

# EPILEPSY12

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

Overview of the methodology for Rounds 3+

As at 13 07 18

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## **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 has already been divided into 17 established Organisation of Paediatric Epilepsy Networks in the United Kingdom (OPEN UK) regions and national clinical networks, each with a defined link/lead person
- Each region is divided into relevant Health Boards/Trusts\* with a defined 'link paediatrician' lead for Epilepsy12. Some Trusts may wish to delegate OPEN UK and Epilepsy12 roles separately
- 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 only 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 will register with Epilepsy12
- Defined Trusts 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

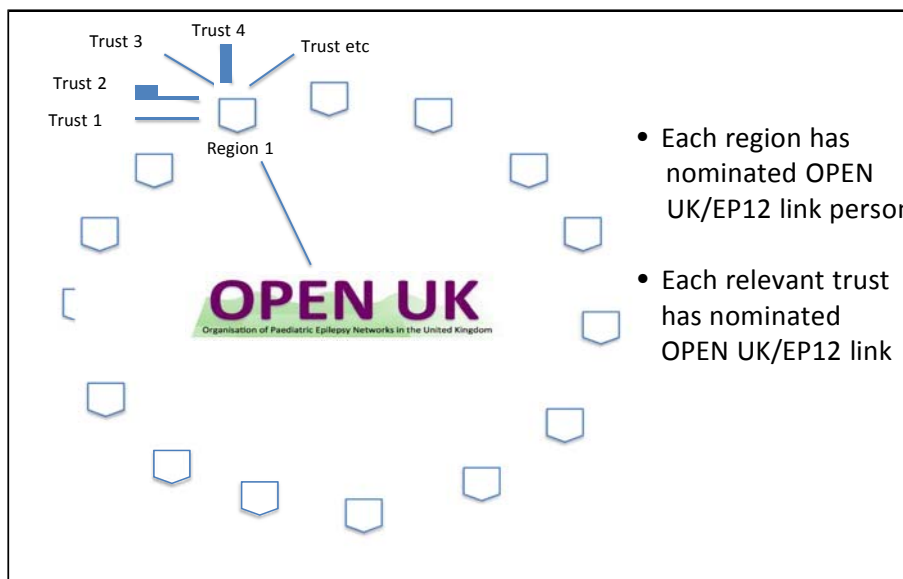
\*For ease of reference the term "Trust" will be used throughout the remainder of this document, however the Epilepsy12 Project Team recognises that participation in the audit will be by "Health Boards" in Wales and "Trusts" in England.

\*\*Where the term "UK" is used throughout this document this refers to England and Wales. This is due to the fact that at the start of the Epilepsy12 Round 3 contract in April 2017, contractual and information governance arrangements meant that it was not possible for Health and Social Care (HSC) Trusts in Northern Ireland and Health Boards in Scotland to participate.

**Map of the 17 OPEN UK regional and national paediatric epilepsy clinical networks**



**Schemata showing the proposed structural alignment of OPEN UK paediatric epilepsy networks with relevant component Trusts participating in Epilepsy12:**

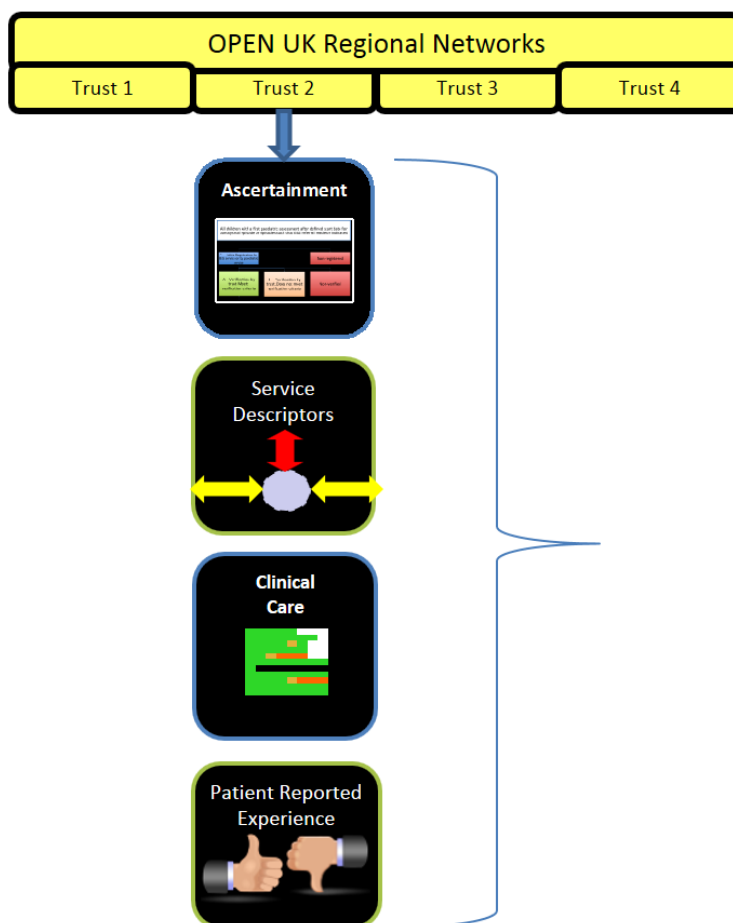


## Epilepsy12 Round 3 Components

The audit will be comprised of 3 audit domains:

- Service descriptor domain (Organisational Audit)
- Clinical care domain
- Patient Reported Experience Measures (PREM) domain

The Epilepsy12 audit domains will align to each participating Trust within OPEN UK networks



Domains will be mapped to participating Trusts at relevant points in time throughout the ongoing audit. The Epilepsy 12 Rounds 3+ Reporting Timeline diagram on page 22 shows how data for the domains will be collected sequentially and analysed and reported on over time.

The work of the project started on 1 April 2017 and the first service descriptor “census day” will be 1 April 2018.

### 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.'

## **Clinical care domain**

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

### **Clinical Cohort Ascertainment**

Epilepsy12 will aim to include all UK children under the care of a paediatric service with suspected epilepsy with a first paediatric assessment from "day 0" (proposed as 12 July 2018) with ongoing audit of those with diagnosed epilepsy.

Ascertainment will include 4 key stages

- Initial registration
- Trust verification
- Ongoing Trust and follow up confirmation
- Diagnostic status confirmation

Each child will have 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 be possible from different individuals and services via the web platform. This initial heterogeneous and non-specific group will be identified principally from both the referring clinical team and EEG services who will be facilitated to register via the Epilepsy12 platform all children and young people referred by a paediatric service for a first EEG after Epilepsy12 Day 0. The initial registration processes will check against the patient's NHS/CHI number to ensure no duplication of individual patients.

The initial registration dataset will cover the following details:

- Confirmation that it is a NHS patient, not private
- Referral made by a paediatric service rather than adult service
- Confirmation no previous EEGs
- First name
- Surname
- Gender
- DoB
- NHS/CHI/ number
- Name of the referring Trust
- Date that first EEG requested or became indicated by assessing Trust

*[In EEG services where sleep or sleep deprived EEGs are done as a first EEG then this is counted as a first EEG. EEG services should also register children referred for EEG who may not achieve the EEG (for example 'was not brought' and cancelled by parents etc.). Defined professionals including EEG administrative staff will be able to register children through this process. Clinical Professionals should also register children in whom first EEG is indicated but in whom EEG is*

*not requested. For example, diagnosis of epilepsy suspected in a child with autistic spectrum disorder where EEG attempt deemed not appropriate to attempt.]*

### **Trust verification**

All children meeting initial registration validation criteria will then be listed for 'Trust verification' by the referring Trust. This phase is about adding key confirmatory information in different ways. For example, case notes may not need to be pulled to include some children e.g. some services may be able to confirm inclusions for some children by review of electronic records.

Trust verification on the Epilepsy12 system will cover the following:

- Whether the child had a paroxysmal episode or episodes prompting first paediatric assessment
- Confirmation of the date on which the very first paediatric assessment for the episode or episodes occurred
- Whether the patient had previous EEG or first paediatric assessment for similar episodes or episodes or epilepsy
- Date of the EEG if first EEG achieved
- Initial home postcode

### **Validation Criteria for next steps**

- Confirmation that the parents or young person have not requested opt out at any time
- The child has had a paroxysmal episode or episodes prompting a first paediatric assessment.
- Young people referred for EEG by an adult service, or who had a first adult assessment or non-NHS service EEG or first assessment would not be included
- The date of 'First paediatric assessment' for the 'paroxysmal episode or episodes' must have occurred after Epilepsy12 day 0 (12 July 2018)
- The patient has not had a first paediatric assessment previously for a similar episode or episodes or epilepsy prior to first paediatric assessment AND prior to Epilepsy12 day 0. In this situation, it would be the original first assessment that counts. If they had a paediatric assessment previously after day 0, and had not been registered for whatever reason, then the child's very first assessment is the key verification date that should be entered
- Children where the verification criteria are not determined 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 audit will include children where an EEG referral is indicated but where an EEG is deemed not obtainable by the EEG service or referring Trust
- Children with previous EEGs should have their very first EEG for paroxysmal episodes considered as first EEG. If previous EEG was for other reasons e.g. HIE, encephalitis then this EEG would not count as first EEG
- If the requested EEG was not for paroxysmal events, but does show seizures not previously clinically recognised, this would count as a first EEG for the audit

