EPILEPSY12

The national clinical audit of health care for children and young people with suspected epileptic seizures

Overview of the methodology for Round 4
(1 April 2022 – 31 March 2025)

As of December 2024

Contents:

Epilepsy12 Aims	**Page 3**
Audit structure and engagement	**Page 3**
Epilepsy12 Round 4 Components	**Page 4**
Service Descriptor Domain	**Page 4**
Clinical Care Domain	**Page 5**
- Clinical Cohort Ascertainment	Page 5
- Initial patient registration	Page 5
- Eligibility Confirmation	Page 5
- Key referencing audit criteria	Page 6
- Verified Patients	Page 6
- Diagnostic status dataset	Page 7
- Ongoing auditing	Page 7
- Diagram showing dataset organisation (dataset macro)	Page 8
- Ascertainment and data completeness	Page 8
- Participation completeness	Page 8
- Ascertainment completeness	Page 8
- Internal Ascertainment completeness	Page 9
- Data completeness	Page 9
Epilepsy 12 Clinical Performance Indicators	**Page 9**
Table of Epilepsy 12 Clinical Performance Indicators	**Page 10**
Involvement of appropriate professionals	Page 10
1. Paediatrician with expertise in epilepsies within 2 weeks	Page 10
2. Access to Epilepsy Specialist Nurse	Page 10
3. a . Tertiary input	Page 10
3. b. Epilepsy Surgery Referral	Page 11
Evidence of appropriate assessment	Page 11
4. ECG	Page 11
5. MRI within 6 weeks	Page 11
Mental Health	Page 11
6. Assessment of mental health issues	Page 11
7. Mental health support	Page 12
Care Planning	Page 12
8. Sodium Valproate / Medication and reproduction risk	Page 12
9. a. Care planning agreement	Page 12
9. b. Care planning components	Page 13
10. School Individual Healthcare Plan	Page 15
NICE Quality Standard (27) - Epilepsy in children and young people	**Page 16**
Epilepsy12 Performance Indicator links to NICE Q27 Statements	Page 16
Best Practice Criteria (BPC) 2019/20	**Page 16**
Care Quality Commission Metrics (CQC)	**Page 17**
Outlier Analysis	**Page 17**
Description of clinical audit patient cohorts	**Page 17**

Epilepsy12 Aims

- To facilitate health providers and commissioners to measure and improve quality of care for children and young people with seizures and epilepsies
- To contribute to the continuing improvement of outcomes for those children, young people and their families

Audit structure and engagement

- The UK is currently divided into 17 established Organisation of Paediatric Epilepsy Networks in the United Kingdom (OPEN UK) regions, national clinical networks, each with a defined link/lead person. The NHS within England is also divided into 7 regions.
- Regions are divided into relevant Health Boards/Trust* with a defined 'link paediatrician' lead for Epilepsy12.
- Relevant Trusts are those within the UK comprising a paediatric service providing initial care and/or ongoing care for children with seizures and/or epilepsies
- Registration and reporting of results will be at a Trust-wide level at the most granular level, but some larger Trusts may choose to view patient data and results at a 'sub-Trust' granularity reflecting separately functioning epilepsy services and the Epilepsy12 data system will allow for this
- Each relevant Trust/ Health Board will register with Epilepsy12
- Defined Trusts/Health Boards will have unique permissions within the audit data platform
- Defined paediatricians, epilepsy specialist nurses and other professionals will have unique functionality, permissions and roles within their Trust's access on the data platform

*For ease of reference the term "Trust" will be used throughout the remainder of this document, however the Epilepsy12 Project Team recognises that participation in the audit will be by "Health Boards" in Wales and "Trusts" in England.

