmacological treatments (section 8). Epilepsy12 measures: Percentage of ongoing children and young people meeting defined epilepsy surgery referral criteria with evidence of epilepsy surgery referral. Percentage of children and young people who met paediatric neurology referral criteria had either input from a paediatric neurologist, or had been referred to CESS, during their first year of care. |
|  | Ring20 Research and Support UK CIO | More equity in access to treatments, especially new, emerging therapies. | New emerging treatments for epilepsy are constrained to prescription for the few, not the many because of poor clinical trial design. Such treatments that do not constitute precision medicine e.g., Epidiolex for seizures associated with Dravet syndrome or the SCN1A gene, LGS or TSC, should be more widely available to be prescribed to other individuals as appropriately determined by the paediatric neurologist/neurologist. | Over 30% or people with epilepsy remain uncontrolled and yet there are few, new emerging treatments available remain inaccessible under prescription.Examples include:EpidiolexFenfluramineCenobamate |
|  | SCM1 | All CYP and adults meeting the NICE guideline referral criteria for tertiary care including CESS/adult surgery assessment should be referred as set out in the guideline | Epilepsy12 audit CYP 2019-2164% (305/480) of children and young people who met paediatric neurology referral criteria had either input paediatric neurologist, or had been referred to CESS, during their first year of care. 28%, 38/135 that met the surgery criteria were referred to the epilepsy surgery service for assessment within the first year of care.  | NICE guideline Epilepsies  |
|  | SCM3 | Improved access to specialist treatments | People with complex epilepsy should be referred to tertiary services for relevant specialist treatments.Epilepsy12 audit reported that 63% of children and young people in England meeting the criteria received tertiary input into their care. Furthermore, only 28% that met the criteria for surgery were referred to the epilepsy surgery service for assessment within the first year of care | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) Recommendations in chapters 3 and 8.[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)Percentage of children and young people meeting the criteria who receive tertiary input into their care.Percentage of children and young people meeting the criteria who are referred for surgical assessment. |
|  | SCM5 | Referral to tertiary epilepsy services within 4 weeks  | Significant variation in the provision of quality care for people with epilepsy.It’s still very hard for some groups to access tertiary epilepsy services despite meeting the criteria.  | NG217Adults, young people and children with epilepsy who meet the criteria for referral to a tertiary epilepsy service, are seen within 4 weeks or within two weeks if a child is under 3yrs, or has a unilateral lesion or there is deterioration in their speech, learning or behaviour [NICE: Link to embargoed document removed] |
|  | SCM5 | Referral for surgery | Epilepsy12 showed that three quarters of children (77%) who should have been considered for **epilepsy surgery** had not been referred as expected.  | NG2178.2.2 Refer people with drug-resistant epilepsy, including those without identified MRI abnormalities, for consideration of assessment for resective epilepsy surgery<https://pn.bmj.com/content/20/1/4> |
|  | SCM7 | Children young people and adults with drug resistant epilepsy 2 or 3 years post diagnosis or with a potentially operable area of the brain found during diagnosis referred for surgical assessment. | Surgical techniques and outcomes have been improving but numbers accessing surgical pathways have not increased. In revision of guideline earlier referral is suggested this will potentially improve quality of life and reduce risk of mortality. |  |
|  | SCM8 | Access to epilepsy surgery |  |  |
|  | UK Rare Epilepsies Together | Access to specialist treatments | Children and young people with complex epilepsy should be referred to tertiary services for relevant specialist treatments.Welcome the recommendations in chapters 3 and 8 of the NICE guidelines, to ensure that people with epilepsy are able to access specialist treatments, including surgery, vagus nerve stimulation and the ketogenic diet.Findings from the Epilepsy12 audit show that 63% of children and young people in England meeting the criteria received tertiary input into their care. Furthermore, only 28% that met the criteria for surgery were referred to the epilepsy surgery service for assessment within the first year of care. | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217)* Recommendations in chapters 3 and 8.

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of children and young people meeting the criteria who receive tertiary input into their care.
* Percentage of children and young people meeting the criteria who are referred for surgical assessment.

  |
|  | Young Epilepsy | Access to specialist treatments | Children and young people with complex epilepsy should be referred to tertiary services for relevant specialist treatments.Young Epilepsy welcomes the recommendations in chapters 3 and 8 of the NICE guidelines, to ensure that people with epilepsy are able to access specialist treatments, including surgery, vagus nerve stimulation and the ketogenic diet.Findings from the Epilepsy12 audit show that 63% of children and young people in England meeting the criteria received tertiary input into their care. Furthermore, only 28% that met the criteria for surgery were referred to the epilepsy surgery service for assessment within the first year of care. [1][RCPCH (2022) Epilepsy12 national clinical audit of seizures and epilepsies for children and young people, Appendix B](https://www.rcpch.ac.uk/sites/default/files/2022-07/appendix_b_-_epilepsy12_2022.pdf) | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) * Recommendations in chapters 3 and 8.

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of children and young people meeting the criteria who receive tertiary input into their care.
* Percentage of children and young people meeting the criteria who are referred for surgical assessment.
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#### Treatment

| ID | Stakeholder | Suggested key area for quality improvement | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- |
|  | Angelini Pharma UK-I Ltd | Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan. | This remains a critical standard needed from the previous quality standards. More needs to be done to ensure connection with tertiary or specialist care as it is limited by the number of centres and clinicians meaning that patients in need can be reviewed and treatment updated when needed | ABN workforce survey, GIRFT report and NHS rightcare highlight issues in resource and variation in access to care/pathways. <https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf> <https://cdn.ymaws.com/www.theabn.org/resource/resmgr/files/temp/girft_report_2021_-neurology.pdf> <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2020/03/rightcare-epilepsy-toolkit-v2.pdf> |
|  | Association of British Neurologists (ABN) | Status Epilepticus | This is a life and brain threatening condition.Rapid and appropriate treatment of status epilepticus is one of the main factors for successful treatment. Surveys often highlight that inappropriate (too low) doses of medications are used which may reduce the chances of success. Protocols are often hospital/trust specific.  | For example on best practice please see<https://bestpractice.bmj.com/topics/en-gb/3000127>  |
|  | Association of British Neurologists (ABN) | Women with epilepsy | The majority of antiseizure medications (ASM) are associated with increased teratogenicity. This is particularly the case for valproate. Although there are clear guidelines from MHRA, patient surveys have found that nearly 20% of women taking valproate reported still not being aware of the teratogenic risks of the drug. Several other the ASM interact with oral contraceptives. The teratogenicity of many medications is not fully documented and information emerges over time.Detailed information is required to reduce risks of unwanted pregnancies and reduce risks to mother and baby during pregnancy and it is important to have regular reviews with women and girls to ensure they have appropriate information and treatment as their circumstances change. | For example see advice on <https://www.gov.uk/drug-safety-update/antiepileptic-drugs-in-pregnancy-updated-advice-following-comprehensive-safety-review>  |
|  | FSRH CEU | Provision of highly effective contraception and adherence to completion of annual risk assessment form for individuals with reproductive potential using valproate drugs. | Fetal exposure to valproate drugs is associated with high incidence of congenital malformation and developmental disorder. A concerning number of pregnancies continue to be exposed to valproate despite the MHRA valproate pregnancy prevention plan. It is considered that this should be reiterated as widely as possible. | Please see the MHRA guidance on use of valproate drugs by women of reproductive age and the Guidance Document on Valproate Use in Women and Girls of Childbearing Years Judy Shakespeare FRCGP1, Sanjay M Sisodiya FRCP (RCGP) |
|  | Glut1 Deficiency UK | Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan. | There is anecdotal evidence of the emergency care plan not being shared with primary and secondary services, or secondary services not in agreement with the care plan that tertiary care have written. | Anecdotal. |
|  | Intractable Epilepsy  | At least 100 children with Intractable Epilepsy are being privately prescribed cannabis oils, in turn creating a 2 tier health system and it’s having a negative impact between NHS paediatric neurologists and parents. (Trials for medicinal cannabis have not started yet. The law was changed in November 2018 to allow this). |  |  |
|  | Intractable Epilepsy  | Drugs currently used haven’t been tested for efficacy and safety. Zonisamide, for example, is approved but not tested on children when given with other multiple drugs. Yet neurologists are telling parents they cannot prescribe cannabis oils due to safety, efficacy and cost. |  |  |
|  | Intractable Epilepsy  | Children are being given palliative care for severe epilepsy instead of medicinal cannabis oils, which are used widely in other countries and privately in the U.K. |  |  |
|  | Intractable Epilepsy  | Many parents are struggling to obtain a nhs prescription for epidiolex, even though current AEDs are not working for their children. |  |  |
|  | Jazz Pharmaceuticals | Limited treatment protocols for diagnosis and management of rare/complex epilepsy | Despite the improvements since the last QS in epilepsy, there remains a lack of consensus on the treatment pathways for patients with complex epilepsy.  | The recent NICE guideline is a step in the right direction but there remains widespread variation and inequity in care for complex epilepsy. This is particularly so for patients transitioning between paediatric and adult services who may face issues in continuation of care. |
|  | National Patient Safety TeamNHS England | Compliance with the Pregnancy Prevention Programme for anyone of childbearing potential prescribed valproate | The Community Pharmacy Quality Scheme – 2019/20 Valproate Audit Report found that:* 5.6% of eligible patients were not provided with advice and information in line with the MHRA Drug Safety Update 2018 - including the potential impact on an unborn child
* 10.6% did not have the patient guide
* 11.1% did not have the patient card
* 17.6% reported they had not had a discussion about their valproate medication and the need for appropriate contraception with a GP or specialist in the last 12 months, and a further 9.1% were unsure.
* 36.2% reported not using highly effective contraception – of those only 26.5% were referred to the GP by the pharmacist about this issue.

