



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

<b>UPCARE: Programme name - please do not change this field.*</b>	National Clinical Audit of Seizures and Epilepsies for Children and Young People
<b>Workstream name (if applicable) - please do not change this field.*</b>	Not applicable
<b>Contract status</b>	Ongoing
<b>Audit or non-audit</b>	Audit
<b>HQIP commissioned*</b>	Yes
<b>HQIP AD</b>	TS
<b>HQIP PM</b>	VED
<b>1.0 Included in current NHS Quality Accounts*</b>	Yes
<b>1.1a Geographical coverage - HQIP agreement*</b>	England; Wales
<b>1.3a Healthcare setting*</b>	NHS secondary or tertiary care
<b>1.4 Inclusion and exclusion criteria*</b>	Children and young people with first paediatric assessment for an episode(s) that was ultimately deemed to be epileptic
	<u>Inclusion</u> The following criteria must ALL be fulfilled to verify registration for Epilepsy12.
	1. Is a patient within NHS England or Wales AND
	2. Has had a first paediatric assessment* for an episode(s) that was ultimately deemed to be epileptic**

\*paediatric service, or a dedicated paediatric team based in A&E. They should not have been referred or assessed by an adult service/team.

\*\*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

1. Previously diagnosed with epilepsy before the first paediatric assessment.
2. Previously had a paediatric assessment for earlier seizure episodes considered to be epileptic.
3. Previously been registered in the Epilepsy12 audit.
4. Has received ongoing care within the first year of care for their epilepsy provided by adult, including non-NHS inpatient and outpatient services, and non-NHS dedicated paediatric teams based in ED.

### **1.5 Methods of data submission\***

Bespoke data submission by healthcare provider

### **1.7 Data flow diagram**

Can be downloaded from our website: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox>

### **1.8 Data quality & analysis plan**

#### Data Analysis:

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. The data platform allows reporting at sub-Health Board/Trust level - 'organisation level' - however, this is only accessible for certified users and will not be publicly available.

Each key performance indicator (KPI) is mapped to the relevant NICE Guidance and Quality Standards recommendations.

Each KPI has a defined method of calculation, numerator and denominator which is indicated in the methodology and data submission page of the Epilepsy12 website: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission>

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 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 key 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, which can be downloaded from our website: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox>

Positive and negative outliers of the average will be defined for 3 clinical performance indicators:

1. Epilepsy Specialist Nurse
2. Tertiary input
3. Ascertainment

Epilepsy12 uses case ascertainment to measure data quality. The process details to the outlier analysis is defined by the RCPCH audit outlier policy, which can be downloaded from our website: <https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox>

### 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 (BPC) – 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

**2.6a Do measures align with any of the following sources of evidence (select all that apply)** NICE clinical guideline; NICE quality standard

**2.6b 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; Interactive online portal (run charts available)

<b>3.2a Levels of reporting*</b>	Trust or health board; National; Integrated care system (ICS); Other (please describe in next question); NHS region or other geographic area
<b>3.3 Timeliness of results feedback</b>	Within 1 year; Within 24 hours; Within 3 months
<b>Dataset #1 name</b>	Clinical Audit
<b>Dataset #1 type*</b>	Clinical audit
<b>Dataset #1 population coverage*</b>	Sample of eligible patients
<b>Dataset #1 items collected (n)</b>	200
<b>Dataset #1 use of existing national datasets</b>	N/A
<b>Dataset #1 specification</b>	<a href="https://www.rcpch.ac.uk/sites/default/files/2023-12/epilepsy12_round_4_clinical_audit_dataset_v1_20231128.pdf">https://www.rcpch.ac.uk/sites/default/files/2023-12/epilepsy12_round_4_clinical_audit_dataset_v1_20231128.pdf</a>
<b>Dataset #2 name</b>	Organisational audit
<b>Dataset #2 type*</b>	Organisational audit
<b>Dataset #2 items collected (n)</b>	30
<b>Dataset #2 use of existing national datasets</b>	N/A
<b>Dataset #2 specification</b>	<a href="https://www.rcpch.ac.uk/sites/default/files/2023-12/epilepsy12_round_4_organisational_audit_dataset_v1_20231128.pdf">https://www.rcpch.ac.uk/sites/default/files/2023-12/epilepsy12_round_4_organisational_audit_dataset_v1_20231128.pdf</a>
<b>Dataset #3 name</b>	Not applicable
<b>Dataset #4 name</b>	Not applicable

<b>When was your Healthcare Improvement Plan (sometimes referred to as a Quality Improvement Plan) last reviewed? Please upload under 'Files' below using naming convention ('yyyymmdd_PROGRAMME-Workstream-HIplan').</b>	01/02/2024
<b>National report publication date (within calendar year 01/01 - 31/12/2023)*</b>	2023 Annual Report was published <a href="#">online</a> in July 2023.
<b>Published/planned national report publication date (within calendar year 01/01 - 31/12/2024)*</b>	The 2024 annual report is scheduled for publication in July 2024.
<b>Please add the most recent date that you have reviewed and updated an online version of UPCARE Workstream section(s) on your project's website (click into the response to see pop-up guidance).</b>	08/03/2024
<b>Please add a hyperlink to UPCARE Workstream section(s) on your website (click into the response to see pop-up guidance)*</b>	<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>
<b>Files</b>	epilepsy12_quality_improvement_strategy_v1.3.pdf