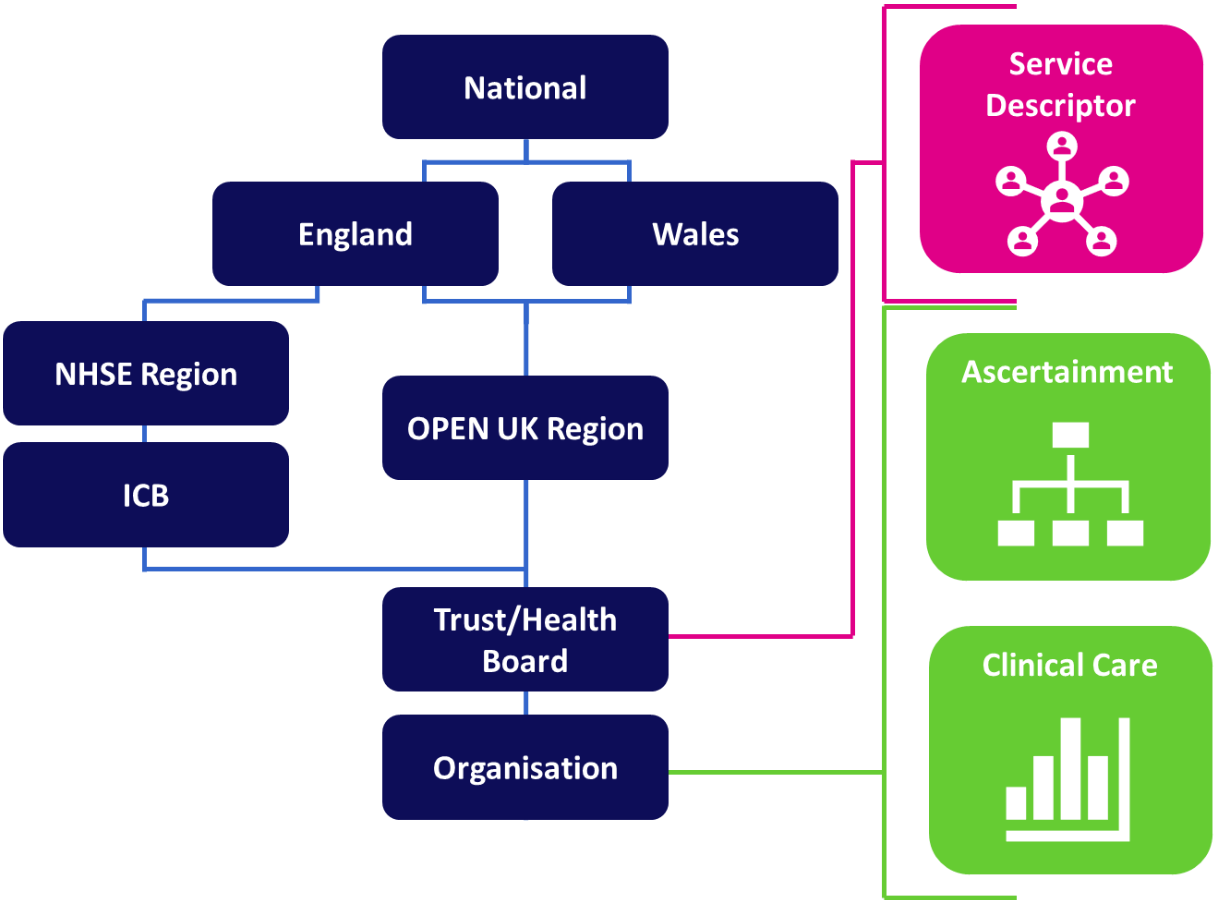
**Where the term "UK" is used throughout this document this currently refers to England and Wales participation. This is due to contractual and information governance arrangements not being currently agreed for Health and Social Care (HSC) Trusts in Northern Ireland and Health Boards in Scotland.

Epilepsy12 Round 4 Components

The audit is comprised of 2 audit domains:

- Service descriptor domain -Organisational Audit
- Clinical care domain – Clinical audit

The Epilepsy12 audit domains align to each participating Trust within a OPEN UK or NHS England regions eg.



Domains are mapped to participating Trusts at relevant points in time throughout the ongoing audit. The Epilepsy 12 Round 4 Reporting Timeline diagram on page 21 shows how data for the domains will be collected sequentially and analyzed and reported on over time.

Round 4 methodology refers to work from 1 April 2022.

Service descriptor domain - Organisational Audit

Each relevant Trust will complete a yearly service descriptor dataset describing their Trust's current epilepsy service. Live updates (for example service improvements, changes to staff workforce or reconfigurations) can be made to this ongoing dataset but all questions must be answered by a defined closing date for a submission for each yearly 'census day.'