Referrals to the GP and/or provision of the patient guide or patient card were recorded in pharmacy medication records for 63.6%. | Please see the audit report here: [B1504\_Community-Pharmacy-Quality-Scheme-2019-20-valproate-audit-report-July-2022.pdf (england.nhs.uk)](https://www.england.nhs.uk/wp-content/uploads/2022/07/B1504_Community-Pharmacy-Quality-Scheme-2019-20-valproate-audit-report-July-2022.pdf) |
|  | Neonatal and Paediatric Pharmacists Group (NPPG) | There should be a quality standard around the MHRA safety advice on valproate use by women and girls and requirement for minimum of annual review? |  |  |
|  | Royal College of Paediatrics and Child Health | Women with epilepsy especially of childbearing age | Certain drugs such as Na Valproate are contra indicated due to the high level of teratogenicity. Seizures may also increase during menstrual cycles and pregnancy due to hormonal influence. |  |
|  | SCM2 | Managing prolonged repeat seizures | The changes in definition of cluster and repeat, prolonged seizure in NICE guidance 2022 needs translation into practice in patient repeat attendance in the emergency department. The risk of missed opportunity to intervene when patients being managed in emergency department and discharged to community/home. The need to implement guidelines of ASM intervention to reduce and prevent repeat experience of cluster and repeat seizure to reduce patient risk. | The NICE guideline 2022 identifies the needs for research and changes in definition of status epilepticus influencing on the definition of prolonged seizure less than 5 mins but 2 mins longer than average seizure. This complex definition requires standards for implementation into care especially for patients presenting with repeat and prolonged seizure in community and emergency room (therefore not epilepsy specialist)<https://www.nice.org.uk/guidance/ng217/chapter/7-Treating-status-epilepticus-repeated-or-cluster-seizures-and-prolonged-seizures> |
|  | SCM2 | Preconception care for all women of childbearing potential to intervene to improve seizure control and reduce or avoid anti-seizure medication risk before conception | Cochrane protocol update (currently underway) identifies a lack of consensus of the content of care, delivery and effectiveness to reduce risks for women and their unborn child. Public Health England reviewed preconception care and identified universal interventions and additional measures required for women with chronic conditions (exampled care of woman with diabetes, and the valproate pregnancy prevention programme). Women with epilepsy have varied needs, are a heterogeneous population. Their preconception care needs differ, relating to seizure control and ASM. In addition, epilepsy syndrome and seizure classification can determine an individual woman at greater risk of seizures deteriorating if intervening to change ASM pre-pregnancy. | Recommendations for improving access to preconception care has been a key recommendation in the Confidential Enquiry of maternal and child health. <https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_Final_v2.pdf>The failure to improve preconception care is highlighted as missed opportunity to intervene, resulting in women entering pregnancy unaware of risks of behaviours such as stopping ASMs on discovery of pregnancy<https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK_Maternal_Report_Dec_2020_v10_ONLINE_VERSION_1404.pdf> |
|  | SCM5 | Referral to a specialist epilepsy team for women and girls who could become pregnant or who are pregnant or are planning pregnancy to enable women and girls and their partners to make informed decisions about their anti-seizure medication during pregnancy and after the birth and to reduce risks of SUDEP | MBRRACE-UK found the number of deaths from Sudden Unexpected Death in Epilepsy (SUDEP) almost doubled compared with the previous three years. Most women who died had clear risk factors for SUDEP, but had not had prevention measures discussed with them, or a medication review.Exposure to harmful antiseizure medications during pregnancy continue to occur - leading to major malformations in babies exposed.The IMMDS Review heard from families who did not receive information about the risks of treatment with sodium valproate during pregnancy. This prevented women from making informed choices about their treatment and family planning options. | NG2174.6.1 Refer women and girls with epilepsy who are planning pregnancy or are pregnant to an epilepsy specialist team for a review of their antiseizure medication options<https://www.npeu.ox.ac.uk/news/2080-mbrrace-uk-report-identifies-epilepsy-and-inequalities-in-maternal-deaths><https://www.immdsreview.org.uk/Report.html><https://www.gov.uk/government/publications/public-assesment-report-of-antiepileptic-drugs-review-of-safety-of-use-during-pregnancy> |
|  | SCM8 | Treatment of status epilepticus |  |  |

#### Management and service provision

| **ID** | **Stakeholder** | **Key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
|  | Angelini Pharma UK-I Ltd | Continuation of prescribing and ongoing management in primary care  | In order to support the quality standards listed above the pathway needs to flow effectively back to primary care. It should be expected that ongoing care for stable patients should take place in primary care in the shape of a transition of care (RMOC) protocols being in place across all ICBs and supporting GPs with education to build confidence and skillset. Currently complex shared care arrangements are often required when not needed or medicines are inconsistently coded (RAG ratings) meaning variation in transition back to primary care (see RMOC recommendations) | <https://www.researchgate.net/publication/13440189_Attitudes_of_GPs_to_the_care_of_people_with_epilepsy> Medicines initiated in the specialist setting or recommended by a specialist for initiation in primary care, which do not require ongoing oversight by a specialist but may require some monitoring within primary care, are not shared care drugs. In many cases it will be the primary care prescriber who is the most appropriate clinician to provide continuing care. In terms of patient experience, those patients who are on long-term medication or are less well may prefer to avoid unnecessary hospital appointments by receiving their prescriptions closer to home (www.sps.nhs.uk/wp-content/ uploads/2020/01/RMOCShared-Care-for-MedicinesGuidance-A-Standard-Approach-Live 1.0.pdf) |
|  | Association of British Neurologists (ABN) | Communication between services | As hospitals, community trusts and GP practices use different record-keeping systems, doctors involved in patient care are often not aware if the person with epilepsy has been seen by other specialists or attends another hospital. This includes the crucial area of emergency department attendance or inpatient stays for epilepsy or other reasons. Mental health problems are common co-morbidities associated with epilepsy. These problems can have huge interaction with a person’s epilepsy control and treatment. Community mental health trusts have separate records which are not generally accessible in secondary care.Communication is therefore reliant on individuals initiating this rather than being integrated at a system level. This can lead to inappropriate prescriptions, lack of awareness about influences on someone’s epilepsy control, or lack of treatment changes when appropriate which may have significant consequences.  | For an example please see <https://bjgpopen.org/content/6/1/BJGPO.2021.0148>[https://www.inquest.org.uk/gaia-pope-inquest-concludes#:~:text=The%20inquest%20has%20today%20concluded,and%2010am%20the%20following%20day](https://ddec1-0-en-ctp.trendmicro.com:443/wis/clicktime/v1/query?url=https%3a%2f%2fwww.inquest.org.uk%2fgaia%2dpope%2dinquest%2dconcludes%23%3a%7e%3atext%3dThe%2520inquest%2520has%2520today%2520concluded%2cand%252010am%2520the%2520following%2520day&umid=689507c8-77ee-4892-987f-02c1933aadd3&auth=214c472b0d4a84553d6481f498015f71ae1db4d5-49743145e6f08750c2a30eb001025223adab8966). |
|  | Epilepsy Action | Adults, children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan. | This quality standard should include discussions around risk management particularly in relation to the use of sodium valproate and other epilepsy medications by people of childbearing potential. This should include ensuring people are made aware of the risks of taking AEDs during pregnancy, especially sodium valproate and that females aged 12 or over are asked to complete a risk acknowledgement form.Care plans should ensure include discussions around SUDEP, risks and management of these risks.  | Risks around the use of sodium valproate during pregnancy are well established, but other epilepsy medications have also been identified by the CHM review as potentially harmful when used during pregnancy - [Antiepileptic drugs in pregnancy: updated advice following comprehensive safety review - GOV.UK (www.gov.uk)](https://www.gov.uk/drug-safety-update/antiepileptic-drugs-in-pregnancy-updated-advice-following-comprehensive-safety-review)The aim of discussions of sudden unexpected death in epilepsy (SUDEP) should be to positively to support a person to understand and manage their seizures and lifestyle - [SUDEP discussions with patients and families - PubMed (nih.gov)](https://pubmed.ncbi.nlm.nih.gov/22450457/) |
|  | Epilepsy Action | Adults, children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews. | This quality standard is support by the NICE epilepsy guidelines and should be maintained. In addition, we would recommend that ESNs provide an Open Access model, where patients are encouraged to contact the Epilepsy Specialist Nurse who will then assess if an appointment is needed or provides advice and treatment over the telephone. This is to enable patients to have a more responsive service, reduce emergency admission, need for appointments particularly at a time of need. | Open Access models are currently operating in several areas and has proved to be effective meeting patient needs and using ESN and clinical neurologist time effectively.This study demonstrates that timely intervention by telephone reduces the need for outpatient appointments and leads to treatment changes being implemented quickly to address individual need - [Managing epilepsy in austerity – Evaluating the utility and value of the epilepsy specialist nurse in an open access model of service delivery. Aneurin Bevan Epilepsy Specialist Team (A.B.E.S.T.) - Seizure - European Journal of Epilepsy (seizure-journal.com)](https://www.seizure-journal.com/article/S1059-1311%2818%2930813-6/fulltext) |
|  | Epilepsy Action | Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services. | The transition from paediatric to adult services is a vitally important period in ensuring continuing epilepsy care. There also needs to be special consideration for young people who have complex or additional health and social care needs, for example young people whose seizures are not yet controlled or those with learning disabilities. | The outcome of poor transition from paediatric to adult healthcare services can be poor compliance with treatment and less successful self-management. It can also affect the health and wellbeing of family and carers, which in return directly impacts on young people and their resilience - [Transition\_doc\_full\_report\_FINAL.PDF (yhscn.nhs.uk)](https://www.yhscn.nhs.uk/media/PDFs/Y%20and%20H%20Transition%20Toolkit/TPR%203B%20Transition%20Guides%20and%20Models/Transition_doc_full_report_FINAL.PDF) |
|  | Glut1 Deficiency UK | Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan. | Not all children with Epilepsy have a written and comprehensive epilepsy care plan | <https://www.nice.org.uk/guidance/qs27/chapter/Quality-statement-4-Epilepsy-care-plan>Plus anecdotal evidence from Parent/Carer forums |
|  | Glut1 Deficiency UK | Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services. | There is a real need for an improvement in transition services for Paediatric to Adult services for Children and Young People with Epilepsy. Whilst there is evidence of good examples of this, it is not available everywhere leading to inequalities.  | <https://www.nice.org.uk/guidance/ng217>Plus anecdotal evidence from Parent/carer forums |
|  | Jazz Pharmaceuticals | Limited use of clinical decision support (e.g. best practice guidelines or personalised patient plans) | The symptoms of complex epilepsies and epilepsy syndromes may be varied both in presentation and severity. The natural course of the disease varies by patient, and there are limited specialists in some rare epilepsies, which can create difficulties for patients. | Clinical decision support to assist in the management of these complex or rare epilepsies may be of benefit to the clinical community and improve patient outcomes. It may also provide a supportive framework for clinicians new to the field and improve cohesiveness in complex epilepsy services. |
|  | Jazz Pharmaceuticals | Transition from paediatric into adult epilepsy services  | Patients face challenges accessing continuation of care when they transition from paediatric to adult. There are also widespread variations in the transition between services.  | This challenge was acknowledged in the existing NICE QS for Epilepsy (2012). There has been improvement over the last 12 years but patients still face challenges in transition. The issues are also mentioned in the recent Epilepsy12 organisational and clinical audits report. |
|  | Kent Community Health Foundation NHS Trust | Patient Education – Information and Support | Nice guideline NG217 [CG138] 1.5.11: Give the patient information, and the support they need to make use of the information, in order to promote their active participation in care and self-management. [CG138] 1.5.28: Ensure that patient-education programmes:* are evidence-based
* have specific aims and learning objectives
* meet the needs of the patient (taking into account cultural, linguistic, cognitive and 11.1.4literacy considerations)
* promote the patient's ability to manage their own health, if appropriate.

