



# National Clinical Audit of Seizures and Epilepsies for Children and Young People

<b>Programme name</b>	National Clinical Audit of Seizures and Epilepsies for Children and Young People
<b>Workstream name (if applicable)</b>	Not applicable
<b>Audit or non-audit</b>	Audit
<b>HQIP commissioned</b>	Yes
<b>Contract status</b>	Ongoing
<b>HQIP AD</b>	TS
<b>HQIP PM</b>	VED
<b>Included in current NHS Quality Accounts</b>	Yes
<b>1.10 Geographical coverage - HQIP agreement</b>	England; Wales
<b>1.3 Healthcare setting</b>	NHS secondary care
<b>1.4 Inclusion and exclusion criteria</b>	Children and young people who have a first paediatric assessment after 12 July 2018 for a paroxysmal episode or episodes where an electroencephalogram (EEG) referral is made or indicated.
<b>1.5 Methods of data submission</b>	Online e.g. webtool or portal
<b>1.8 Data quality &amp; analysis plan</b>	<p><u>Data Analysis:</u></p> <p>The Epilepsy12 audit will provide clinical audit reporting outputs for users at a Health Board/Trust provider level and will also produce annual national reports of analysis of data at Health Board/Trust, Regional, National (England and Wales individually) and Overall (England and Wales combined) levels which will be made available in the public domain.</p> <p>Each performance indicator (PI) is mapped to the relevant NICE Guidance and Quality Standards recommendations.</p> <p>Each PI has a defined method of calculation, numerator and denominator which is indicated in the methodology and data submission page of the Epilepsy12 website: <a href="https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission">https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission</a></p> <p>For each PI 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</p>

with all models of care. PIs are designed such that the 100% end of the scale represents better care rather than 0%

#### Data Quality:

Examples of validation include:

- Piloting and refining data collection methods and dataset changes
- Building in validation processes at the point of data entry
- Validation by clinical teams
- Data cleaning
- Statistical analyses of data quality (e.g. missing data)
- Validation of statistical models and algorithms
- Quality assurance and unit testing of analytical code

### **1.9 Outlier policy**

Epilepsy12 will undertake outlier analysis for a defined set of performance indicators to facilitate clinical improvement and reduce practice variation. Audit data is used to identify areas of improvement and to encourage units to use quality improvement methodologies.

Epilepsy12 measures trusts on three metrics with reference to outlier analysis. These include two of the 10 performance indicators; Epilepsy Specialist Nurse input and Tertiary input, as well as case ascertainment. The complete outlier analysis is defined by the RCPCH audit outlier policy: [https://www.rcpch.ac.uk/sites/default/files/2021-02/epilepsy12\\_outlier\\_management\\_policy\\_2021.pdf](https://www.rcpch.ac.uk/sites/default/files/2021-02/epilepsy12_outlier_management_policy_2021.pdf)

Positive and negative outliers of the average will be defined for 2 of the 12 clinical performance indicators:

1. Epilepsy Specialist Nurse
2. Tertiary input

Epilepsy12 uses case ascertainment to measure data quality. The process details to the outlier analysis is defined by the RCPCH audit outlier policy: [https://www.rcpch.ac.uk/sites/default/files/2021-02/epilepsy12\\_outlier\\_management\\_policy\\_2021.pdf](https://www.rcpch.ac.uk/sites/default/files/2021-02/epilepsy12_outlier_management_policy_2021.pdf)

### **2.1 Outcome measures**

The Epilepsy12 performance indicators align with NICE Guidelines and Quality Standards and cover the following areas:

- Comprehensive care planning agreement and content
- School individual healthcare plan
- Recognition of mental health issues

### **2.2 Process measures**

The Epilepsy12 performance indicators align with NICE Guidelines and Quality Standards and cover the following areas:

- Input from a paediatrician with expertise in epilepsies
- Input from an epilepsy specialist nurse
- Tertiary input
- Epilepsy surgery referral

- Access to electrocardiogram (ECG)
- Access to magnetic resonance imaging (MRI)
- Discussion of the risks of treatment with sodium valproate
- Access to mental health support

### 2.3 Organisational measures

- Consultant paediatrician with expertise in epilepsy
- Epilepsy Specialist Nurse
- Defined epilepsy clinic
- ~~Epilepsy Best Practice Tariff (BPG) – England only~~
- Paediatric neurology services
- Investigations
- Service contact
- Transition services for young adults
- Mental Health screening and support
- Neurodevelopmental support
- Care planning
- Patient database or registry

**2.6 Source of evidence for measures** NICE clinical guideline; NICE quality standard

**2.7 Evidence supplemental information** The Epilepsy12 clinical audit performance indicators are described in detail on pages 11 to 15 of the Epilepsy12 round 4 methodology, which is available to view and download at: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox>

**3.1 Results visualisation** Annual report; Patient report; Static data files

**3.2 Levels of reporting** Trust or Health Board; National; Regional network

**3.3 Timeliness of results feedback** Within 1 year

**Dataset #1 name** Clinical Audit

**Dataset #1 type** Clinical audit - cohort; Organisational audit

**Dataset #1 items collected (n)** 200

**Dataset #1 specification** [https://www.rcpch.ac.uk/sites/default/files/2019-06/epilepsy12\\_r3\\_patient\\_reg\\_and\\_clin\\_audit\\_dataset\\_june\\_19.pdf](https://www.rcpch.ac.uk/sites/default/files/2019-06/epilepsy12_r3_patient_reg_and_clin_audit_dataset_june_19.pdf)

**Dataset #2 name** Patient Reported Experience Measure

**Dataset #2 type** Patient reported experience measure

**Dataset #3 name** National Organisational Audit and Trust Profile

<b>Dataset #3 type</b>	Organisational audit
<b>Dataset #3 items collected (n)</b>	30
<b>Dataset #3 specification</b>	<a href="https://www.rcpch.ac.uk/sites/default/files/2018-07/epilepsy12_organisational_audit_dataset_may_2018_0.pdf">https://www.rcpch.ac.uk/sites/default/files/2018-07/epilepsy12_organisational_audit_dataset_may_2018_0.pdf</a>
<b>Dataset #4 name</b>	Not applicable