Where we have been informed of a Health Board/Trust merger, but the original Health Boards/Trusts have completed the organisational audit separately, we will merge the data. For numerical data, these figures will be added together. For categorical data, the response that reflects a more mature service will be chosen. Detailed methodology will be published alongside annual ouputs.

Clinical care domain – Clinical audit

Defined children and young people and their ongoing care will be captured within the Epilepsy12 audit.

Where we have been informed of a Health Board/Trust merger, but the original Health Boards/Trusts have submitted clinical data separately, we will combine the caseloads.

Clinical Cohort Ascertainment

Epilepsy12 will aim to include all UK children and young people under the care of a paediatric service with a new diagnosis of epilepsy and a defined first paediatric assessment date. The Epilepsy12 audit's inclusion criteria is defined as '*A child or young person (1) having a first paediatric assessment for a paroxsysmal episode or episodes, and subsequently diagnosed as having epilepsy.'*

Clinical data entry will include key stages

- Initial registration
- Eligibility Confirmation
- First year of care clinical dataset entry

Each child has only one lifetime entry in the Epilepsy12 platform *[even if their seizures or epilepsy is uncertain, has a remission phase or if they have successive seizure or epilepsy diagnoses]. In other words, they may not meet registration or inclusion criteria initially but may later.*

Initial patient registration

Initial registration will occur when a user adds a patient to the web platform, and this step will be completed bythe referring clinical team. This process will check against the patient's NHS/CHI number to ensure no duplication of individual patients.

To create a patient record, the following details must be provided:

- First name
- Surname
- Date of Birth
- Sex
- Home postcode
- NHS/CHI Number
- Ethnicity

Eligibility Confirmation

Registered patients will need to meet the eligibility criteria as the first step of the patient care form to validate the remaining form. To confirm that a patient is eligible for the audit, clinicians will be asked to confirm that the patient meets the following criteria:

Inclusion

- Is a patient under the care of a NHS service within NHS England or Wales
  AND
- Has had a first paediatric assessment for an episode that was ultimately deemed to be epileptic
  AND
- Has had two or more epileptic seizure episodes at least 24 hours apart OR diagnosed with epilepsy for any other reason.

Exclusion:

The child or young person has had ONE or MORE of the following exclusion criteria:

- Previously been diagnosed with epilepsy before the first paediatric assessment recorded at the Trust
- Previously had a paediatric assessment for earlier seizure episodes considered to be epileptic
- Previously been registered in the Epilepsy12 audit
- Has ongoing care within the first year of care for their epilepsy provided by adult or non-NHS services by an inpatient or outpatient, hospital or community paediatric service, or a dedicated paediatric team based in ED. This also includes any treatment outside of the UK.

Children where the eligibility criteria is not met or are not determinable (e.g. notes not available or unclear labelled as not done/uncertain) will not be included. The non-inclusion of such children will be reflected in a reduced ascertainment completeness.

The system will be configured to allow re-joining of the audit for those children previously registered who need to re-join. For example, due to:

- Late initial registration
- Previous initial registration but left out of the ongoing audit because of non-attendance, diagnosis of no epileptic, epilepsy or uncertain episodes at 1 year after initial first assessment and then new concern regarding epileptic seizures
- Entry to the UK from another country where the first paediatric assessment was undertaken elsewhere

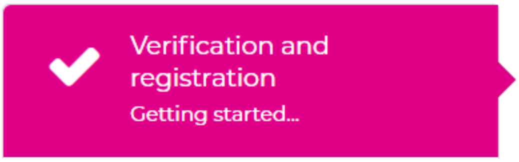
Key referencing audit criteria

If a patient meets the eligibility criteria, users will be asked to confirm their primary centre for Epilepsy12 and the date of their first paediatric assessment. This will be used to allocate their cohort number and determine the submission deadline for their record.

- Date of first paediatric assessment
- Relevant Organisation

- Epilepsy12 defines ‘organisation’ as any secondary care service within a Trust providing ongoing care for the seizure and epilepsy at one year after the first paediatric assessment.