[CG138] CG1381.5.29 Give the patient the opportunity to take part in evidence-based educational activities, including self-management programmes that are available and meet the criteria listed in recommendation 1.5.28.11.1.4 Consider epilepsy specialist nurse-led group sessions for education and information giving in young people and adults with epilepsyRationale for education sessions:Patients were found to be lacking basic knowledge of epilepsy and seizure management when first assessed. During periods of short staffing (for example during Covid-19 redeployment of staff) the number of patients awaiting their first appointment increased and resulted in a long wait to be seen. It was felt that education sessions would have a two-fold benefit:Provide vital safety education for patients whilst on a waiting list.Reduce the time taken at initial appointments imparting standard information, thus allowing time for tailored discussion of patient needs. | Study: Ridsdale et al (2017),“People with epilepsy obtain added value from education in groups: results of a qualitative study ”, European Journal of Neurology. [People with epilepsy obtain added value from education in groups: results of a qualitative study - Ridsdale - 2017 - European Journal of Neurology - Wiley Online Library](https://onlinelibrary.wiley.com/doi/full/10.1111/ene.13253)Patient education online groups: The epilepsy nursing service has recently started offering hour-long online education sessions. This aims to introduce patients (age 16+) to our service, provide evidence-based information about epilepsy, seizure management, anti-seizure medication, SUDEP, risk factors, safety advice and lifestyle support.In the future we hope to provide online education sessions for specific patient groups for example: Women; Pregnancy & Parenting; Transition to Adult Services; and Introductory Sessions with Easy Read Information for People with Intellectual Disability.The education sessions will form the basis for a service quality improvement project which we hope to undertake within the next twelve months.Success will be measured using the “Patient Outcome Measures” which are used to assess improvement on patient knowledge and understanding of their condition (this is measured upon initial assessment and again upon discharge), together with patient feedback.If resources allow, this may be extended to online support groups. At present we signpost to The Epilepsy Action & Epilepsy Society websites which have online group platforms. However, it is not known how many patients explore these groups. In the past, our service has trialled a one-off face to face support group session for transition patients which was successful. Due to Covid-19 restrictions and lack of service resources this has not been replicated. Please note: this service continues to offer individual tailored education and support to the patient at their initial and follow up review assessments. |
|  | Kent Community Health Foundation NHS Trust | SUDEP | Conversations with patients at their initial epilepsy nursing assessment have highlighted that they often lack knowledge of SUDEP, and that this information is rarely cascaded to patients either by their Consultant Neurologist or other Epilepsy Nurses that they may seen in the past.Communication: NICE guideline NG217 1.2.3 states that the clinician should “be prepared to raise and discuss sensitive issues … as these are unlikely to be raised by some patients”10.1.1Be aware that epilepsy is associated with an increased risk of premature death, including a risk of sudden unexpected death in epilepsy (SUDEP).10.1.2Be aware that potentially modifiable risk factors for SUDEP include:* non-adherence to medication
* alcohol and drug misuse
* having focal to bilateral tonic-clonic seizures or generalised tonic-clonic seizures
* having uncontrolled seizures
* living alone
* sleeping alone without supervision.

10.1.3 Be aware that the risk of epilepsy-related death is increased in people with:* previous brain injury
* previous central nervous system infection
* metastatic cancer
* previous stroke
* abnormal neurological examination findings.

10.1.4 Discuss with people with epilepsy, and their families and carers if appropriate, their individual risk of epilepsy-related death, including SUDEP, from the time of diagnosis onwards. Discussion should include:* supporting them to understand the risks of epilepsy-related death, including SUDEP
* exploring and agreeing ways to reduce the risks.

10.1.5 Discuss the risk of SUDEP with people who have seizures during sleep and, if appropriate, include their families and carers. Provide information on minimising risks, including taking their medication as prescribed. | SUDEP topic has been introduced in patient education sessions.Initial assessment conversations with patient include a brief discussion around SUDEP.New clinical staff to attend communication workshopsClinical Lead currently carrying out research as part of Masters degree into communication barriers around discussing SUDEP with patientsShankar et al (2020) “Bridging the gap of risk communication and management using the SUDEP and Seizure Safety Checklist”, Epilepsy & Behaviour, 106419, 103Use of the checklist has been discussed at Team Meetings in the past, but this tool has not been routinely used due to time/resource pressures. This will be raised again with the possibility of using it to help those patients most at risk to recognise the need of acknowledging risk factors and make the necessary steps to modify behaviour/lifestyle choices. The Prevent21 Campaign highlighted that over 21 years 21,000 people with epilepsy died suddenly. In 2017 the campaign looked to bring this to public attention. The vision for Prevent21 is “reducing deaths from epilepsy and ensuring that critical lifesaving knowledge and awareness of risk management is brought to the attention of hundreds and thousands of people”.[Prevent21 Summit on tackling epilepsy related deaths: consensus recommendation summary – Neurological Alliance (neural.org.uk)](https://www.neural.org.uk/publication/epilepsy-consensus-recommendations/) |
|  | Kent Community Health Foundation NHS Trust | Epilepsy Nursing | NICE guideline NG21711.1 Ensure that all young people and adults with epilepsy have access to an epilepsy specialist nurse who:* has a central role in providing information, education and support
* supports epilepsy specialists and healthcare professionals in primary and secondary care, and in educational, respite and social care settings
* is a point of contact for, and facilitates access to, other community and multi-agency services.