- 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
  - Remission of epilepsy and discharge and then subsequent new concern regarding epileptic seizures or epilepsy
  - Entry to the UK from another country where the first paediatric assessment was undertaken elsewhere

**Key referencing audit criteria**

- Date of first paediatric assessment
- Relevant Trust
  - Trust where the first paediatric assessment is undertaken
  - Trust providing relevant care during the year after the first paediatric assessment
  - Trust providing relevant care at each successive year after the first paediatric assessment

**Verified Patients**

Each child identified as verified for inclusion by the referring Trust will be added to a platform worklist for the relevant Trust. The patient data will be submitted by defined times after the first paediatric assessment and each subsequent year. Times will be determined by the individual patient’s first paediatric assessment date and by key annual audit dates, for example census day 0. Data will be updatable via a ‘Live Update’ functionality within the system. Data will be obtained by a series of predominantly mandatory questions to be completed after the first paediatric assessment, in the 12 months after the first paediatric assessment and after subsequent yearly reviews until the patient achieves a defined ‘exit’ from the audit. Questions and ‘exit’ parameters are listed in dataset section.

**Diagnostic status dataset**

Diagnostic status will be a key dataset item determined at ongoing points in time to confirm those children having achieved a diagnosis of epilepsy.

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?



				<ul style="list-style-type: none"> <li>• single epileptic seizure and epilepsy syndrome diagnosis made</li> <li>• other reason</li> </ul>
Non-Epileptic	Episode or episodes			ILAE selection list of epilepsy imitators [Can have multiple selected]
Uncertain	Episode or episodes			

### Epilepsy confirmation and ongoing auditing

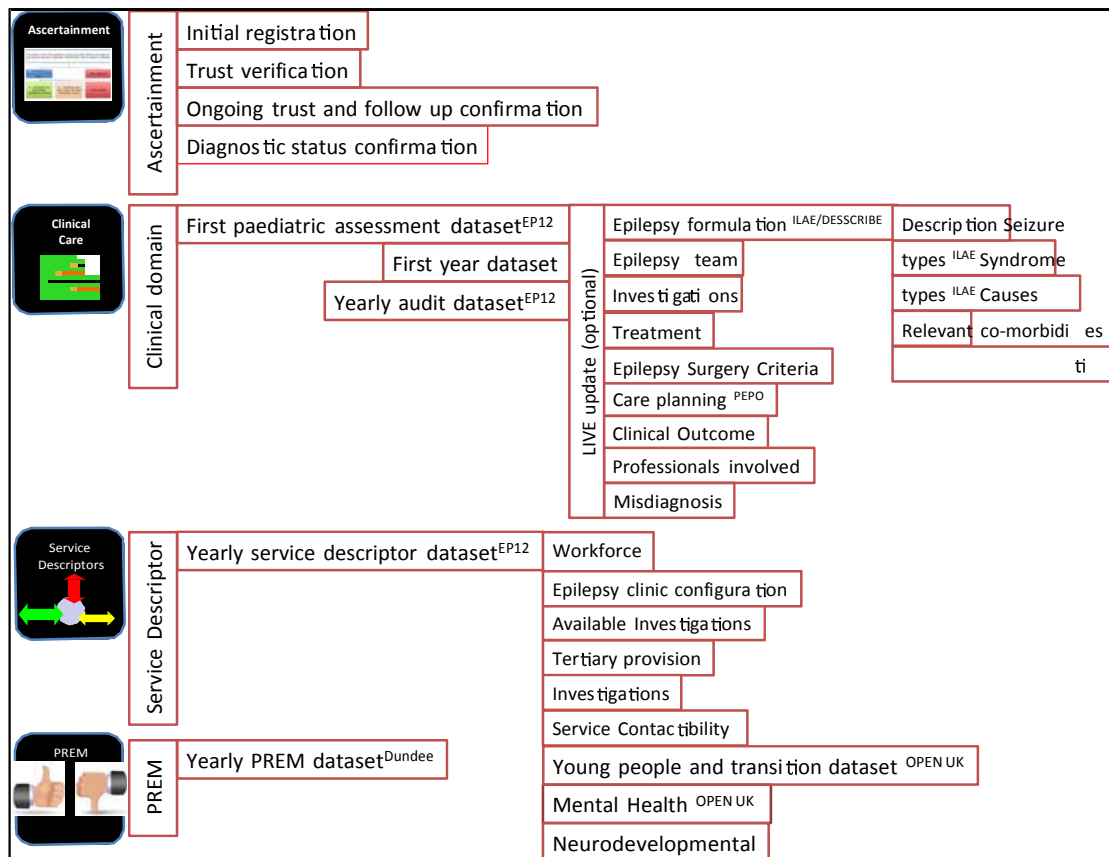
Children whose updated diagnostic status at any time is '2 or more epileptic episodes' or 'considered as having epilepsy for other reason' at any time will be deemed as eligible for the clinical audit datasets (as summarised in the datasets macro diagram). Children with a diagnostic status that does not include epilepsy will not have full auditing datasets required at that point in time.