Verified Patients



Each child identified as verified for inclusion will be added to a platform worklist for the relevant Trust.The patient data will be submitted by describing the care provided during the first 12 months following the first paediatric assessment date. Data will be automatically updatable via a ‘Live Update’ functionality within the system, removing the need to manually save changes.

Data will be obtained by a series of predominantly mandatory questions to be completed throughout the first 12 months after the first paediatric assessment and before a defined audit year closing date. Questions can be completed in any order and can be edited/updated at any point before the submission deadline. Please refer to the clinical data dictionary for a list of the questions asked.

Data should be provided by the auditing team at the Trust providing careat the point 12 months from the first paediatric assessment.

Diagnostic status dataset

As per the inclusion criteria, the audit will not collect diagnostic status as a dataset item, but will instead confirm that children have achieved a diagnosis of epilepsy in the verification step.

The following table illustrates the way that diagnostic status can be considered at the defined points in time and that some children may have a mixture of types of episodes that are considered as uncertain initially but later become diagnosed as non-epileptic or epileptic episodes.

Episode type	Number of episodes			Other factors affecting diagnostic status
Epileptic	Single	Cluster within 24 hours	2 or more episodes more than 24 hour apart	If single or cluster, is the child or young person considered as having epilepsy for other reason • single epileptic seizure and epilepsy syndrome diagnosis made • other reason
Non-Epileptic	Episode or episodes			ILAE selection list of epilepsy imitators [Can have multiple selected]
Uncertain	Episode or episodes			

Ascertainment and data completeness

Data will be reported at Trust, NHS England Integrated Care Board (ICB) and regional, OPEN UK regional, national and UK levels for each audit year.

Participation completeness

The degree of audit participation that will be reported for all UK secondary paediatric service health providers. This will include the following statuses: Not relevant; No participation; Organisational domain only: Organisational and clinical domain participation (full participation).

Ascertainment completeness

Number of children and young people with newly diagnosed epilepsy for a given Trust with completed data entry for a given cohort/Number with estimated newly diagnosed epilepsy based on population and published incidence data.

Internal Ascertainment completeness

Number of children and young people verified or excluded via the eligibility confirmation process for a given Trust/ Number of children and young people registered for a given Trust.

Data completeness

Number of children with completed and submitted data entry/ total number of verified.

Epilepsy12 Clinical Key Performance Indicators (KPI)

There are 10 defined Key Performance Indicators (KPIs) derived from national guidelines and recommendations with a defined percentage score. The Epilepsy12 audit will provide a Live Dashboard for clinicians entering data at Organisation, Trust, ICB, Regional, National, and UK levels. The Epilepsy12 audit will provide a frequent reporting dashboard and annual reports of analysis of data at Trust, ICS, Regional, National and UK levels, which will be made available in the public domain.

Each Key Performance Indicator (KPI) is mapped to the relevant recommendation. Eg. NICE guideline recommendations, NICE quality standards or other national recommendations. In some cases, the KPI is looking for internal consistency within the diagnosis/management rather than objectively assessing management. For example, MRI is deemed ‘appropriate’ if the assessor diagnoses epileptic seizures under 2 years; the ‘correctness’ of this diagnosis however is not ratified by the audit process i.e. if the diagnosis was incorrect (e.g. non-epileptic) MRI may not have been indicated.

Each KPI has a defined method of calculation, numerator and denominator. Some measures include all children and young people with epilepsy in the particular cohort, and others are refined to certain criteria. For each KPI, 100% is the maximum ‘score’. However, it may not be optimal for a service to score 100% as patients and circumstances differ and not all children fit with all models of care. KPIs are designed such that the 100% end of the scale represents better care compared to 0%

Individual Trust's scores will be shown alongside others (e.g. in a funnel plot type representation). 'League tables' remain considered as an inappropriate and non-meaningful approach to displaying results.

Interpretation should be guided by knowledge of ascertainment methods and composition of the cohorts of children and the methodological limitations of retrospective case-not analysis.

Epilepsy12 Clinical Key Performance Indicators (KPI) Table

Following the change in Epilepsy12 methodology from cohort 6 onwards, which now only includes data collection for **children and young people (CYP) with a confirmed epilepsy diagnosis**, the criteria outlined below for the KPIs exclusively applies to these individuals. The full inclusion/exclusion criteria can be found on page 6.