11.1.2 Offer people with epilepsy an information and care-planning session with an epilepsy specialist nurse that includes emotional wellbeing and self-management strategies promoting inclusion and participation. | Campbell F., et al (2019), “Epilepsy Specialist Nurses: The Evidence (ESPENTE): A Systematic Mapping Review”, Epilepsy Action/University of Sheffield.[The ESPENTE Study 8.7.19 Version 1.pdf (epilepsy.org.uk)](https://www.epilepsy.org.uk/sites/epilepsy/files/research/The%20ESPENTE%20Study%208.7.19%20Version%201.pdf)The ESPENTE study creates much needed context to the argument for the development of the ESN as an integral part of the care provided to people with epilepsy, their family and carers. The epilepsy nursing service is undergoing a period of change and is reviewing working practice after changes made as a result of Covid-19One area that requires review is the Epilepsy Specialist Nurses competencies framework., many aspects of the existing framework do not reflect current practice within our trust. Therefore, it is the team’s intention to update the competencies so that they are inline with our present working methods and ESNA Adult Epilepsy Specialist Nurse Competency Framework and NICE Guidance.[ESN\_Adult\_Competency\_Framework.pdf (esna-online.org)](https://esna-online.org/wp-content/uploads/2018/12/ESN_Adult_Competency_Framework.pdf)Future plans also include upskilling the current clinical staff, so that in the future all epilepsy nursing clinicians will undertake the Postgraduate Non-Medical Prescribing course. |
|  | Kent Community Health Foundation NHS Trust | Transition | 1.2 Transition from children's to adults' epilepsy services11.2.1 Involve young people with epilepsy in planning for their transition from children's to adult epilepsy services in line with the [NICE guideline on transition from children's to adults' services for young people using health or social care services](https://www.nice.org.uk/guidance/ng43).1.2.2 Ensure transition from children's to adults' epilepsy services is individually tailored to the young person with epilepsy.11.2.3 Begin planning transition early for young people who have complex or additional health and social care needs, for example young people whose seizures are not yet controlled or those with learning disabilities.11.2.4 During transition of young people with epilepsy to adult services, the paediatric and adult multidisciplinary teams should jointly review the person's diagnosis and management plan, taking a person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their care.11.2.5 Ensure that information about the young person's management plan and support for transition to adult services is discussed with the young person with epilepsy and shared in an accessible format that meets their needs and uses language they understand. Repeat this information at different time points to establish that the young person understands their care plan and the support that will be provided. | The Espente study highlighted that “Audits of epilepsy-related deaths demonstrate fragmented provision of services in the UK to people with epilepsy (Lewis et al 2011). Certain groups of patients with epilepsy are particularly vulnerable to services which fail to adequately link up. Young people, as they transition from child to adult services, and enter adulthood, often get insufficient help (Davis 2015).Lewis, S. (2011). *“Advances in epilepsy management: the role of the specialist nurse”*. Nurse Prescribing, 9(3), 131-15.Davis, C. (2015). *“Champions needed.”* Nursing Standard, 30(3), 63.[The ESPENTE Study 8.7.19 Version 1.pdf (epilepsy.org.uk)](https://www.epilepsy.org.uk/sites/epilepsy/files/research/The%20ESPENTE%20Study%208.7.19%20Version%201.pdf)NCEPOD study and audit: The aim of this study is to explore the process of the transition of young people with complex chronic conditions from child to adult health services. Inclusions Organisations providing healthcare to young people aged between 13 years and their 25th birthday with a complex chronic condition, transitioning from child to adult health services. Data is being collected on the services provided to young people identified over an 18-month period, from 1st October 2019 - 31st March 2021 As part of the study the epilepsy nursing team carried out an audit of patients transitioning from paediatric to adult epilepsy services. The audit highlighted the need for closer working with the paediatric team and children’s epilepsy nurses to ensure a smooth transition and to manage patient/parent expectation of the service.The service currently receives referral information after the patient has transitioned to the adult services neurology team who then refer to the adult epilepsy nursing service; there is no joint involvement prior to transition to adult services. We offer follow up reviews which are tailored to the young person’s needs, the young person/parents/caregivers are reassured that they can contact the service if they have any concerns about the young person’s epilepsy medication and seizures where their call will be taken promptly and an appointment made with the next available clinician.We also offer advice and support for young people leaving home, going to college and on to university.We recognise that this is an area that requires improvement.In the future we hope to be able to offer transitional online nurse-led group sessions. At present we signpost to Young Epilepsy, the Epilepsy Society and Epilepsy Action.<https://www.youngepilepsy.org.uk/for-young-people/adult-health-services.html> https://www.epilepsy.org.uk/info/children-young-adults/young-people [Adult health services: transition guide | For young people (youngepilepsy.org.uk)](https://www.youngepilepsy.org.uk/for-young-people/adult-health-services.html) |
|  | LivaNova | Children, young people & adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews. | Specialist epilepsy nurses are able to locally manage patients holistically along their patient pathway, including post-intervention for non-pharmacological treatments  | NG 217 states to “ensure that all children, young people and adults with epilepsy have access to an epilepsy specialist nurse who: * has a central role in providing information, education and support
* supports epilepsy specialists and healthcare professionals in primary and secondary care, and in educational, respite and social care settings
* is a point of contact for, and facilitates access to, other community and multi-agency services.

 Offer people with epilepsy an information and care-planning session with an epilepsy specialist nurse that includes emotional wellbeing and self-management strategies promoting inclusion and participation. For people with epilepsy who continue to have seizures, offer epilepsy specialist nurse sessions: * at least twice a year and
* after A&E department visits.

Consider epilepsy specialist nurse-led group sessions for education and information giving in young people and adults with epilepsy”. |
|  | NHS England | Access to specialist epilepsy nurses and learning disability health liaison nurses | Improving **access, and experience of epilepsy care and support** for people with a learning disability and autistic people including for Children and Young people and children transitioning to adult services  | LeDeR report (v.s.) has highlighted the impact of health liaison nursing support for people with a learning disability in potentially reducing avoidable deaths |
|  | NHS England- Children and Young People’s Transformation Programme | Access to Epilepsy Specialist Nurses  | Access to an epilepsy specialist nurse is associated with; * Decrease in emergency paediatric epilepsy admissions,
* Cost savings both long term and within the first year of care,
* Improving the quality of life for CYP with epilepsy, including improving knowledge and self-care, as well as reducing anxiety and depression, and
* supporting continuity of care between settings, as well as during transition.

