



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

<b>UPCARE:</b>	National Clinical Audit of Seizures and Epilepsies for Children and Young People
<b>Programme name</b> - please do not change this field.*	
<b>Workstream name</b> (if applicable) - please do not change this field.*	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>	GC
<b>1.0 Included in current NHS Quality Accounts*</b>	Yes
<b>1.1a Geographical coverage - HQIP agreement*</b>	England; Wales
<b>1.2a Topic - please select which ONE of the following best describes the topic area for the programme or workstream. If more than one apply, please select 'Other' and add comment to the next question.*</b>	Neurological
<b>1.3a Healthcare setting*</b>	NHS secondary or tertiary care; NHS community care; Paediatric
<b>1.4 Inclusion and exclusion criteria*</b>	<p>A child or young person, aged 0-24 years, under the care of an NHS service in England and Wales having a first paediatric assessment for a paroxysmal episode(s) AND subsequently diagnosed as having epilepsy.</p> <p><u>Inclusion</u></p> <ul style="list-style-type: none"> <li>• Is a patient under the care of a NHS service within NHS England or Wales AND</li> <li>• Has had a first paediatric assessment for an episode that was ultimately deemed to be epileptic AND</li> <li>• Has had two or more epileptic seizure episodes at least 24 hours apart OR diagnosed with epilepsy for any other reason.</li> </ul>

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.

**1.5 Methods of data submission\***

Bespoke data submission by healthcare provider

**1.6a 2023/24 data submission closes - please indicate date, series of dates or frequency.\***

2023/24 data submission deadline was 9 January 2024 and included clinical data for cohort 5 (first assessment between 1 December 2021 - 30 November 2022) and 2023 organisational audit data.

(Annual data submission deadlines on the second Tuesday of January each year.)

**1.6b 2024/25 data submission closes - please indicate date, series of dates or frequency.\***

2024/25 data submission deadline was 14 January 2025 and included clinical data for cohort 6 (first assessment between 1 December 2022 - 30 November 2023) and 2024 organisational audit data.

(Annual data submission deadlines on the second Tuesday of January each year.)

**1.6c 2025/26 data submission closes - please indicate date, series of dates or frequency.\***

2025/26 data submission deadline will be 13 January 2026 and include clinical data for cohort 7 (first assessment between 1 December 2023 - 30 November 2024) and 2025 organisational audit data.

(Annual data submission deadlines on the second Tuesday of January each year.)

**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, NHS region and Integrated Care Board (ICB), OPEN UK regional network, Country (England and Wales individually) and overall National (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 Health Boards and Trusts on two metrics with reference to outlier analysis. These are two of the 10 key performance indicators; Access to Epilepsy Specialist Nurse (KPI 2) and Tertiary input (KPI 3a). 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>

Outliers are defined as Health Boards and Trusts with a performance outside of 2 and 3 standard deviations on the national (England and Wales combined) average for the metric. Positive and negative outliers are defined for the 2 clinical performance indicators:

1. Access to Epilepsy Specialist Nurse (KPI 2)
2. Tertiary input (KPI 3a)

Additionally, non-participation outliers are identified. Participation is defined as submitting at least one first year of care record in the relevant cohort before the data submission deadline. Any Health Boards or Trusts not meeting this will be a non-participation outlier.

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 [NG217], and Quality Standards [QS211] and cover the following areas:

- Comprehensive care planning agreement and components
- School Individual Health Care Plan
- Identification of mental health conditions
- Identification of neurodevelopmental conditions/learning disabilities
- Annual risk acknowledgement forms and/or initiation of a Pregnancy Prevention Programme for females aged 12 years and over currently on valproate treatment

### 2.2 Process measures

The Epilepsy12 performance indicators align with NICE Guidelines [NG217], and Quality Standards [QS211] and cover the following areas:

- Input from a paediatrician with expertise in epilepsies within 2 weeks of referral
- Access to an epilepsy specialist nurse
- Tertiary input
- Epilepsy surgery referral
- Access to electrocardiogram (ECG)
- Access to magnetic resonance imaging (MRI) within 6 weeks of referral
- Assessment of mental health issues
- 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

<b>2.6a Do measures align with any of the following sources of evidence (select all that apply)</b>	NICE clinical guideline; NICE quality standard
<b>2.6b Evidence supplemental information</b>	The Epilepsy12 clinical audit key performance indicators are described in detail on pages 9 to 15 of the Epilepsy12 round 4 methodology, which is available to view and download at: <a href="https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox">https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/methodology-data-submission#downloadBox</a>
<b>3.1 Results visualisation</b>	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 1 month
<b>3.4 Link to dynamic reporting*</b>	<a href="https://www.rcpch.ac.uk/resources/epilepsy12-audit-dashboard">https://www.rcpch.ac.uk/resources/epilepsy12-audit-dashboard</a>
<b>2023/24 Dataset covers the period FROM/TO (within financial year 01/04 to 31/03)*</b>	12/01/2021 - 11/30/2023
<b>2024/25 Dataset covers the period FROM/TO (within financial year 01/04 to 31/03)*</b>	12/01/2022 - 11/30/2024
<b>2025/26 Dataset covers the period FROM/TO (within financial year 01/04 to 31/03)*</b>	12/01/2023 - 11/30/2025
<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="http://www.rcpch.ac.uk/sites/default/files/2023-12/epilepsy12_round_4_clinical_audit_dataset_v1_20231128.pdf">http://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="http://www.rcpch.ac.uk/sites/default/files/2023-12/epilepsy12_round_4_organisational_audit_dataset_v1_20231128.pdf">http://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 quality improvement plan (referred to as a QI Plan) last reviewed? Please upload under 'Files' below using the HQIP naming convention (click on response to see pop-up help text).</b>	02/01/2024
<b>Please add the hyperlink to where your clinical performance indicators (referred to as metrics) are published on your project website.*</b>	<a href="http://www.rcpch.ac.uk/sites/default/files/2024-12/Epilepsy12%20Round%204%20Methodology%20Overview%20V6%20%28December%2024%29.pdf">http://www.rcpch.ac.uk/sites/default/files/2024-12/Epilepsy12%20Round%204%20Methodology%20Overview%20V6%20%28December%2024%29.pdf</a>
<b>National report publication date</b>	The 2023 Annual Report was published <a href="#">online</a> in July 2023.

<b>(within calendar year 01/01 - 31/12/2023)*</b>	
<b>Published/planned national report publication date (within calendar year 01/01 - 31/12/2024)*</b>	The 2024 annual report was published <a href="#">online</a> in July 2024.
<b>Planned national report publication date (within calendar year 01/01 - 31/12/2025)*</b>	The 2025 annual report will be published in July 2025.
<b>Planned national report publication date (within calendar year 01/01 - 31/12/2026)*</b>	The 2026 annual report will be published in July 2026.
<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>	03/08/2024
<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