No.	Brief Title	Full Title	Epilepsies in children, young people and adults [NG217] April 2022	Other Recommendation Source	Additional Rationale	Calculation for the relevant audit cohort	Notes
1	**Paediatrician with expertise in epilepsy within 2 weeks**	Percentage of children and young people seen by a 'consultant paediatrician with expertise in epilepsies' within two weeks from first paediatric assessment	The diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy and this should be within 2 weeks of initial referral [Statement 1.1.1]	N/A	N/A	**Numerator** = **(** Number of children and young people, who were seen by: a paediatrician with expertise in epilepsy **OR** a paediatric neurologist, within 2 weeks from first paediatric assessment **)** **Denominator** = Number of children and young people.	
2	**Access to Epilepsy Specialist Nurse**	Percentage of children and young people seen by an epilepsy specialist nurse by first year	Ensure that all children, young people and adults with epilepsy have access to an epilepsy specialist nurse [Statement 11.1.1]	N/A	N/A	**Numerator** = Number of children and young people, who were seen by an epilepsy specialist nurse within the first year of care **Denominator** = Number of children and young people with epilepsy.	
3	**a. Tertiary Input**	Percentage of children and young people meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral by first year	Referral should be considered when tertiary paediatric epilepsy service are present [Statement 3.1.4]	N/A	National recommendations state indications for neurologist referral other than is appearing in this PI. However, the PI is limited to those	**Numerator** = Number of children and young people, who are: **(** less than 3 years old at first paediatric assessment, **OR** less than 4 years old with myoclonus, **OR** who had 3 or more maintenance AEDs at first year, **OR** have ongoing seizures and meet CESS criteria **)** **AND**	Myoclonus refers to CYP with focal or generalized myoclonic seizures. It does not refer to absence with eyelid myoclonia, myoclonic absence, myoclonic-atonic, or myoclonic-tonic-clonic

					children where the indications for neurology referral are determinable using this retrospective methodology	**(** had evidence of involvement of a paediatric neurologist **OR** referral to CESS within the first year of care **)** **Denominator** = Number of children and young people, who are: **(** less than 3 years old at first paediatric assessment, **OR** less than 4 years old with myoclonus, **OR** who had 3 or more maintenance AEDs at first year, **OR** who have ongoing seizures and meet CESS criteria **)**	seizures. Tertiary input is considered as input from a paediatric neurologist and/or a referral to CESS. Input does not have to be received from CESS within the first year of care to meet this performance indicator.
	b. Epilepsy Surgery Referral	Percentage of ongoing children and young people meeting defined Children's Epilepsy Surgery Service (CESS) referral criteria with evidence of CESS referral	N/A	N/A	Based on current CESS referral criteria	**Numerator** = **(** Number of children and young people meeting CESS criteria **AND** have evidence of referral or involvement of Epilepsy Surgery Service **)** **Denominator** = Number of children and young people meeting CESS criteria at first year	
4	**ECG**	Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year	Evaluate people after a first suspected seizure with a 12-lead ECG to help identify cardiac-related conditions that could mimic an epileptic seizure. [Statement 1.2.2]	N/A	NICE and SIGN are more aligned now but this indicator will remain attributed to those children with convulsive epileptic seizures	**Numerator** = **(** Number of children and young people who had convulsive episodes at first year **AND** who obtained 12 lead ECG **)** **Denominator** = Number of children and young people with convulsive episodes at first year	

5	**MRI within 6 weeks**	Percentage of children and young people with defined indications for an MRI, who had timely MRI brain within 6 weeks of request	MRI should be the imaging investigation of choice in individuals with epilepsy [Statement 1.3.1]	N/A	National recommendations state MRI for children other than is appearing in this PI. The PI is limited to those children where the indications for MRI are objectively determinable using a retrospective methodology	**Numerator** = **(** Number of children and young people who: are NOT JME **AND** are NOT JAE **AND** are NOT CAE **AND** are NOT Epilepsy with generalised tonic clonic seizures alone **AND** are NOT self-limited epilepsy with centrotemporal spikes ~(SELECT) **AND** who had an MRI within 6 weeks of request **)Denominator** = (Number of children and young people who: are NOT JME **AND** are NOT JAE **AND** are NOT CAE **AND** are NOT Epilepsy with generalised tonic clonic seizures alone **AND** are NOT self-limited epilepsy with centrotemporal spikes ~(SELECT))	
Mental Health							
6	**Assessment of mental health issues**	Percentage of children and young people with epilepsy where there is documented evidence that they have been asked about mental health either through clinical screening, or a questionnaire/ measure	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; Emotional health and psychological wellbeing (depression, anxiety or low mood) neurobehavioural disorders commonly associated with			**Numerator** = Number of children and young people over 5 years who had documented evidence of enquiry or screening for their mental health **Denominator** = Number of children and young people over 5 years	