The below graph shows variation in access to ESNs within NHSE Regions based on Epilepsy12 data:[chart not included in this table] | 1) NG217 Epilepsies in children, young people and adultsSection 11.1 in the above guidance makes clear that “all children, young people and adults with epilepsy have access to an epilepsy specialist nurse”2) [Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study - The Lancet Child & Adolescent Health](https://www.thelancet.com/pdfs/journals/lanchi/PIIS2352-4642%2819%2930201-9.pdf)The above paper demonstrates that reduced access to an epilepsy specialist nurse was associated with an increase in paediatric epilepsy admissions. 3) [A UK survey of the experience of service provision for children and young people with epilepsy – ScienceDirect](https://www.sciencedirect.com/science/article/pii/S105913111830147X)The above paper shows that the strongest influence [for parents/carers/young people in the satisfaction of services] was perceived ease of contacting the health service, and those reporting ease of contact were 106 times more likely (than those not finding contact easy) to be satisfied with their epilepsy care4) ESPENTE study from Epilepsy Action The study concludes *[k]ey to their [epilepsy specialist nurses] value is their specialist knowledge, their accessibility, the ability to cross boundaries, their ability to link up services and their leadership in service development and being a point of contact. RCTs and systematic reviews have demonstrated measurable benefits for patients including improvements in knowledge and quality of life.* However, the study also concludes *[t]here is also very limited research which reflects the very different models of practice and patient groups that they work with.*Epilepsy12 Measures:Percentage of Health Boards and Trusts who had some ESN provision within their paediatric service |
|  | NHS England- Children and Young People’s Transformation Programme | Transition Care | The need for continuity of care during transition from paediatric to adult services is particularly important for young people managing the physical and mental transition from adolescence to adulthood. 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. It also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood.[Epilepsy12 audit data](https://www.rcpch.ac.uk/sites/default/files/2022-07/epilepsy12-_main_report_2022.pdf) that only 64% of NHS trusts in England have an outpatient epilepsy service involving both adult and paediatric professionals. When analysing Epilepsy12 audit data, variation is evident across Regions and within ICSs within Regions, as per below graph.[Chart not included in this table]In addition, A [2021 Young Epilepsy survey](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) showed that:* 40% of young people said they had no joint appointments with children’s and adults’ epilepsy services as part of the transition process
* 32% of young people said their transition experience had a negative impact on their mental health.
 | NG217 [Epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) Section 11.2 in the above standard contains relevant guidance on Transition from children's to adults' epilepsy services. This includes the paediatric and adult multidisciplinary teams *should jointly review the person's diagnosis and management plan, taking a person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their care*.We would also encourage that ‘transition’ is explicitly separated from ‘handover’ within the standard, recognising that transition is a process whereas handover is an event. Epilepsy12 Measures: Percentage of Trusts where there is an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals |
|  | Ring20 Research and Support UK CIO | More epilepsy nurses | Epilepsy nurse support is fragmented and almost a postcode lottery.Determining the need for an epilepsy nurse is based on the number of A&E admissions for seizures. There is much more to epilepsy than emergency admissions and whilst these represent the most acute scenarios, support for those with rare and complex epilepsies is vital for optimum care and management. |  |
|  | Ring20 Research and Support UK CIO | Provision for appropriate transition services from paediatric to adult, especially among those affected by rare and complex epilepsies. | For individuals where epilepsy is a key symptom and is refractory to treatment, it is imperative that transition from paediatric to adult services is handled sensitively and appropriately, ensuring the young person and their family have the level of support req’d to continue their medical care for the remainder of their life. | Anecdotal evidence from families in our community. |
|  | Ring20 Research and Support UK CIO | Provision for multi-disciplinary team care for people with rare and complex epilepsies. | Rare and complex epilepsies are often associated with multiple comorbidities aside from difficult to treat seizures.It is important that the individual receives appropriate holistic care from their medical team for all their medical needs, not just in respect of their epilepsy and that this care package is coordinated, such that multiple specialisms are joined-up and working together to optimise outcomes and QoL. |  |
|  | Royal College of Paediatrics and Child Health | Access to patient centred care  | Optimised patient care and effective therapy approaches improves outcomes. Patient safety and patient experience including being treated according to what the individual wants with compassion, dignity, and respect. |  |
|  | SCM1 | All children and adults diagnosed with epilepsy should have immediate access to an epilepsy specialist nurse | Epilepsy12 audit 2019-1021showed that:* 71% (1644/2106) of children and young people diagnosed with epilepsy had an input from an ESN in their 1st year of care
 | NICE guideline Epilepsies 2022 |
|  | SCM2 | Risk communication, patient and healthcare professional information and knowledge gaps remain | The advancements in epilepsy and new terminology requires embedding into practice and communicated effectively to patients. The recognition of complex information and risk sensitive information requiring skilled communication by healthcare professionals and patient groups. The communication of SUDEP is exampled here, individual variability of healthcare practice, of when and what to communicate, and have different referral criteria for psychological support for the patient coping with risk information, adequacy of follow-up after sensitive information presented. | The NICE Guideline 2022 continues a long list of items of information to be provided to the patient. The delivery and methods of communication are not detailed resulting in variability of care<https://www.nice.org.uk/guidance/ng217/chapter/2-Information-and-support> |
|  | SCM2 | Transition care for young people with epilepsy into adult epilepsy care | There remains a vulnerable population of young people who miss-out on transition and fail to be seen until crisis. The variable nature of seizures in remission during transitional year of age can result in young people seen at low risk, discharged to primary care and not routinely seen in specialist transition clinics. Those young people with complex health needs having different aspects of their healthcare transitioned at different time, can be at risk of epilepsy if controlled at the start of transition of a lack of preparation if seizures relapsed leaving the young person between adult and child seizures. A delay in transition results in the young person and their family/carers not having knowledge of who to contact if seizure deteriorated.Young people who have become stable and not having regular review, stable on ASM discharged to primary care on ASM, at risk of failing to receive updates of information to influence care decisions. Example, woman of childbearing age missing preconception updates and stopping ASM on discovery of unplanned pregnancy. Or, young person seizure free withdrawing from ASM when driving unaware of risks of seizure relapse and DVLA guidance.  | Combination of NICE guidance on transition and information provision.<https://www.nice.org.uk/guidance/ng217/chapter/11-Service-provision-and-transition><https://www.nice.org.uk/guidance/ng217/chapter/2-Information-and-support> The research recommendation 3 for care of young people discharged from child services to primary care was highlighted in the NICE Transition guideline<https://www.nice.org.uk/guidance/ng43/chapter/Recommendations-for-research>Further the recommendation 4 NICE transition guideline, to research the consequences and costs of poor transition, is relevant for young people with complex health conditions where transition can be interrupted not streamlined due to differing priority needs at the start of transition. |
|  | SCM3 | For all people with epilepsy to have access to an Epilepsy Nurse Specialist (ENS) | NICE recommends that all people with epilepsy should have access to an epilepsy specialist nurse who provides information and support (11.1.1) and assists with care planning, including self-management (11.1.2).Epilepsy12 data shows that 89% of NHS trusts in England employ epilepsy specialist nurses, this varies across regions. However, this is as low as 67% in some trusts. People felt it is easier to speak with their epilepsy nurse than their epilepsy doctor and feel they explain things more clearly (Young Epilepsy survey 2021)ESPENTE (2019) found that the ENS is highly valued by patients, their families and other professionals. There are measurable benefits to patients having access to an ENS. The role is highly valued and cost effective. They work across boundaries (hospital, community, school and home). They support transition from childhood to adulthood. Currently the ENS’s have excessively large caseloads and the service becomes quickly overburdened.  | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) Recommendations 11.1.1 and 11.1.2.[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)Percentage of NHS trusts in England that employ epilepsy specialist nurses.[Young Epilepsy (2021) *Young people’s changing experiences of epilepsy care: Summary of survey findings*](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf)<https://www.epilepsy.org.uk/sites/epilepsy/files/research/The%20ESPENTE%20Study%208.7.19%20Version%201.pdf> |
|  | SCM3 | Better transition between paediatric and adult services  | NICE recommendation that during a young person’s transition to adult epilepsy care, their diagnosis and management plan should be jointly reviewed with paediatric and adult servicesthe Epilepsy12 audit shows that only 64% of NHS trusts in England have an outpatient epilepsy service involving both adult and paediatric professionals.There is significant difference between transition in different areas People can be lost in transition and miss out of services There needs to be better preparation for patients and their families when starting transition The ENS has a key role to play in supporting a seamless transition  | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) Recommendation 11.2.4[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)Percentage of NHS trusts in England that have an epilepsy clinic where both adult and paediatric professionals are present.<https://www.epilepsy.org.uk/sites/epilepsy/files/research/The%20ESPENTE%20Study%208.7.19%20Version%201.pdf> |
|  | SCM4 | Epilepsy specialist nursing provision | Epilepsy specialist nursing provision for people with epilepsy is variable in the UK, and the roles adopted by the nurses is also variable. A standard of rapidity of response to an enquiry or number of wte epilepsy nurses per head of population would be useful in helping to standardize care across England and Wales | NICE guideline recommendation 11.1 covers the provision of nursing support |
|  | SCM6 | Provision of epilepsy nurses  | My experience as a lay member and hearing about other’s experiences is that the provision of epilepsy nurses is patchy across the UK. Some people have one, some don’t and the degree of responsiveness from the epilepsy nurse varies as well. This may be due to caseload size. A fourth measure in process may be proportion of people who receive a response within X days from an epilepsy specialist nurse. The epilepsy nurse can also provide a valuable service in training other caregivers in seizure management including administering emergency medication. This is not currently mentioned. This work ensures that caregivers, (e.g. other family members, teachers school transport escorts) can be confident in seizure management.  |  |
|  | SCM6 | Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually. | This statement seems to be very wide as it could encompass both people who have epilepsy controlled by drugs and therefore rarely experience seizures (around 70%) and people who are drug resistant (around 30%) and experience very regular seizures and have very complex and difficult to control epilepsy. It would seem more meaningful to recognised these differences in severity and recommend the frequency of appointments accordingly.  |  |
|  | SCM7 | Children young people and adults having an information and care planning session with an epilepsy specialist nurse in last 12 months. | Epilepsy 12 audit has tracked an improvement in access to nurses in first year of care for children but this is still not universal. Economic evidence supported the recommendation 12 in the guideline re specialist nurse input for adults too. NASH report showed adults attending A&E following seizures had often not had review in past 12 months and many were not followed up. In some services nurses are notified and follow up epilepsy patients who have been admitted or attended A&E |  |
|  | SCM8 | Reduction of mortality in people with epilepsy |  |  |
|  | SCM8 | Improving transition of adolescents with epilepsy  |  |  |
|  | UK Rare Epilepsies Together | A written epilepsy care plan, including information for families and other settings | Children and young people with epilepsy should have an agreed, written epilepsy care plan to ensure continuity of support across different settings.Welcome the NICE recommendation that all people with epilepsy should have access to an epilepsy specialist nurse who assists with care planning, including self-management (11.1.2). Also welcome the NICE recommendations on the development and content of care plans, including emergency care plans (2.1.7 and 7.1.12).The Epilepsy12 audit’s most recent data shows that 72% of children and young people with epilepsy in England had evidence of a care plan that had been both updated as needed and agreed between the child, their family and their healthcare provider. | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217)* Recommendations 11.1.2, 2.1.7 and 7,1,12.

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of children and young people that had evidence of a care plan that had been both updated as needed and agreed between their child, their family and their healthcare provider.

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|  | UK Rare Epilepsies Together | Access to an epilepsy specialist nurse for all | All children and young people with epilepsy should have access to an epilepsy specialist nurse.Welcome the NICE recommendation that all people with epilepsy should have access to an epilepsy specialist nurse who provides information and support (11.1.1) and assists with care planning, including self-management (11.1.2).Whilst Epilepsy12 data shows that 89% of NHS trusts in England employ epilepsy specialist nurses, this varies across regions. | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217)* Recommendations 11.1.1 and 11.1.2.

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of NHS trusts in England that employ epilepsy specialist nurses.

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|  | UK Rare Epilepsies Together | Joint review of young people’s care by paediatric and adult services during transition | Young people with epilepsy should participate in a joint review of their care with both paediatric and adult services, as part of the transition process.Welcome NICE recommendation that during a young person’s transition to adult epilepsy care, their diagnosis and management plan should be jointly reviewed with paediatric and adult services, ‘taking a person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their care’. (11.2.4)Data from the Epilepsy12 audit shows that only 64% of NHS trusts in England have an outpatient epilepsy service involving both adult and paediatric professionals. | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217)* Recommendation 11.2.4

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of NHS trusts in England that have an epilepsy clinic where both adult and paediatric professionals are present.