The following table illustrates the different points in time when ongoing audit data will be captured by the Epilepsy12 platform.

Audit dataset	Completed by	Focus of questions	When completed	Audit context
First paediatric assessment audit dataset	Auditing team at the Trust where first paediatric assessment undertaken	What is recorded during the first paediatric assessment	Retrospectively at any time after the first paediatric assessment but before the audit year closing date for the respective yearly Epilepsy12 cohort	Informs Performance indicators for the Trust where the assessment was undertaken within the relevant audit year
First year audit dataset	Auditing team at the Trust providing care at the point 12 months on from the first paediatric assessment	Summary of the care provided during the first year of care after the first paediatric assessment.	After completion of first paediatric data set. Can be completed prospectively via Live Updates or retrospectively at any time but with a mandated dataset for the first year of care completed by a defined audit year closing date	Informs Performance indicators for the Trust where care is provided at the point 12 months after the first paediatric assessment
Yearly audit dataset update	Auditing team at Trust providing care at defined	Summary of care during the second and ongoing years of care until child or	Can be completed prospectively via Live Update or retrospectively at any time after each previous year's dataset submitted	Informs Performance indicators for the Trust where care is provided at

	years after the first paediatric assessment undertaken	young person not followed up and exits from audit for whatever reason	but with a mandated dataset for the year of care completed by a defined audit year closing date	relevant yearly points after the first paediatric assessment
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**Diagram showing dataset organisation (dataset macro)**