7	**Mental health support**	Percentage of children and young people with epilepsy and a mental health problem who have evidence of mental health support	epilepsy, including autism or attention deficit hyperactivity disorder and stigmatisation of epilepsy [Statement 2.1.11]			**Numerator** = **(** Number of children and young people with a mental health issue identified **<u>AND</u>** had evidence of mental health support received **)** **Denominator** = Number of children and young people with a mental health issue identified	
Below is the previous version of KPI 8 that was applied in Cohort 6.							
8	**Sodium Valproate**	Percentage of all females 12 years and over currently on valproate treatment with an annual risk acknowledgement form completed	In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the risk of the drugs causing harm to an unborn child should be discussed with the child and/or her carer, and an assessment made as to the risks and benefits of treatment with individual drugs [Statement 4.4.4]	Valproate and developmental disorders: new alert asking for patient review and further consideration of risk minimisation measures, MHRA, April 2017	Females 12 years and over is an operational interpretation of 'child-bearing Potential' the current risk acknowledgment process is relevant. This includes those with intellectual disability.	**Numerator** = Number of females 12 years and over on valproate in defined audit year, with: **(** evidence of Valproate annual risk acknowledgement form completed **<u>OR</u>** Pregnancy Prevention Programme in place **)** **Denominator** = All females 12 years and over on valproate at first year	
Below is the updated version of KPI 8, which is applicable from Cohort 7 onwards.							
8	**Medication and reproduction risks**	Percentage of females on valproate treatment and females aged 12 years and above on topiramate with a risk acknowledgement form completed or Pregnancy Prevention	As above	MHRA 2024 update		**Numerator =** **(**Number of all females on valproate **OR** females aged 12 years and above on topiramate**)** **AND** **(**evidence of a risk acknowledgement form completed **OR** Pregnancy Prevention Programme in place**)**	

		Programme in place.				**Denominator =** Number of all females on valproate **OR** females aged 12 years and above on topiramate	
9	**a. Care planning agreement**	The percentage of children and young people with epilepsy after 12 months where there is evidence that:	All children, young people and adults with epilepsy should have a comprehensive care plan that is agreed between the person, their family and/or carers as appropriate, and primary and secondary care providers. [Statement 2.1.7]	N/A	N/A	**Numerator** = **(**Number of children and young people with an individualised epilepsy document **OR** copy clinic letter that includes care planning information**)** **AND** evidence of agreement **AND** care plan is up to date including elements where appropriate as below. **Denominator** = Number of children and young people with Epilepsy	
		a. care planning includes a patient held individualised epilepsy document or copy clinic letter that includes care planning information		N/A	In some situations, the individualised epilepsy document is contained within a copy clinic letter.	**Numerator** = **(**Number of children and young people with individualised epilepsy document **OR** copy clinic letter that includes care planning information**)** **Denominator** = Number of children and young people	
		b. there is patient/carer/parent agreement to the care planning		N/A	N/A	**Numerator** = Number of children and young people with evidence of agreement **Denominator** = Number of children and young	