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|  | University Hospitals Birmingham | Access to epilepsy specialist nurses (ESNs) for patients presenting acutely with seizures | NG217 recognises that patients with ongoing seizures should have six monthly access to ESNs and access to ESNs following A/E visits.There is limited direct access to ESNs via A/E (especially for those not known to neurology services)- there needs to be a standardised acute seizure pathway facilitating this. | Epilepsy Specialist Nurses: The Evidence (ESPENTE) Epilepsy Action October 2019 highlights value of ESN in coordinating services between healthcare professionals and specialties. |
|  | Young Epilepsy | A written epilepsy care plan, including information for families and other settings | Children and young people with epilepsy should have an agreed, written epilepsy care plan to ensure continuity of support across different settings.Young Epilepsy welcomes the NICE recommendation that all people with epilepsy should have access to an epilepsy specialist nurse who assists with care planning, including self-management (11.1.2). We also welcome the NICE recommendations on the development and content of care plans, including emergency care plans (2.1.7 and 7.1.12).Recommendation 2.1.7 states, for example, ‘*Provide the person with epilepsy, and their family or carers if appropriate, with a copy of their care plan, which includes details of their care and support as discussed and agreed with the person, and their family or carers if appropriate’.*The Epilepsy12 audit’s most recent data shows that 72% of children and young people with epilepsy in England had evidence of a care plan that had been both updated as needed and agreed between the child, their family and their healthcare provider. [1]Care plans developed with healthcare providers can help ensure continuity of support across different settings, for example at home and at school. These medical plans can inform (or be incorporated into) wider support plans, such as Individual Healthcare Plans (IHPs) used in schools. In state schools in England, schools are expected to have IHPs in place for children with medical conditions. However, emerging findings from a recent Young Epilepsy survey of young people and parents show that only 56% of children with epilepsy at school have an IHP.[RCPCH (2022) Epilepsy12 national clinical audit of seizures and epilepsies for children and young people, Appendix B](https://www.rcpch.ac.uk/sites/default/files/2022-07/appendix_b_-_epilepsy12_2022.pdf)Young Epilepsy survey on epilepsy support at school, due to be published later this year. | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) * Recommendations 11.1.2, 2.1.7 and 7,1,12.

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of children and young people that had evidence of a care plan that had been both updated as needed and agreed between their child, their family and their healthcare provider.
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|  | Young Epilepsy | Access to an epilepsy specialist nurse for all | All children and young people with epilepsy should have access to an epilepsy specialist nurse.Young Epilepsy welcomes the NICE recommendation that all people with epilepsy should have access to an epilepsy specialist nurse who provides information and support (11.1.1) and assists with care planning, including self-management (11.1.2).Whilst Epilepsy12 data shows that 89% of NHS trusts in England employ epilepsy specialist nurses, this varies across regions. For example, in several OPEN UK regions, there are epilepsy specialist nurses in 100% of trusts, in others this is as low as 67%. [1]A Young Epilepsy survey [2] found that more young people in paediatric care felt listened to by their epilepsy nurse (72%) than by their epilepsy doctor (59%). More young people also said their paediatric epilepsy nurse explained things clearly (68%), in comparison to their epilepsy doctor (59%).1 [RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people, Appendix A*](https://www.rcpch.ac.uk/sites/default/files/2022-07/appendix_a_-_epilepsy12_2022.pdf)2 [Young Epilepsy (2021) *Young people’s changing experiences of epilepsy care: Summary of survey findings*](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) * Recommendations 11.1.1 and 11.1.2.

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of NHS trusts in England that employ epilepsy specialist nurses.
 |
|  | Young Epilepsy | Joint review of young people’s care by paediatric and adult services during transition | Young people with epilepsy should participate in a joint review of their care with both paediatric and adult services, as part of the transition process.Young Epilepsy welcomes the NICE recommendation that during a young person’s transition to adult epilepsy care, their diagnosis and management plan should be jointly reviewed with paediatric and adult services, ‘taking a person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their care’. (11.2.4)Data from the Epilepsy12 audit shows that only 64% of NHS trusts in England have an outpatient epilepsy service involving both adult and paediatric professionals. [1]A Young Epilepsy survey [2] found significant disparities in how many joint appointments young people with epilepsy received as part of the transition process. The largest proportion of young people who had transitioned to adult epilepsy care said they had no joint appointments with children’s and adults’ epilepsy services (40%). However, 27% had more than three joint appointments. Around 1 in 3 young people (32%) said their experience of moving from children’s to adults’ epilepsy services had a negative impact on their mental health.The survey also found that nearly half of the young people (45%) said their treatment or diagnosis changed when they moved to adults’ epilepsy services. 1 [RCPCH (2022) Epilepsy12 national clinical audit of seizures and epilepsies for children and young people, Appendix A](https://www.rcpch.ac.uk/sites/default/files/2022-07/appendix_a_-_epilepsy12_2022.pdf)2 [Young Epilepsy (2021) *Young people’s changing experiences of epilepsy care: Summary of survey findings*](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) * Recommendation 11.2.4

[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)* Percentage of NHS trusts in England that have an epilepsy clinic where both adult and paediatric professionals are present.
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#### Psychological, neurobehavioural, cognitive and developmental comorbidities