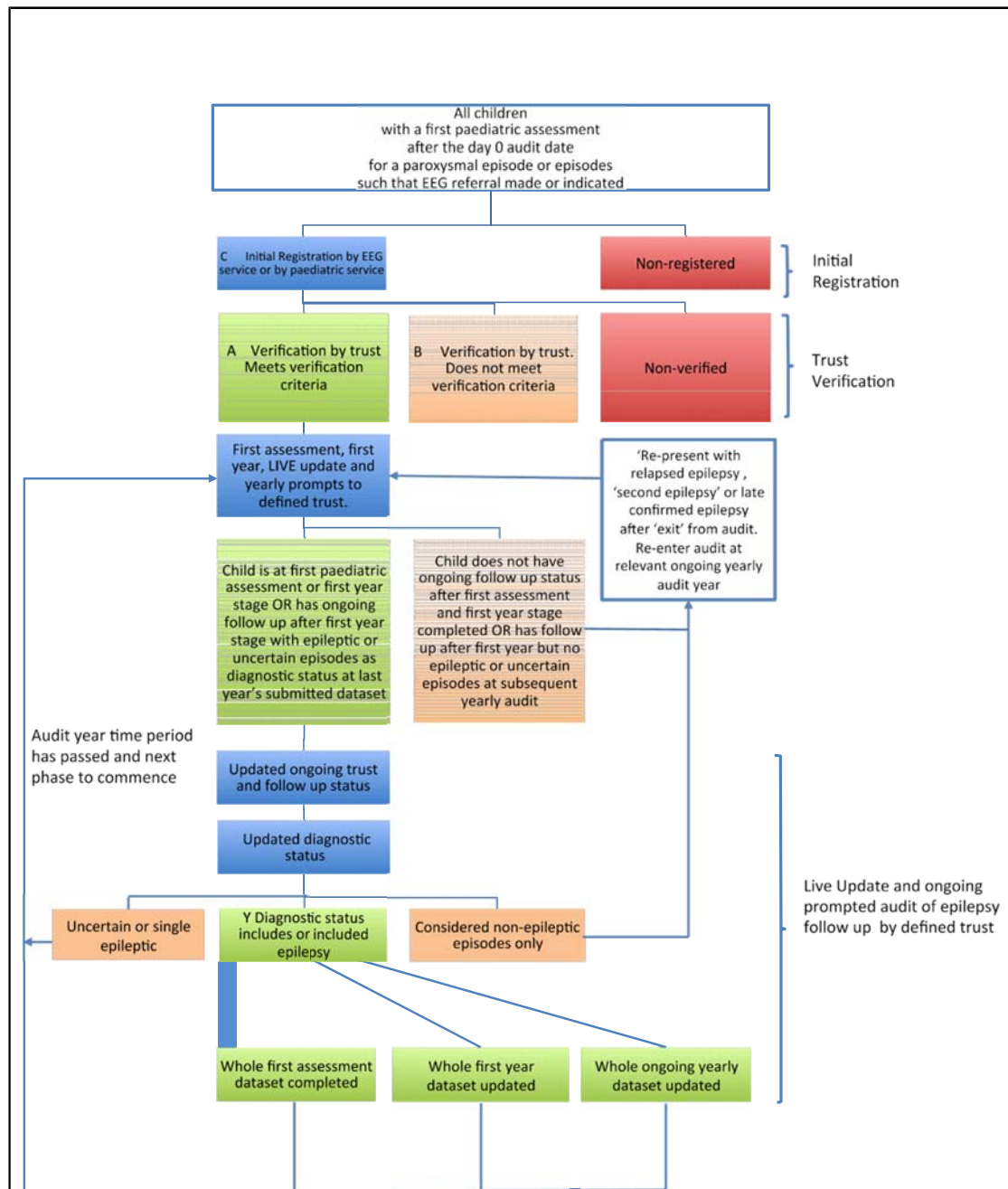


**Ascertainment and auditing worklists**

Initial registration, Trust verification, ongoing Trust and follow up status, diagnostic status confirmation and ongoing auditing will be supported by live dashboard and worklists.

**Diagram showing the ascertainment and audit processes:**

Due to the operational complexity of the ongoing ascertainment process and need to work closely with the platform developers, the following diagram is provisional and may be changed during platform build and testing.



## Ascertainment and data completeness

Will be reported at Trust, regional, national and UK levels for each audit year:

### External ascertainment completeness

Epilepsy12 new epilepsy diagnoses for given audit year and defined age group/estimated new epilepsy diagnoses based on population and published incidence data  
Epilepsy12 first EEG in audit year/HES first EEG procedure codes for audit year

### Internal Ascertainment completeness

(A+B)/C for referring Trust

First paediatric assessment data completeness = X completed/Y and relevant Trust at first paediatric assessment

First year data completeness = V completed/Y and relevant Trust at 1 year

### **Participation completeness**

The degree of audit participation that will be reported for all UK secondary paediatric service health providers

### **Data completeness**

Number of children with completed data entry for submission stage each year/ total number of verified children at each submission stage each year

## **PREM domain**

The PREM questionnaire from Round 2 is currently being validated. The previous methodology included a paper-based questionnaire being handed out to consecutive families with epilepsy attending clinics and completed in the waiting area before clinic review. Forms were handed in and anonymously analysed centrally by the project team and reported. The PREM for rounds 3+ will be based on an updated and validated PREM dataset which will be developed in conjunction with engagement activities led by the RCPCH Children and Young People's Engagement team. This will be introduced in year 3 of the project timeline after the first yearly patient cohort has completed 12 months of care following their first paediatric assessment. The dataset and methodology for this domain is not currently finalised.

## **Epilepsy 12 Clinical Performance Indicators**

There will be 12 defined performance indicators derived from national guidelines and recommendations with a defined percentage score.

Some performance indicators are applied to those children who are newly diagnosed with epilepsy within a specific audit year. Some performance indicators are cumulative and apply to all ongoing children with epilepsy in each audit yearly cohort.

The Epilepsy12 audit will provide Live Dashboard reporting outputs for users at a Trust provider level and will then produce annual reports of analysis of data at Trust, Regional, National and UK levels which will be made available in the public domain.

- Each performance indicator (PI) is mapped to the relevant SIGN recommendation\*, NICE guideline recommendations, NICE quality standards or other national recommendations. \*The 2005 SIGN guidelines are no longer active and their review is pending.
- Each PI has a defined method of calculation, numerator and denominator.
- 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 with all models of care. PIs are designed such that the 100% end of the scale represents better care rather than 0%
- 'League tables' remain considered as an inappropriate and non-meaningful approach to displaying results.
- Individual Trust's scores will be shown alongside others (e.g. in a funnel plot type representation) in Epilepsy12 public facing yearly annual reports

- There may be a few larger Trusts where additional epilepsy service reporting is offered in addition to other reporting levels but only within the data system itself for the purpose of local, internal reporting in support of service improvement
- Interpretation should be guided by knowledge of ascertainment methods and composition of the cohorts of children and the methodological limitations of retrospective case-note analysis.
- In some cases, the performance indicator 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.