		c. care planning has been updated when necessary		N/A	N/A	**Numerator** = Number of children and young people with care plan which is updated where necessary **Denominator** = Number of children and young people	
9	**b. Care planning components**	Percentage of children and young people diagnosed with epilepsy with documented evidence of communication regarding core components of care planning	All children, young people and adults with epilepsy should have a comprehensive care plan that is agreed between the person, their family and/or carers as appropriate, and primary and secondary care providers. [Statement 2.1.7]	N/A	Key elements of a comprehensive care plan have been defined. Those children fulfilling all elements are defined as having evidence of a comprehensive care plan. SUDEP added	**Numerator**= (Number of children and young people with evidence of written prolonged seizures plan **IF** prescribed rescue medication) **AND** evidence of discussion regarding water safety **AND** first aid **AND** participation and risk **AND** service contact details **AND** evidence of discussions regarding SUDEP **Denominator**= Number of children and young people	
		Parental prolonged seizures Care Plan	Treatment should be administered by trained clinical personnel or, if specified by an individually agreed protocol drawn up with the specialist, by family members or carers with appropriate training. [Statement 7.3]	N/A	Rescue medication is generally recommended for children with history of a generalised convulsive seizure > 5 mins. Some children with prolonged focal seizures will also have rescue medication.	**Numerator** = Number of children and young people prescribed rescue medication **AND** evidence of a written prolonged seizures plan **Denominator** = Number of children and young people prescribed rescue medication	

				An emergency plan should be in place for those children with rescue medication		
	Water safety	All children, young people and adults with epilepsy and learning disabilities should have a risk assessment including: bathing and showering [Statement 2.1.11]	N/A	N/A	**Numerator** = Number of children and young people with evidence of discussion regarding water safety **Denominator** = Number of children and young people	
	First aid	Children, young people and adults with epilepsy and their families and/or carers should be given, and have access to sources of, information about…first aid… [Statement 1.1.8]	N/A	N/A	**Numerator** = Number of children and young people with evidence of discussion regarding first aid **Denominator** = Number of children and young people	
	General participation and risk	…, safety and injury prevention at home and at school or work [Statement 1.1.8]		This may or may not encompass elements like road safety, heights, cooking, sleep, adherence, SUDEP and is likely to include emphasising what the child can do to ensure continuing participation at home and school.	**Numerator** = Number of children and young people with evidence of discussion regarding general participation and risk **Denominator** = Number of children and young people	
	SUDEP	… and reducing epilepsy-related risks, including sudden unexpected death in epilepsy			**Numerator** = Number of children and young people with evidence of discussions regarding SUDEP	

			(SUDEP) [Statement 10.1.4]			**Denominator** = Number of children and young people	
		Service contact details	The child, young person or adult with epilepsy and their family and/or carers as appropriate should know how to contact a named individual when information is needed. [Statement 1.1.8]	N/A	N/A	**Numerator** = Number of children and young people with evidence of discussion of been given service contact details **Denominator** = Number of children and young people	
10	**School Individual Health Care Plan**	Percentage of children and young people with epilepsy aged 5 years and above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment.	Healthcare professionals have a responsibility to educate others about epilepsy so as to reduce the stigma associated with it. They should provide information about epilepsy to all people who come into contact with children, young people and adults with epilepsy, including school staff, social care professionals and others [Statement 1.1.11]	Supporting pupils with medical conditions at school [Department for Education, December 2015]	N/A	**Numerator** = Number of children and young people aged 5 years and above with evidence of IHP **Denominator** = Number of children and young people aged 5 years and above	

NICE Quality Standard (27) - Epilepsy in children and young people

NICE quality standard 27 will be derivable from the Epilepsy12 methodology and dataset. Epilepsy12 annual reports will include results of the analysis of these metrics at a Trust, Regional, National and UK levels

Statement 1 People presenting with a first suspected seizure are seen by a clinician with expertise in epilepsy within 2 weeks of presentation.

Statement 2 People who meet the criteria for referral to a tertiary epilepsy service are seen within 4 weeks of referral, or 2 weeks if they meet the criteria for urgent referral.

Statement 3 People with epilepsy have access to an epilepsy specialist nurse.

Statement 4 People with epilepsy have an up-to-date and agreed comprehensive epilepsy care plan.

Statement 5 People with epilepsy are asked about their memory, mental health, and social and emotional wellbeing at epilepsy appointments.

Statement 6 Children and young people with epilepsy are asked at epilepsy appointments about neurodevelopment and learning difficulties or changes in their learning progress, and adults who have learning disabilities are asked at epilepsy appointments about changes in their condition and other comorbidities.