| **ID** | **Stakeholder** | **Key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
|  | NHS England | Improving personalised care to meet the needs of people who have a learning disability and autistic people and people who may be under-recognised, ensuring reasonable adjustments are made to support care.  | In similar vein to quality improvement 1, ensuring that services and staff offer and make reasonable adjustments for people who have a learning disability and autistic people and people who may be under-recognised e.g: people in the Criminal Justice System; Gypsy, Roma and Traveller communities, ethnic minorities and refugees. And those who present severe behavioural challengesReasonable adjustments could include: e.g: easy read, longer appts, carer/family member present, accessible information, extra follow up, flexibility in appts | Please see the Kings College London LeDeR report which highlights that epilepsy is a significantly occurring condition in people with intellectual disability and a significant cause of premature mortality as identified in the LeDeR annual report 2021 by Kings College London [leder-main-report-hyperlinked.pdf (kcl.ac.uk)](https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf): KCL found that having a diagnosis of epilepsy …[was] associated with younger age at death. This suggests that improvements in treatment of these conditions may help to delay age at death.  |
|  | NHS England | Improving safety procedures for people with a learning disability and autistic people | Improving safety procedures to reduce unnecessary mortality of people with epilepsy who also have a learning disability and autism which place them at higher risk (e.g inappropriate supervision and inappropriate prescribed medications).  | Please see the Kings College London LeDeR report which highlights that epilepsy is a significantly occurring condition in people with intellectual disability and a significant cause of premature mortality as identified in the LeDeR annual report 2021 by Kings College London [leder-main-report-hyperlinked.pdf (kcl.ac.uk)](https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf): KCL found that having a diagnosis of epilepsy …[was] associated with younger age at death. This suggests that improvements in treatment of these conditions may help to delay age at death.  |
|  | NHS England- Children and Young People’s Transformation Programme | Access to Mental Health Screening and Psychosocial Support  | Research suggests 37% of five to 15 year olds with epilepsy had a co-existing mental health condition ([A population survey of mental health problems in children with epilepsy)](https://psycnet.apa.org/record/2003-00506-002). However, [Epilepsy12 audit data](https://www.rcpch.ac.uk/sites/default/files/2022-07/epilepsy12-_main_report_2022.pdf) shows that only 5% of CYP aged five to 15 years and diagnosed with epilepsy, had an identified mental health condition.This may be due to only 19% of Trusts screening for mental health disorders ([Epilepsy12 Cohort 3](https://www.rcpch.ac.uk/sites/default/files/2022-07/epilepsy12-_main_report_2022.pdf))**,** possibly resulting in missed opportunities for referrals into appropriate mental health pathwaysA [Young Epilepsy survey](https://www.youngepilepsy.org.uk/dmdocuments/Young%20people%27s%20experiences%20of%20epilepsy%20and%20mental%20wellbeing%20-%20Survey%20findings%20-%20Nov%2021.pdf) found that 77% of young people said living with epilepsy has had a significant impact on their mental wellbeing, including their thoughts, feelings and how they are able to cope with everyday life.In addition, [another Young Epilepsy survey](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf) found that only 45% of young people (aged 11 to 25) said their epilepsy doctor or nurse had spoken to them about how epilepsy might impact on their mental health.[Response included a chart that is not shown in this table.] | NG217 [Epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) Section 9.1 and 9.2 contains relevant guidance towards psychological, neurobehavioural, cognitive and developmental comorbidities in epilepsy. This includes *the need to provide coordinated care for people with epilepsy who have a mental health condition or learning disability using a multidisciplinary team approach and to offer assessment and provide mental health support and treatment for people with epilepsy and depression.* *We would encourage if the quality standard could explore further any standards on a multidisciplinary team approach and on screening.*Epilepsy12 measures:Percentage of Health Boards and Trusts routinely providing formal [mental health] screening servicesPercentage of Health Boards and Trusts that had agreed referral pathways for children and young people with mental health conditions |
|  | Royal College of Paediatrics and Child Health | Easy access to psychologist and Child and Adolescent Mental Health services | It has been well reported that the incidence of mental health problems is high in children with epilepsy.Children with intelligence disabilities have the most difficult to control forms of epilepsy. These children often have coexisting co-morbidities such as ASD, ADHD etc in addition to Mental disorders such as Anxiety disorders, Depression, CD, ODD, OCD etc. Interactions between medications also poses a problem. | Unfortunately, it is not quite easy for the CAMHS referral being accepted for children with epilepsy and suspected mental health issues such as emotional dysregulation or anxiety.This group of children should have a separate fast track pathway for CAMHS referral and assessment. |
|  | SCM1 | All children and young people with epilepsy should have ongoing screening for mental health problems using a validated tool as part of their routine epilepsy care. Where there are concerns about mental health, children and young people should be referred to an appropriate mental health service via an agreed pathway. There should be timely access to diagnosis and treatment.  | There is a lack of psychosocial support for CYP with epilepsy Research studies showed that 37% of 5 to 15 year olds with epilepsy had a co-existing mental health condition.However the Ep12 national audit showed: * 5% (68/1358)of children and young people, between the age of 5-15 years and diagnosed with epilepsy, had an identified mental health condition.
* 17% (20/119)of Health Boards and Trusts have formal screening for mental health disorders.
 | NICE guideline 2022 |
|  | SCM2  | Diagnosis and Care of persons with dementia presenting with seizures | The population risk of dementia and Alzheimer’s with co-morbidity with seizures is increasing. This is a vulnerable group who care is provided across varied healthcare professionals and establishments delivering care. This results in inconsistent care provision across regions and postcodes. Service variation is influenced by professional specialism. Patients in care homes and cared in own home by elderly relatives are vulnerable in gaining access to diagnosis and treatment and subsequent access to follow-up care. | Refer to NICE Dementia guideline [NG97] 2018 and the implementation of the guideline refers to the need to raise awareness of dementia. With dementia a cause of seizures this links to this guideline.<https://www.nice.org.uk/guidance/ng97/chapter/Putting-this-guideline-into-practice>To apply NICE guideline for the Epilepsies for access to diagnosis and treatment.<https://www.nice.org.uk/guidance/ng217/chapter/1-Diagnosis-and-assessment-of-epilepsy> |
|  | SCM3 | Improved mental health screening, support, resources and treatment incorporated into epilepsy care | Mental health screening and support should be an integrated into every patient’s epilepsy care NICE recommend that mental health should be reviewed as part of epilepsy care Epilepsy12 show shortfall in mental health screening in epilepsy clinics Patients report living with epilepsy has a significant impact on their mental health.Screening tools could be improved  | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) Recommendations 9.1.2 and 9.2.2.[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)Percentage of NHS trusts in England that a) formally screen for mental health disorders and b) facilitate mental health provision in paediatric epilepsy clinics.[Young Epilepsy (2021) *Young people’s experiences of epilepsy and mental wellbeing: Summary of survey findings*](https://www.youngepilepsy.org.uk/dmdocuments/Young%20people%27s%20experiences%20of%20epilepsy%20and%20mental%20wellbeing%20-%20Survey%20findings%20-%20Nov%2021.pdf) |
|  | SCM3 | Improve the quality of service patients with a epilepsy and a learning disability (LD) and their families and carers receive | NICE report that there is higher prevalence of LD in people with epilepsy than the general population and coordinated care must be provided. LeDeR found: Epilepsy affects about 1 in 5 people with a learning disability. Epilepsy is harder to control for individuals with a LD and has greater potential to negatively impact the quality of life if an individual and their family’s needs are unmet.Individuals with a LD can die up to 25 years earlier than the general population. A major direct and contributory cause is epilepsy. Five percent of people died as a direct result of seizures and seizures were an associated condition in 45 % of all premature deaths. Sudden Unexpected Death in Epilepsy (SUDEP) is considered to be three to nine-fold higher in LD than general populations.Premature avoidable deaths in people with a learning disability have been linked to problems with treatment plans and the lack of reasonable adjustments for better access and management of health conditions.Avoidable emergency attendances are five times higher in people with learning disabilities than the general population and the most common cause is seizures | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) Recommendations 9.1LeDeR Learning from lives and deaths – People with a learning disability and autistic people [leder-main-report-hyperlinked.pdf (kcl.ac.uk)](https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf) |
|  | SCM4 | Psychotherapy provision | Psychotherapeutic support for patients with epilepsy is variable and usually inadequate in the UK. This is even more true for patients with non-epileptic seizures, who often have experienced severe psychological trauma. Provision of adequate therapeutic support, as measured by access waiting times, would be helpful | NICE guideline recommendation 9.1,5 covers this aspect |
|  | SCM7 | Children young people and adults with epilepsy are more likely than the general population to experience problems with cognitive function and with their mental health. | Annual reviews do not routinely include basic assessments of anxiety and depression or difficulties with concentration and memory. Referral to psychological services is not always easily enabled or designed into pathways of care. | Epilepsy 12 has tracked access to mental health services for children and young people. The Neurological Alliance ‘Parity of Esteem’ report showed that access to IAPT type psychological support services was problematic for people with neurological conditions. |
|  | SCM7 | The care of people with learning disabilities and epilepsy. | The care of people with learning disabilities and epilepsy is not well co-ordinated in many areas as it is provided by different professionals and services may not offer holistic care. Joint appointments are best practice neurology may not be able to see LD care records and vice versa. The guideline recognised that people with LD may not have accessed the same quality of service and provided a summary document of recommendations for this vulnerable population.  | The Step Together report covers the issues of fragmented care, sub optimal treatment and mortality risk in people with learning disabilities who have seizures. It recommends improved training across the health and social care workforce. Inclusion in a quality standard of need to develop shared care plans could help implementation and patient safety. |
|  | SCM8 | Improving care of people with epilepsy and learning disability |  |  |
|  | UK Rare Epilepsies Together | Mental health screening and support integrated into epilepsy care  | Mental health screening and support should be an integrated part of children and young people’s epilepsy care. Welcome the NICE recommendation to provide coordinated care for people with epilepsy who have a mental health condition (9.1.2). Also welcome the recommendation to review mental health as part of routine epilepsy care (9.2.2). Epilepsy12 audit show that only 19% of paediatric epilepsy clinics in England formally screen for mental health disorders. Audit figures also show that only 19% of NHS trusts in England facilitate mental health provision in paediatric epilepsy clinics.Over 10,000 people in the UK have supported the call for mental health screening and support to be integrated into paediatric epilepsy care. | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217)Recommendations 9.1.2 and 9.2.2.[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)Percentage of NHS trusts in England that a) formally screen for mental health disorders and b) facilitate mental health provision in paediatric epilepsy clinics. |
|  | University Hospitals Birmingham | Timely access to psychological support for patients with epilepsy | NG217 recognises that patients with epilepsy should be offered mental health support and treatment if, for example, they are suffering from concurrent depression.However, timely access to mental health services, neuropsychology in particular, is limited in various parts of the UK. There needs to be a standardised pathway enabling patients to access specialist mental health support.  | Cochrane Review 2020: Psychological treatments for people with epilepsy concluded that skills-based psychological interventions improve Health-Related Quality of Life in this population. |
|  | Young Epilepsy | Mental health screening and support integrated into epilepsy care | Mental health screening and support should be an integrated part of children and young people’s epilepsy care.Young Epilepsy welcomes the NICE recommendation to provide coordinated care for people with epilepsy who have a mental health condition (9.1.2). We also welcome the recommendation to review mental health as part of routine epilepsy care (9.2.2).Figures from the Epilepsy12 audit show that only 19% of paediatric epilepsy clinics in England formally screen for mental health disorders. Audit figures also show that only 19% of NHS trusts in England facilitate mental health provision in paediatric epilepsy clinics. [1]A Young Epilepsy survey found that 77% of young people said living with epilepsy has had a significant impact on their mental wellbeing, including their thoughts, feelings and how they are able to cope with everyday life. [2]Despite the increased risk of experiencing mental health problems, a further Young Epilepsy survey found that only 45% of young people (aged 11 to 25) said their epilepsy doctor or nurse had spoken to them about how epilepsy might impact on their mental health. [3]Over 10,000 people in the UK have supported the call for mental health screening and support to be integrated into paediatric epilepsy care. [4]1 [RCPCH (2022) Epilepsy12 national clinical audit of seizures and epilepsies for children and young people, Appendix A](https://www.rcpch.ac.uk/sites/default/files/2022-07/appendix_a_-_epilepsy12_2022.pdf)2 [Young Epilepsy (2021) *Young people’s experiences of epilepsy and mental wellbeing: Summary of survey findings*](https://www.youngepilepsy.org.uk/dmdocuments/Young%20people%27s%20experiences%20of%20epilepsy%20and%20mental%20wellbeing%20-%20Survey%20findings%20-%20Nov%2021.pdf)3 [Young Epilepsy (2021) *Young people’s changing experiences of epilepsy care: Summary of survey findings*](https://www.youngepilepsy.org.uk/dmdocuments/NEW%20Young%20people%27s%20experiences%20of%20epilepsy%20care%20-%20Survey%20findings.pdf)4 [Young Epilepsy (2022) *Petition: Children with epilepsy need better mental health support*](https://supporter.youngepilepsy.org.uk/children-epilepsy-need-better-mental-health-support) | [NICE (2022) *Guideline NG217: Epilepsies in children, young people and adults*](https://www.nice.org.uk/guidance/ng217) Recommendations 9.1.2 and 9.2.2.[RCPCH (2022) *Epilepsy12 national clinical audit of seizures and epilepsies for children and young people*](https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2022)Percentage of NHS trusts in England that a) formally screen for mental health disorders and b) facilitate mental health provision in paediatric epilepsy clinics. |