## Epilepsy12 Clinical Performance Indicators

No.	Brief title	Full title	Epilepsies: diagnosis and management, CG137, NICE 2012	Epilepsies: diagnosis and management, SIGN, 2005	Other Recommendation Source	Additional Rationale	Calculation for the relevant audit cohort
<b>Involvement of appropriate professionals</b>							
<b>1</b>	<b>Paediatrician with expertise in epilepsies</b>	Percentage of children with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' by first year	The diagnosis of epilepsy in children should be established by a specialist paediatrician with training and expertise in epilepsy	The diagnosis of epilepsy should be made by a paediatric neurologist or Paediatrician with expertise in childhood epilepsy	n/a	n/a	Numerator = Number of patients diagnosed with epilepsy AND who had input from a paediatrician with expertise in epilepsy OR a paediatric neurologist by first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>2</b>	<b>Epilepsy Specialist Nurse</b>	Percentage of children with epilepsy, referred for input by an epilepsy specialist nurse by first year	Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy.	Each epilepsy team should include paediatric epilepsy nurse specialists	n/a	n/a	Numerator= Number of patients diagnosed with epilepsy AND who had input from or referral to an Epilepsy Specialist Nurse by first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>3</b>	<b>Tertiary input</b>	Percentage of children meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral by first year	Referral should be considered when 1 or more of the following criteria are present:	Referral to tertiary specialist care should be considered if a child fails to respond to two AEDs appropriate to the epilepsy in adequate dosages over a period of 6 months.	n/a	National recommendations state indications for neurologist referral other than is appearing in this PI. However, the PI is limited to those children where the indications for neurology referral are determinable using this retrospective methodology	Numerator = Number of children less than 2 years old at first assessment with epilepsy OR who had 3 or more maintenance AEDS at first year OR have ongoing seizures and meet CESS criteria AND had evidence of referral or involvement of a paediatric neurologist or CESS  Denominator = Number of children less than 2 years old at first assessment with epilepsy OR who had 3 or more maintenance AEDS at first year OR who have ongoing seizures and meet CESS criteria with epilepsy at first year
<b>3b</b>	<b>Epilepsy Surgery referral</b>	Percentage of ongoing children meeting defined Epilepsy Surgery referral criteria with evidence of Epilepsy surgery referral	n/a	n/a	n/a	Based on current CESS referral criteria	Numerator = In defined audit year have ongoing seizures and meet CESS criteria AND have evidence of referral or involvement of Epilepsy Surgery Service  Denominator = Number of children who have ongoing seizures and meet CESS criteria within defined audit year

Evidence of appropriate assessment and classification							
4	Appropriate first paediatric assessment	Percentage of all children, with evidence of appropriate first paediatric clinical assessment	In an individual presenting with an attack, a physical examination should be carried out. This should address the individual's cardiac, neurological and mental status, and should include a developmental assessment where appropriate.	All children with epilepsy should have their behavioural and academic progress reviewed on a regular basis by the epilepsy team.	n/a	National guidance does not define "where appropriate" nor does it define the key components of clinical assessment. Epilepsy12 has defined these components in order to facilitate objective retrospective analysis of this recommendation  * Note that this is now confined to just children with epilepsy which is a change from round 2	Numerator = Number of patients with evidence of descriptions of episode AND age of child/timing of the first episode AND frequency and general examination AND neurological examination AND the presence or absence of developmental, learning or schooling problems AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year*
4a		% children with evidence of descriptions of episode					Numerator = Number of children diagnosed with epilepsy at first year AND with evidence of descriptions of episode  Denominator = Number of children diagnosed with epilepsy at first year
4b		% children with evidence of descriptions of age of child/timing of the first episode					Numerator = Number of children diagnosed with epilepsy at first year AND evidence of description of age of child/timing of the first episode  Denominator = Number of children diagnosed with epilepsy at first year
4c		% children with evidence of descriptions of frequency					Numerator = Number of children diagnosed with epilepsy at first year AND evidence of description of frequency  Denominator = Number of children diagnosed with epilepsy at first year
4d		% children with evidence of descriptions of general examination					Numerator = Number of children diagnosed with epilepsy at first year AND evidence of description of general examination  Denominator = Number of children diagnosed with epilepsy at first year
4e		% children with evidence of descriptions of neurological examination					Numerator = Number of children diagnosed with epilepsy at first year AND evidence of evidence of description of neurological examination  Denominator = Number of children diagnosed with epilepsy at first year