Best Practice Criteria (BPC) 2023/25

BPC tariff is applicable to England only.

BPC elements are collected within the organisational domain and considered relevant for all trusts

Care Quality Commission Metrics (CQC)

Epilepsy12 has defined 2 of the 10 clinical key performance indicators, as well as 'non-participation', as suited for use within the CQC inspection framework. These are:

1. Epilepsy Specialist Nurse
2. Tertiary input
3. Non-participation

Alongside other Epilepsy12 reporting processes these 3 metrics will be provided to the CQC for inclusion within their reporting visualisations and processes

Outlier Analysis

Epilepsy12 will undertake outlier analysis for a defined set of performance indicators. Positive and negative outliers will be defined for 2 of the 10 clinical key performance indicators. These are:

1. Epilepsy Specialist Nurse
2. Tertiary input

Additionally, non-participation outliers will be identified. The approach to outlier analysis will be defined by the RCPCH audit outlier policy.

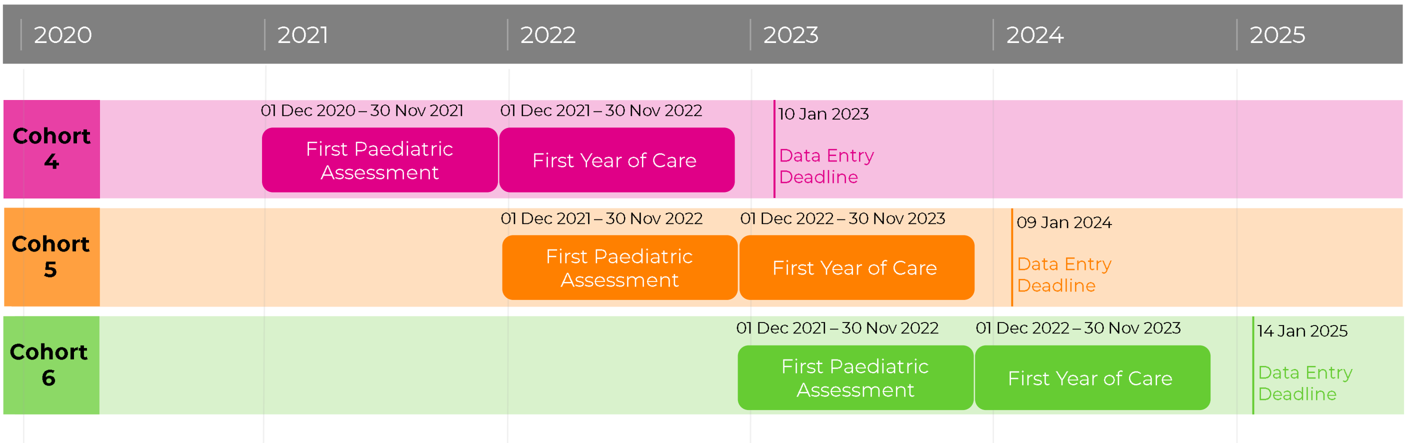
Description of Clinical Audit Cohorts

The clinical audit phase focuses on care provided to patients with a suspected new diagnosis of epilepsy. Clinical audit data entry is prospective, with eligible patients grouped into the following cohorts. These updated criteria are to be implemented from Cohort 5 onwards.

Round 4:

- Cohort 4 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2020 to 30 September 2021
- Cohort 5 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2021 to 30 September 2022
- Cohort 6 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2022 to 30 September 2023

The date of first paediatric assessment is the key date as the Epilepsy12 clinical performance indicators relate to the care that is provided to each patient in the 12 months that follow the date of their first paediatric assessment. The data platform will allow clinical teams to capture data for each child within each cohort for the first year of their care.



Useful Links

1. About the Epilepsy12 Audit
2. Data Entry Platform
3. Data Entry Platform Guidance
4. Epilepsy12 External Data Flow Diagram
5. Epilepsy12 Methodology and Data Submission
6. Epilepsy12 Outlier Policy
7. Epilepsy12 Privacy Notice
8. Epilepsy12 Reports and Resources
9. Epilepsy12 Round 4 Clinical Audit Dataset

10. Epilepsy12 Round 4 Organisational Audit Dataset