#### Additional Areas

| **ID** | **Stakeholder** | **Key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
|  | Angelini Pharma UK-I Ltd | Evidence based formularies and prescribing (access to treatments)  | To minimise inequalities, we propose there is a quality standard around access to and prescribing of evidence based, cost-effective treatments as per NICE assessments and evidence reviews  | Please the Evidence summary [NG217 Evidence review F (nice.org.uk)](https://www.nice.org.uk/guidance/ng217/evidence/f-addon-therapy-for-generalised-tonicclonic-and-focal-onset-seizures-pdf-398366282815)  |
|  | Jazz Pharmaceuticals | Audit of specialised service provision | There are some patients who face challenges in accessing tertiary centres in England or cannot access treatments reimbursed by NICE. This creates inequity and contributes to the variability in complex epilepsy care across the UK.  | An audit of specialised service provision would outline areas for improvement and where there are gaps in resources or funding for these services. |
|  | Jazz Pharmaceuticals | Urgent need for recording epilepsy patient data (e.g. registries) | Data on the prevalence, incidence and management of epilepsy including rare and complex epilepsies in England (and the UK) are extremely limited. Optimising the epilepsy services requires a thorough and concise understanding of the size of the problem, issues or barriers to care and the approaches to treatment. An epilepsy registry would go some of the way to addressing this evidence gap.  | There is a lack of Epilepsy registries in the UK, and therefore a lack of UK‑specific epidemiology and management data in epilepsy and rare epilepsy directly applicable to the UK population.  |
|  | Matthew’s Friends for Ketogenic Dietary Therapies  | Full extent of KDT outcomes are not reflected in the research | Research outcomes are based on seizure numbers, so other areas of improvement in patient health & wellbeing become anecdotal evidence | NICE guidelines 1.1.10.1 & 1.1.10.3<https://www.sciencedirect.com/science/article/pii/S1059131122001133?utm_campaign=STMJ_AUTH_SERV_PUBLISHED&utm_medium=email&utm_acid=81680743&SIS_ID=&dgcid=STMJ_AUTH_SERV_PUBLISHED&CMX_ID=&utm_in=DM258621&utm_source=AC_> Need for specific Q of L measuring toolsPossible national data base with 3 – 6 monthly input following clinic appointments |
|  | Matthew’s Friends for Ketogenic Dietary Therapies  | Poor quality of research into dietary treatments due to heterogeneity & low numbers | KDT ***is a*** ***heterogenous therapy***. One size does not fit all, and the choice of KD approach depends on the medical, nutritional, practical & support requirements etc. of the individual. The prescription is then adjusted over the weeks and months according to mutually agreed home monitored outcomes. KDT requires a commitment to learn new knowledge and skills around food choice, meal preparation and self-monitoring (for both the KDT treatment team and the patient). It will only ever be used by those patient’s (or carers) who are fortunate to be offered a chance to explore it and then actively ***choose*** it. KDT has far less commercial potential than drug-based treatments/ medical devices therefore investment in services and evaluation has been extremely limited. The provision of adult KDT services in the UK is extremely limited; 3 small services in England and no provisions in Scotland, Wales or Northern Ireland. For the 25-30% of UK adults with poorly controlled epilepsy *for whom other treatment options have been exhausted*, KDT will continue to be unavailable to the majority, despite *their individual clinical need.* Standard care is compared to dietary therapy, yet taking a tablet is a passive requirement, changing the way you eat We need a way to evaluate the treatments as a whole, with follow up research tools to examine trends for types of treatment particularly suiting a certain age group, syndrome etcAs it stands efficacy of dietary treatments cannot be evaluated as a whole.  | **A national database of real life KDT therapy could collect information on quality of life across therapy stages at 3-6 mnthly intervals**?**UK Multi-centre studies of selected groups.**Growth from paediatric centres & Keto college to educate new/extended centres to develop adult services across UK. Low numbers in studies especially adults reflects lack of adult centres to refer to. |
|  | Matthew’s Friends for Ketogenic Dietary Therapies  | Economics of dietary treatment | NICE guidance is not based on UK information. Information is lacking. | Section 1.1.10.4**Need for research into economics in UK dietary services.** There is evidence for effectiveness of KDT in specific epilepsy syndromes – need early treatment to save costs long term. Note infant data not included? Why?  |
|  | Matthew’s Friends for Ketogenic Dietary Therapies  | Safety of long term dietary treatment if required | Little long term research especially in adults | Section 1.1.10.3 **A national database of KDT therapy could** **gather overall safety information that could be used to understand safety I selected groups such as the enterally fed (adults and children) or self-caring adults .**  |
|  | Matthew’s Friends for Ketogenic Dietary Therapies  | Evidence regarding adverse effects in Dietary Therapies.  | The guideline misrepresents the purpose and emphasis of the KD monitoring as just about adverse effects (1.1.1) when in practice the monitoring primarily provides the navigational data, informing prescription adjustments to optimise efficacy. The list of adverse events depends on the evidence included – see variance between included meta-analysis and another on infants not included (next column). From 10+ years of clinical KDT practice treating adults and children, our experience has been that adverse effects are usually mild and easily managed, rarely leading to cessation of the therapy.  | *1.1.10.3****Included in NICE assessment****‘Adverse effects Follow-up: 3 months to 6 months The most frequent adverse effects reported by children were vomiting, constipation and diarrhoea. Two studies reported weight loss, with one study stating that weight loss and gastrointestinal disturbances were more frequently reported with 4:1 KD versus 3:1 KD. One study reported a significantly high incidence rate for hypercalciuria amongst children receiving classic KD compared to MAD at three months. There was no significant difference in weight loss between treatment groups given 20 mg/d versus 10 mg/d carbohydrates. Other adverse effects reported included: dysphagia, lethargy, lower respiratory tract infection, hyperammonaemic encephalopathy, nausea, infections (pneumonia, sepsis), acute pancreatitis, decrease in bone matrix density, gallstones, fatty liver, nephrocalcinosis, hypercholesterolaemia, status epilepticus, acidosis, dehydration, tachycardia, hypoglycaemia, hunger, abdominal pain, clinically relevant reduction in height, hypercalcinaemia and renal stones’****Not included in NICE assessment****Adverse events were reported in 83 infants, across six studies including a total of 171 infants (Table 3). The most commonly reported side effects were dyslipidemia (20/171, 12%), vomiting (11/171, 6%), constipation (7/171, 4%), gastroesophageal reflux (6/171, 4%), and diarrhea (6/171, 4%). The time points at which side effects occurred was mostly unspecified (Table 3). Vomiting was more frequently reported within the first 3 months of KDT. Dyslipidemia was reported in 17 of 104 infants (16%) in one study, although only one child required dietary intervention to resolve this. Another study reported a mild elevation in serum triglycerides in one infant, who continued the diet, and “markedly elevated triglyceride level concerning for lipoprotein lipase deficiency” in another; one infant had type I hyperlipidemia after following KDT for 23 months.* *Lyons L, Schoeler NE, Langan D, Cross JH. Use of ketogenic diet therapy in infants with epilepsy: A systematic review and meta-analysis. Epilepsia. 2020;61:1261–1281.* https://onlinelibrary.wiley.com/doi/10.1111/epi.16543**A national database of KDT therapy could collect information on adverse events, resolutions and outcomes****at 3 – 6 monthly time points?**  |
|  | NHS England | Improving use of digital and AI technologies in diagnosis and management of epilepsies  | * high levels of diagnostic and clinical skills are required in the assessment and support of epilepsies in people with intellectual disability
* Seizures are commonly of multiple types and are often resistant to single-drug treatment

Poorly controlled epilepsy can have major impact on quality of life and mortality | See Royal College of Psychiatrists – Good Psychiatric Practice Guide Management of epilepsy in adults with intellectual disability *e*.g. Paper in Lancet on AI systems in analysing EEG data<https://doi.org/10.1016/j.ebiom.2021.103275> |
|  | Royal College of Paediatrics and Child Health | Addressing the considerable gaps in epilepsy treatment and knowledge | The considerable heterogeneity in disease burden in terms of social status, culture, ethnicity and genetics, in addition to the taboos, stigmas and misconceptions widen the treatment and knowledge gaps which ultimately result in big challenges |  |
|  | Royal College of Paediatrics and Child Health | RIGHT tool [Reporting Items for practice Guidelines in HealThcare] | Adhering to the RIGHT tool - reporting terms for practice guidelines in healthcare - produced by a component of WHO. |  |

#### No comments / other comments

| **ID** | **Stakeholder** | **Key area for quality improvement** | **Why is this a key area for quality improvement?** | **Supporting information** |
| --- | --- | --- | --- | --- |
|  | Association of British Neurologists (ABN) | Previously published quality standards | We believe that the majority of the quality standards published in 2013 are still valid. In addition to these, we would like to highlight some additional areas for improvement.  |  |
|  | Royal College of General Practitioners | The RCGP did not have any comments for the topic engagement portion of the development of this quality standard, however we aim to engage further down the development process during the consultation stages. |  |  |
|  | Royal College of Nursing | We do not have anything to add on this topic engagement. Thank you for the opportunity to contribute. |  |  |