4f		% children with evidence of description of developmental, learning or schooling progress					<p>Numerator = Number of children diagnosed with epilepsy at first year AND evidence of the presence or absence of developmental, learning or schooling problems</p> <p>Denominator = Number of children diagnosed with epilepsy at first year</p>
4g		% children 3 years and over with evidence of consideration of emotional or behavioural problems					<p>Numerator = Number of children diagnosed with epilepsy at first year AND evidence of description of the presence or absence of emotional or behavioural problems</p> <p>Denominator = Number of children diagnosed with epilepsy at first year</p>
5	<b>Seizure Formulation</b>	Percentage of children with epilepsy, with appropriate seizure classification at first year	Epileptic seizures and epilepsy syndromes in individuals should be classified using a multi-axial diagnostic scheme. The axes that should be considered are: description of seizure (ictal phenomenology); seizure type; syndrome and aetiology	n/a	n/a	Terminology for classification is complex as constantly evolving. ILAE terminology forms the best way of assessing appropriateness of terminology. Unclassified is accepted.	<p>Numerator = Number of children with diagnosis of epilepsy at first year AND who had ILAE seizure classification (all ILAE seizure types including 'unclassified' excluding grand mal seizures, petit mal seizures, no seizure type stated and unanswered)</p> <p>Denominator = Number of children diagnosed with epilepsy at first year</p>
<b>Evidence of appropriate investigation</b>							
6	<b>ECG</b>	Percentage of children with convulsive seizures and epilepsy, with an ECG at first year	In children, a 12-lead ECG should be considered in cases of diagnostic uncertainty.	All children presenting with convulsive seizures should have an ECG with a calculation of the QTc interval.	n/a	NICE and SIGN vary in their recommendations. SIGN recommendations are easier to objectively audit and therefore selected for this PI	<p>Numerator = Children diagnosed with convulsive episodes and epilepsy at first year AND who have 12 lead ECG obtained</p> <p>Denominator = Children diagnosed with convulsive episodes and epilepsy at first year</p>
7	<b>MRI</b>	Percentage of children with defined indications for an MRI, who had MRI by at first year	MRI should be the imaging investigation of choice in individuals with epilepsy	Children under 2 with epilepsy or with recurrent focal seizures (other than CECTS) should have an elective MRI brain scan	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	<p>Numerator = Number of children less than 2 years old at first assessment with a diagnosis of epilepsy at first year OR children with a diagnosis of epilepsy at first year who are NOT JME or JAE or CAE or CECTS/Rolandic AND who had an MRI</p> <p>Denominator = Number of children less than 2 years old at first assessment with a diagnosis of epilepsy at first year OR children with a diagnosis of epilepsy at first year who are NOT JME or JAE or CAE or BECTS/Rolandic</p>



Management and outcome							
8	Accuracy of diagnosis	Percentage of children diagnosed with epilepsy, who still had that diagnosis at 1 year	AED therapy should only be started once the diagnosis of epilepsy is confirmed, except in exceptional circumstances that require discussion and agreement between the prescriber, the specialist and the individual and their family and/or carers as appropriate.	n/a	n/a	Evaluation of incidence of children in whom there may be a misdiagnosis of epilepsy or who may have received a 'trial of treatment'	Numerator = Number of children with diagnosis of epilepsy at first year who have not had their diagnosis withdrawn  Denominator = Number of children who had a diagnosis of epilepsy at first year or children had their diagnosis withdrawn
9	Sodium Valproate	Percentage of all females >9 years currently on valproate treatment with evidence of discussion of fetal risk	In girls of childbearing potential, including young girls who are likely to need treatment into their childbearing years, the risk of the drugs (see 1.8.13C) 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	Adolescent girls taking Valproate and their parents should be advised of the risks of fetal malformations and developmental delay.	Valproate and developmental disorders: new alert asking for patient review and further consideration of risk minimisation measures, MHRA, April 2017	Females 9 years and over is an operational interpretation of 'child-bearing potential'. This includes those with intellectual disability.	Numerator = All females 9 years and over with epilepsy on valproate in defined audit year AND evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes.  Denominator = All females 9 years and over with epilepsy on valproate in defined audit year
9b		Percentage of all females currently on valproate treatment with evidence of discussion of fetal risk				Numerator = All females with epilepsy on valproate in defined audit year AND evidence of previous discussion of risk regarding birth defects and/or neurodevelopmental outcomes.  Denominator = All females with epilepsy on valproate in defined audit year	
10 (NEW)	Comprehensive Care Planning agreement	<i>The percentage of children with epilepsy after 12 months where there is evidence that:</i>	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.				Numerator = Number of children with individualised epilepsy document AND evidence of agreement AND care plan is up to date including elements where appropriate as below AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
10a (NEW)		<i>care planning includes a patient held individualised epilepsy document or copy clinic letter that includes care planning information</i>				<i>In some situations, the individualised epilepsy document is contained within a copy clinic letter.</i>	Numerator = Number of children with individualised epilepsy document or copy clinic letter that includes care planning information AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year

<b>10b</b> <b>(NEW)</b>		<i>there is patient/carer/parent agreement to the care planning</i>					Numerator = Number of children with evidence of agreement AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>10c</b> <b>(NEW)</b>		<i>care planning has been updated when necessary</i>					Numerator = Number of children with care plan which is updated where necessary AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>11</b> <b>(NEW)</b>	<b>Comprehensive Care Planning content</b>	Percentage of children diagnosed with epilepsy with documented evidence of communication regarding core elements 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.	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.		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.	Numerator= Number of children with diagnosis of epilepsy as defined at 1 year AND 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  Denominator= Number of children with diagnosis of epilepsy at first year
<b>11a</b> <b>(NEW)</b>		<b>Parental prolonged seizures Care Plan</b>	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.			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. An emergency plan should be in place for those children with rescue medication.	Numerator = Number of prescribed rescue medication AND evidence of a written prolonged seizures plan AND diagnosed with epilepsy at first year  Denominator = Number of children with prescribed rescue medication AND diagnosed with epilepsy at first year
<b>11b</b> <b>(NEW)</b>		Water safety	All children, young people and adults with epilepsy and learning disabilities should have a risk assessment including: bathing and showering				Numerator = Number of children evidence of discussion regarding water safety AND evidence of a written prolonged seizures plan AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>11c</b> <b>(NEW)</b>		First aid	Children, young people and adults with epilepsy				Numerator = Number of children evidence of first aid advice AND evidence

			and their families and/or carers should be given, and have access to sources of, information about...first aid...				of a written prolonged seizures plan AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>11d (NEW)</b>		General participation and risk	..., safety and injury prevention at home and at school or work	Children with epilepsy should be encouraged to participate in normal activities with their peers. Supervision requirements should be individualised taking into account the type of activity and the seizure history.		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 evidence of discussion regarding participation and risk AND evidence of a written prolonged seizures plan AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>11e (NEW)</b>		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.				Numerator = Number of children evidence of been given local epilepsy service contact details AND evidence of a written prolonged seizures plan AND diagnosed with epilepsy at first year  Denominator = Number of children diagnosed with epilepsy at first year
<b>12 (NEW)</b>	<b>School Individual Healthcare Plan</b>	Percentage of children and young people with epilepsy aged 4 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.	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.	Supporting pupils with medical conditions at school Department for Education, December 2015		Numerator = Evidence of IHP AND 5 years and above and diagnosed with epilepsy at first year  Denominator = All s children with epilepsy 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

**Epilepsy12 performance indicators as designed also encompass the following statements from NICE Quality Standard 27.** (*qualifications in italics*). Clicking on the numbered statement in blue will take you to full details for the statement on the NICE website:

[Statement 3](#). Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

[Statement 4](#). Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.

[Statement 5](#). Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews. (*New questions regarding ESN functions have been added to the service descriptor dataset. Epilepsy12 will report those services with an ESN who fulfills these functions and those children who have evidence of access to the ESN*)

[Statement 6](#). Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

[Statement 7](#). Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

(criteria within Epilepsy12 methodology are simplified to children < 2 years and children with 3 or more AEDs or fulfilling CESS criteria; timeliness of referral not currently captured)

**Epilepsy12 Dataset rounds 3+ will also include metrics to encompass the following NICE Quality Standards:**

[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.

[Statement 2](#). Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

[Statement 8](#). Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

[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.

## Best Practice Criteria (BPC) 2019/20

- BPC criteria are applicable to England only.
- BPC elements will be built into the Epilepsy12 web platform Live Dashboard area for audit users with an ability for all to view and download related quarterly reports
- BPC adherence will be published at Trust level
- BPC adherence will be reported for the whole of the UK (notwithstanding the fact that Northern Ireland is not participating as at the start of the project) including nations where the best practice tariff is not implemented

The Epilepsy12 dataset and reporting outputs may be updated to align with the best practice tariff as and when it is amended and agreed. The agreed 2019/20 best practice tariff criteria and wording will be informed such that they can be captured where possible within the ongoing Epilepsy12 dataset and methodology.

## Care Quality Commission Metrics (CQC)

Epilepsy12 has defined 3 of the 12 clinical performance indicators as suited for use within the CQC inspection framework. These are:

1. Paediatrician with expertise in epilepsies
2. Epilepsy Specialist Nurse
3. Tertiary input

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 3 of the 12 clinical performance indicators. These are:

1. Paediatrician with expertise in epilepsies
2. Epilepsy Specialist Nurse
3. Tertiary input

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 three cohorts as follows:

- Cohort 1 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between the “Go live” date of 12 July and 30 September 2018
- Cohort 2 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 October 2018 to 30 September 2019
- Cohort 3 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 October 2019 to 30 September 2020

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 each year of their care as shown in the example below for patients within Cohort 1:

