

**RCPCH**

Royal College of  
**Paediatrics and Child Health**

*Leading the way in Children's Health*

# **EPILEPSY12**

## **Full Methodology Document**

February 2011

United Kingdom collaborative clinical audit of  
health care for children and young people  
with suspected epileptic seizures



Royal College  
of Nursing

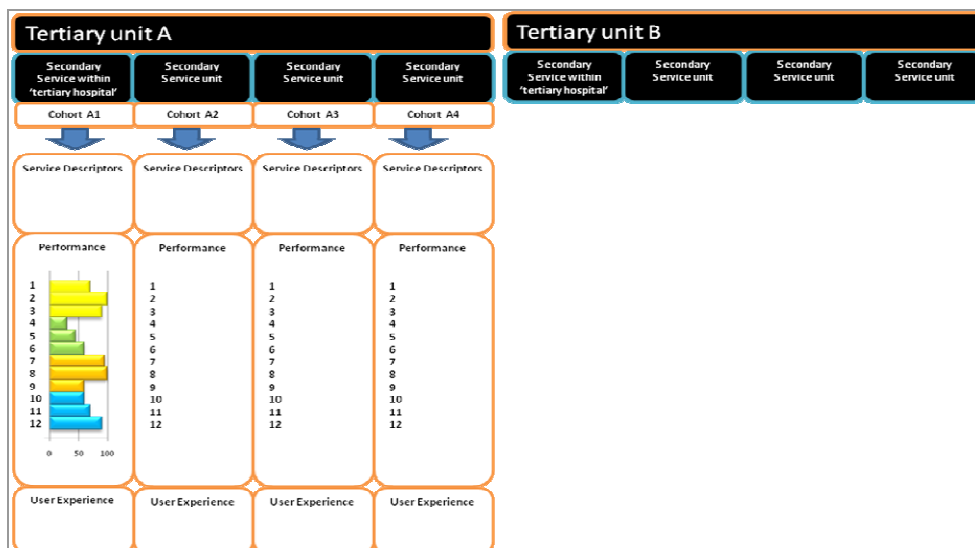


## 1. Aims

- 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

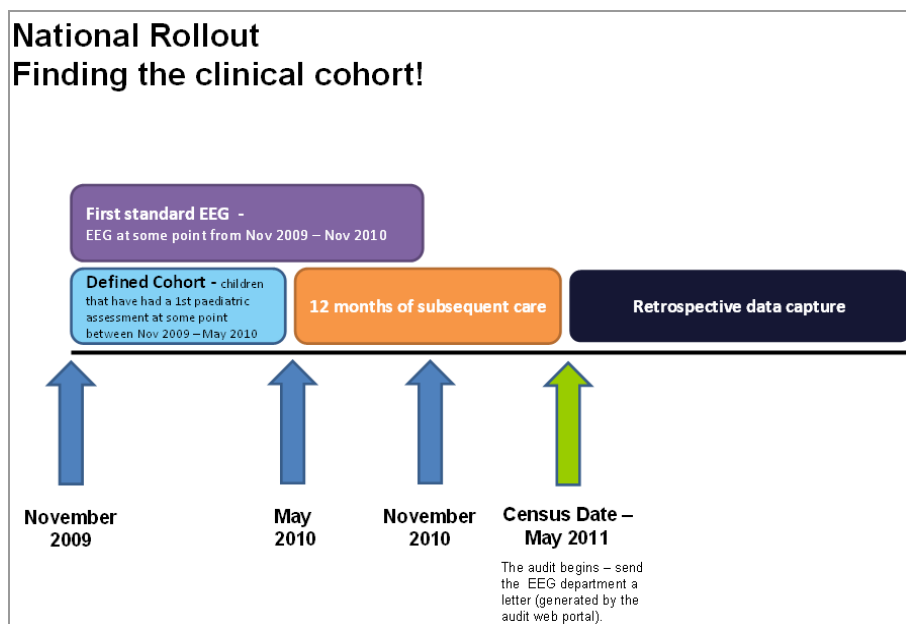
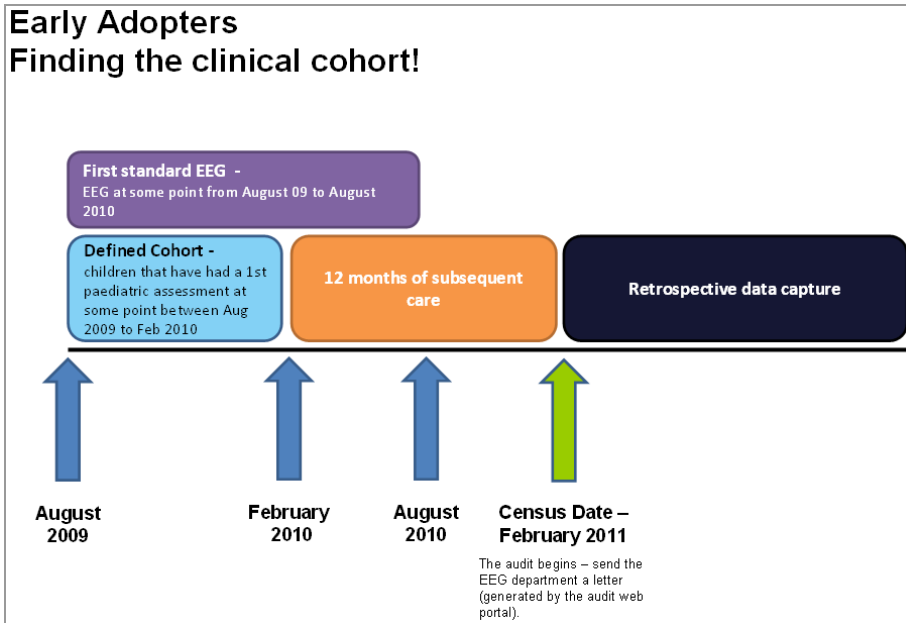
## 2. Engagement

- UK divided into tertiary areas with a defined 'link neurologist'
- Each tertiary area divided into secondary 'audit units' with a defined 'link paediatrician'
- Each 'audit unit' comprises all participating paediatricians within that unit and may include groupings of hospital and community services
- Each 'audit unit' will register with Epilepsy12 website and receive 'Epilepsy12 audit pack'



## 3. Census Day' and retrospective methodology

This is the key point in time defined by the project team which determines when an audit unit can become 'live' via the web tool and begin to enter data. It is the date which is considered by the audit unit team when describing attributes of the audit unit's services. It also determines the various dates which identify the target cohort for the audit. All children and young people included in the audit will have presented to paediatric service at least 12 months prior to census day. **The census day for 'early adopter' audit units will be 1<sup>st</sup> February 2011. The census day for the rest of the UK will be 1<sup>st</sup> May 2011.**



#### 4. Service descriptors

Each audit unit lead will complete a service descriptor questionnaire to describe the epilepsy service within their audit unit. (See dataset 2)

## 5. Clinical Cohort Ascertainment

An initial heterogeneous group will be identified from EEG services which will be filtered by the audit unit to form the cohort by application of inclusion and exclusion criteria.

- All children having a first EEG referred from the 'audit unit' between census day minus 18 months and census day minus 6 months.
- If possible this will include those referred for EEG without EEG achieved.
- In departments where sleep or sleep deprived are done as a first EEG then this is counted as a first EEG.
- EEG unit will send written list of ascertained names with DOB to 'audit unit' link paediatrician.
- 'Audit unit' apply inclusion and exclusion criteria applied to EEG list.
- Children where inclusion/exclusion not determined (e.g. notes not available or unclear) labelled as uncertain and these children not included.
- Participation/Inclusion/exclusion tracked and documented for all children and all audit units.
- Tracking of ascertainment will be aided by audit pack proforma. All children identified from EEG will be listed and for each one inclusion criteria will be applied. This may be done differently by different units. For example case notes may not need to be pulled to exclude some children e.g. some services may be able to exclude some children by review of departmental databases or electronic records.
- Case notes for those children meeting inclusion criteria will be analysed.
- Audit units will be encouraged to make available all relevant health records at the time of data entry.
- Children meeting inclusion criteria will have clinical details entered into Epilepsy12 website.

**Inclusion criteria:**

- First EEG during defined 12 month period.
- The child has a 'first paediatric assessment' for the 'paroxysmal episode or episodes' during defined 6 month time period.
- Child is older than 1 month and younger than 16 years at 'first paediatric assessment'.
- The EEG was prompted by the patient having one or more afebrile paroxysmal episodes.

**Exclusion criteria:**

- All 'paroxysmal episodes' in question were diagnosed as 'febrile seizures'. (Children with a history of febrile seizures being assessed for different afebrile 'paroxysmal episodes' may be included).
- The patient has had a paediatric assessment previously for similar episode or episodes or epilepsy prior to first paediatric assessment.
- All the paroxysmal episodes that the patient had were acute symptomatic seizures or occurred within a week of a traumatic head injury.
- The patient's care was permanently transferred to a secondary paediatric service outside the 'audit unit' boundaries or an adult service during the year after first paediatric assessment.

## 6. Clinical Performance Indicators

### Principles

- Each performance indicator (PI) correlates with specific SIGN and/or NICE recommendations.
- 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.
- No target percentages will be set.
- 'League tables' will be considered as an inappropriate and non-meaningful approach to displaying results.
- Individual audit unit's scores will be shown alongside others (e.g. in a funnel plot type representation).
- 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.

## Clinical Performance Indicators Definitions

	Title	NICE	SIGN	Rationale	Calculation	
<b>Involvement of appropriate professionals</b>						
<b>1</b>	<b>Paediatrician with expertise</b>	% with evidence of input by Paediatrician with expertise in Epilepsy (or paediatric neurologist) by 1 year	1.5.1C 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	Evidence of input important for children with epilepsies but even more important for those receiving AEDS hence supplemental PI.	(Children input by a Paediatrician with expertise in 1 <sup>st</sup> year <b>OR</b> Paediatric Neurologist) <b>AND</b> diagnosed as two or more epileptic seizures at 1 year X100%
<b>1 (Supplement)</b>						(number of Children with input by a Paediatrician with expertise in 1 <sup>st</sup> year <b>OR</b> Paediatric Neurologist) <b>AND</b> commenced on AEDs at any time during first year X100%
<b>2</b>	<b>Epilepsy Specialist Nurse</b>	% with evidence of input by, or referral to, an epilepsy specialist nurse by 1 year	1.8.3 Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child's education, welfare and well-being	Each epilepsy team should include paediatric epilepsy nurse specialists	Evidence of input important for children with epilepsy but even more important for those receiving AEDs therefore split into 2 subgroups.	Children diagnosed two or more epileptic seizures at 1 year <b>AND</b> evidence of input by, or referral to, an Epilepsy Specialist Nurse X100%
<b>2 (Supplement)</b>						Diagnosed as two or more epileptic seizures at 1 year
						Children commenced on AEDs at any time during first year <b>AND</b> evidence of input by, or referral to, an Epilepsy Specialist Nurse X100%
						Children commenced on AEDs at any time during first year

Evidence of appropriate assessment						
3	First Paediatric assessment	% with evidence of descriptions of episode <u>and</u> onset/frequency <u>and</u> general <u>and</u> neurological examination	1.4.6 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.	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	Children with evidence of description of episode <b>AND</b> onset/frequency <b>AND</b> general examination <b>AND</b> neurological examination X100%
3 (Supplement)		% with evidence of descriptions of developmental history <u>or</u> educational progress				Children with evidence of description of developmental history <u>or</u> educational X100%
3 (Supplement)		% with evidence of descriptions of emotional or behavioural problems				Children 3 or over with evidence of description of presence or absence of emotional or behavioural problems X100%
Evidence of appropriate diagnosis						
4	Diagnosis of epilepsy maintained	% with a diagnosis of epilepsy maintained by 1 year.	1.8.15 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.		Is looking for incidence of children in whom there may be a misdiagnosis of epilepsy or who may have received a 'trial of treatment'	$\frac{\text{No. of children with diagnosis of two or more epileptic seizures at 1 year}}{\text{No. of children with diagnosis of two or more epileptic seizures at 1 year + no. with evidence diagnosis withdrawn}} \times 100\%$
5	Epileptic seizures classified	% diagnosed as two or more epileptic seizures in 1st year with appropriate seizure classification by 1 year	1.7.1 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		Terminology for classification is difficult as constantly evolving. ILAE terminology forms the best way of assessing appropriateness of terminology. Unclassified is accepted.	$\frac{\text{Children with ILAE seizure classification or 'unclassified' AND diagnosed two or more epileptic seizures at 1 year}}{\text{Children diagnosed two or more epileptic seizures at 1 year}} \times 100\%$
6	Epilepsy classified	% diagnosed as two or more epileptic seizures with ILAE syndromal classification (or identified as 'unclassified') by 1 year	1.7.1 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;	The choice of first AED should be determined where possible by syndromic diagnosis and potential adverse effects	Terminology for classification is difficult as constantly evolving. ILAE terminology forms the best way of assessing appropriateness of terminology.	$\frac{\text{Children with ILAE syndrome classification or 'unclassified' epilepsy AND diagnosed 2 or more epileptic seizures at year}}{\text{Children diagnosed 2 or more epileptic seizures at 1 year}} \times 100\%$

			syndrome and aetiology.		Unclassified is accepted.	
<b>Evidence of appropriate investigation</b>						
<b>7</b>	<b>'Appropriate' EEG</b>	% children have an EEG for reasons other than defined non-epileptic episodes at first paediatric assessment	1.6.6 The EEG should not be used to exclude a diagnosis of epilepsy in an individual in whom the clinical presentation supports a diagnosis of a non-epileptic event		The purpose of the EEG is not always explicitly stated by the assessor. However if the child's episodes are diagnosed as certain non-epileptic episodes and they have EEG then it will be assumed that the EEG was inappropriate.	Children NOT (diagnosed with 'faints' OR 'tics') at first paediatric assessment <hr/> N
<b>8</b>	<b>'Appropriate' neuroimaging</b>	% with two or more epileptic seizures at 1 year with appropriate indication for neuroimaging, having neuroimaging by 1 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 BECTS) should have an elective MRI brain scan	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 determinable using a retrospective methodology	((Having MRI (or CT if between 6 months-7 years) by 1 year <b>AND</b> diagnosed with two or more epileptic seizures at 1 year <b>AND</b> (under 2 years at first paediatric assessment <b>OR NOT</b> IGE, JME, JAE, CAE, BECTS/Rolandic) X100%) <hr/> diagnosed with two or more epileptic seizures at 1 year <b>AND</b> (under 2 years at presentation <b>OR NOT</b> IGE, JME, JAE, CAE, BECTS/Rolandic)
<b>9</b>	<b>'Appropriate' ECG</b>	% with convulsive seizures having ECG by 1 year	1.6.27C 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.	NICE and SIGN vary in their recommendations. SIGN recommendations are easier to objectively audit and therefore selected for this PI	Children diagnosed with convulsive episodes <b>AND</b> 12 lead ECG obtained X100% <hr/> Children diagnosed with convulsive episodes
<b>Evidence of appropriate communication</b>						
<b>10</b>	<b>Pregnancy and AEDs</b>	% females >12 years old commenced on AEDs with evidence of discussion regarding pregnancy and/or contraception related issues	1.11.4C 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 AEDs and their parents should be advised of the risks of fetal malformations and developmental delay.	Age of >12 is a pragmatic way of defining adolescence or 'childbearing' age	females older than 12 <sup>th</sup> birthday at first paediatric assessment <b>AND</b> commenced AEDs during first year <b>AND</b> evidence of discussion regarding pregnancy and/or contraception X100% <hr/> females older than 12 <sup>th</sup> birthday at first paediatric assessment <b>AND</b> commenced AEDs during first year

Evidence of appropriate drug treatment						
<b>11</b>	<b>'Appropriate' carbamazepine</b>	% commenced on carbamazepine with absence of contraindication for carbamazepine	NICE Appendix G	List of antiepileptic drugs which may worsen specific syndromes or seizures.	This has been selected as an achievable measure of appropriate drug choice using the methodology chosen	Commenced on CBZ <b>AND</b> no contraindication for CBZ (IGE, JME, JAE, CAE, LGS, Symptomatic generalised) X100% <hr/> commenced on CBZ
Evidence of appropriate referral						
<b>12</b>	<b>'Appropriate' neurology referral</b>	% diagnosed epileptic seizures meeting referral criteria with evidence of referral to or discussion with tertiary care by 1 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.	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	Children with evidence of referral or involvement paediatric neurologist by 1 year following first assessment <b>AND</b> fulfilling criteria X100% <hr/> Children fulfilling criteria: <ul style="list-style-type: none"> <li>• 3 or more maintenance AEDS by 12 months after first paediatric assessment</li> <li>• Before 2<sup>nd</sup> birthday at first paediatric assessment</li> </ul>

## 7. Data Completeness

- **Participation completeness** = degree of audit participation will be reported for all UK secondary paediatric health providers
- **Ascertainment completeness** = number of children given UIN + defined as excluded on ascertainment tracking form/ total number identified from EEG phase x 100%
- **Date entry completeness** = number of children with complete clinical questionnaires /total number of children given UIN
- **EEG waiting time** = EEG appointment date – first paediatric assessment date

## 8. User Experience module

Participating audit units will be supported such that an anonymous user experience survey can be undertaken

1. A cohort subgroup will be identified for each audit unit
2. This will include those children and young people commenced on AEDs and not deceased
3. A paper questionnaire and cover letter sent to each family by the audit unit team
4. Anonymous questionnaires will be returned in prepaid envelope to the RCPCH project team or questionnaire answered online

## 9. Other potential data items

- Rates of 3 month and 6 month seizure freedom will be piloted as a potential future outcome measures

## Dataset 1 – Audit unit profile

This dataset will be derived during the engagement phase prior to census day. At the time of user registration and data entry these fields will be pre-populated. The user will not be able to edit these fields directly via the website.

Data item	Details
Type of participation	<i>Early adopter or regular adopter</i>
Census day date	<i>First or second census day date</i>
Name (handle) of audit unit	
Names of Acute and Community Trusts	
Names of component paediatric services/hospitals	
Affiliated Tertiary service(s)	
Name of audit unit lead	
Audit unit lead contact details	
List of all participating consultant paediatricians within this audit unit	<i>This will be used to inform EEG department letter</i>
Names of individuals with audit units helper status	<i>Populated from user dataset. Those users with help status for that audit unit</i>
EEG departments	

## Dataset 2 - Service Description Questionnaire for Secondary Services

Online web form completed via web tool by registered audit unit link person after census day. All questions must be answered.

- I understand that in answering these questions I am referring to all paediatric services contained within 'audit unit' as defined within the 'audit unit' profile.
- I understand that I am referring to services as they were on 'census day'.

1. How many whole time equivalent (WTE) general paediatric consultants (community or hospital based) are there employed within the 'audit unit'?	<ul style="list-style-type: none"> <li>• Decimal field</li> </ul>	
2. How many whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy' are there employed within the 'audit unit'?	<ul style="list-style-type: none"> <li>• Decimal field</li> </ul>	
3. What are the names of the consultant paediatricians defined by the audit unit as having 'expertise in epilepsy'?	<ul style="list-style-type: none"> <li>• Free text</li> </ul>	<i>This field is referred to in the clinical dataset when the user is asked whether evidence of input from a 'paediatrician with expertise'</i>
4. How many whole time equivalent (WTE) epilepsy specialist nurses (ESNs) are there employed within the 'audit unit'?	<ul style="list-style-type: none"> <li>• Decimal field</li> </ul>	
5. On average, how many consultant (or associate specialist) led secondary level 'epilepsy clinics' for children or young people take place within your audit unit per week?	<ul style="list-style-type: none"> <li>• Decimal field</li> </ul>	
6. Do any of the paediatric services within the 'audit unit' maintain a database or register of children with epilepsies?	<ul style="list-style-type: none"> <li>• Yes for all children</li> <li>• Yes for some children</li> <li>• No</li> </ul>	
7. Which of the following investigations can be obtained at a location within the 'audit unit'? <ul style="list-style-type: none"> <li>• 12 lead ECG</li> <li>• 'awake' MRI</li> <li>• MRI with sedation</li> <li>• MRI with general anaesthetic</li> <li>• Routine EEG</li> <li>• Sleep-deprived EEG</li> <li>• Melatonin induced EEG</li> <li>• Sedated EEG</li> <li>• 24-48h ambulatory EEG</li> <li>• Video telemetry</li> <li>• Portable EEG on paediatric ward within audit unit</li> </ul>	<ul style="list-style-type: none"> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> </ul>	

<p>8. Does the 'audit unit' host paediatric neurology clinics? (e.g. a paediatric neurologist visits a site within the audit unit or is based within that 'audit unit')</p>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul>	
<p>9. Which of the following 'transition services' are available within the 'audit unit'?</p> <ul style="list-style-type: none"> <li>• A specific clinic for 'young people' or 'teenagers' with epilepsies</li> <li>• a 'Handover clinic'</li> <li>• Other defined handover or referral process</li> <li>• Local adult specialist epilepsy nurse</li> <li>• Youth worker</li> <li>• From what age do 'outpatient' adult services within your audit unit begin to accept referrals from General Practitioners (GPs) for young people with a seizure or seizures?</li> </ul>	<ul style="list-style-type: none"> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Yes/No/Uncertain</li> <li>• Number</li> </ul>	

## Dataset 3 – Add a patient / Inclusion criteria

Patients identified as meeting inclusion criteria will be registered with the web tool via the following form. Patients not fulfilling validation rules for this form will not be encrypted and not registered with the web tool. Those fulfilling the validation rules of this form will be registered with the audit and given a UIN. Each data item remains linked to the UIN.

Question	Answer	Help / Validation Rules
What is the NHS, CHI or H&C number?	10 alphanumeric characters	10 letters or numbers must be entered in this field in order to progress. If the NHS, CHI or H&C number you are trying to enter is not 10 letters or numbers please contact the administrator on <a href="mailto:Epilepsy12@rcpch.ac.uk">Epilepsy12@rcpch.ac.uk</a>
What is the patient's date of birth?	dd/mm/yyyy	The date field must be entered only in the dd/mm/yyyy format either by typing the date or by using the calendar function
What was the date on which the <u>first paediatric assessment</u> for this <u>episode</u> or these <u>episodes</u> occurred?	dd/mm/yyyy	First paediatric assessment - A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting. Assessment within emergency department counts if performed by paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input
How old was the patient at first paediatric assessment (decimal age)?	System generated	No response required
Is the patient male or female	Male/Female	
What was the date on which the patient received their first EEG?	dd/mm/yyyy	This date refers to the child's first ever EEG which should fall within the defined inclusion dates set for your audit unit. Your EEG department should have already only sent you names of patients who date of EEG meets these criteria
<p>1. Does the child have any of the following exclusion criteria?</p> <p>a. All the episodes that the patient had were 'febrile seizures' (an episode diagnosed by the assessing team as a 'febrile seizure' or 'febrile convulsion' or 'febrile fit')</p> <p>b. All the episodes that the patient had were acute symptomatic seizures or occurred within a week of a traumatic head injury (seizures occurring at the time of a diagnosis of an acute disorder e.g. meningitis, encephalitis, electrolyte disturbance etc)</p> <p>c. The patient has had a paediatric assessment previously for similar episode or episodes or epilepsy prior to first paediatric assessment</p> <p>d. The patient's care was permanently transferred to a secondary paediatric service outside the 'audit unit' boundaries or an adult service during the year after first paediatric assessment</p>	<p>No to all Yes to one or more</p>	<p>If yes then this child's data should not be entered</p> <p>The user should be prompted to record the patient as excluded the ascertainment tracking form If no to all then can proceed</p>

## Dataset 4 – Clinical questionnaire

This form will be completed for each successfully registered patient with a UIN. Each question must have an answer before submission accepted. No default answers. Each data item is always linked to UIN.

SECTION A: OTHER INFORMATION		
Question	Answer	Help / Validation Rules
Has the UIN been noted on the ascertainment sheet?	Yes   No	<i>The UIN is the Unique Identifying Number that can be found on the top left hand corner of this page. The UIN should be recorded in the ascertainment sheet.</i>
1a. General Practice code	Number	<i>Each practice is identified by a unique code. The general practice code can be found on the hospital electronic record.</i>
1b. Which is the main trust that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment?	Drop down list	
1c. Which is the main hospital, if any, that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment?	Free text	
1d. Which is the main community paediatric service, if any, that has been involved in managing this patient's seizure(s) during the 12 months after first paediatric assessment.	Free text	
SECTION B: FIRST PAEDIATRIC ASSESSMENT		
2. Was the first paediatric assessment in an acute or non-acute setting?	- Acute - Non-acute - Don't know	<i>Acute - Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting. Non acute - Paediatric outpatients or clinic</i>
3. During the time period from the patient's first paroxysmal episode to the first paediatric assessment was there documentation		

of the following:		
a. A description of the episode or episodes	Yes   No	
b. Approximately when the first episode was, or how old the child was at that time?	Yes   No	
c. The approximate frequency or number of episodes since the first episode?	Yes   No	<i>If only one episode then as long as when this occurred is approximately defined then this can be answered yes</i>
d. A general examination?	Yes   No	<i>Any documentation accepted</i>
e. A neurological examination?	Yes   No	<i>Any documentation that suggests that part of the neurological system has been formally examined (e.g. mention of reflexes, tone, cranial nerves, funduscopy or neuro ?) should be answered "yes"; If neurological system is not specifically mentioned (e.g. examination normal) then answer "no".</i>
f. The presence or absence of developmental, learning or schooling problems	- Yes, this issue was assessed - No, this issue was not assessed	<i>Note that this question is determining whether this was assessed not whether there were problems.</i>
g. The presence or absence of behavioural or emotional problems?	- Yes, this issue was assessed - No, this issue was not assessed	<b><i>Only asked if child [age at first paediatric assessment] is 36 months or greater</i></b> <i>This question is determining whether this was assessed not whether there were problems and is only asked if the child older than 3 years at first paediatric assessment.</i>
Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>
<b>SECTION C: DIAGNOSIS AT FIRST PAEDIATRIC ASSESSMENT</b>		
4. Which statement best describes the number of paroxysmal episodes by the time of the first paediatric assessment?	- A single episode - A cluster of episodes within a 24 hour period - 2 or more episodes (occurring over a time period greater than 24 hours)	<i>For children with a mixture of different episodes some of which were clearly defined as epileptic just refer to those defined as epileptic. E.g. if the child was felt to have 1 epileptic seizures and 3 faints then this would be answered a single episode</i>
5. Which statement best describes the diagnosis made by the paediatric team by the end of the <u>first paediatric assessment</u> ?	- Epileptic or probably epileptic episode(s) - Non-epileptic episode(s) - Uncertain or unclear episode(s)	<i>Diagnosis is that made by the child's health professional assessment as documented within the clinical records. Even if the user considers the diagnosis is wrong it is the health professionals diagnosis at the time that is counted.</i>

6. Was a diagnosis of probable syncope, faints, breath-holding episodes or reflex anoxic seizures made?	Yes   No	<b>Only for those where Q5 answered “non-epileptic episode(s)” at first assessment</b>
7. Was a diagnosis of probable tics made?	Yes   No	<b>Only for those where Q5 answered “non-epileptic episode(s)” at first assessment</b>
Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>
<b>SECTION D: DIAGNOSIS AT 12 MONTHS AFTER FIRST PAEDIATRIC ASSESSMENT</b>		
8. Which statement best describes the <b>total</b> number of paroxysmal episodes occurring by 12 months after first paediatric assessment?	<ul style="list-style-type: none"> <li>- A single episode</li> <li>- A cluster of episodes (confined to a 24 hour period)</li> <li>- 2 or more episodes (occurring over a time period greater than 24 hours)</li> </ul>	<i>If no further episodes have occurred following the first assessment then this question will have the same answer as the number of episodes at first assessment</i>
9. Which statement best describes the diagnosis made by the paediatric team by the end of the 12 months after first paediatric assessment?	<ul style="list-style-type: none"> <li>- Epileptic or probably epileptic episode(s)</li> <li>- Non-epileptic episode(s)</li> <li>- Uncertain or unclear episode(s)</li> </ul>	<i>Diagnosis that is made by the child’s health professional assessment as documented within the clinical records. Even if the user considers the diagnosis is wrong it is the health professionals diagnosis at the time that is counted</i>
10. Was there any evidence that a diagnosis of epilepsy (two or more epileptic seizures) was made and then later withdrawn at any time during 12 months after first paediatric assessment?	Yes   No	
11. Were any afebrile episodes documented as convulsive?	Yes   No	<i>Convulsive episode - An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic) Myoclonic seizures excluded.</i>
12. Which of the listed epileptic seizure type(s) were identified?	<p>Drop down list of epilepsy seizures</p> <p>See Appendix A</p>	<p><b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 AND [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b></p> <p><i>Can select more than one option</i></p>

13. Which of the listed epilepsy syndromes were diagnosed?	Drop down list of epilepsy syndromes See Appendix B	<b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</b> <b>AND</b> <b>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b>
Other Epilepsy syndrome types	Drop down list of epilepsy syndromes See Appendix B	<b>“Other” dropdown menu only available if “Common” drop down selected as “Other”</b>
14. Were there any of the listed epilepsy syndrome category identifiers used?	<ul style="list-style-type: none"> <li>- Idiopathic (or primary)</li> <li>- Symptomatic</li> <li>- Probably symptomatic (or cryptogenic)</li> <li>- Genetic</li> <li>- Structural/Metabolic</li> <li>- Unknown cause</li> <li>- None of above</li> </ul>	<b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</b> <b>AND</b> <b>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b>
15. Were there any of the listed <u>epilepsy syndrome categories</u> identifiers used?	<ul style="list-style-type: none"> <li>- Focal (or partial)</li> <li>- Multifocal</li> <li>- Generalised</li> <li>- Uncertain</li> <li>- None of the above</li> </ul>	<b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</b> <b>AND</b> <b>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b>
16. Was there evidence of a <u>neurodisability</u> diagnosis recorded by professionals involved?	Yes   No	<i>Neurodisability - Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team: Autistic spectrum disorder, Moderate, severe (or profound) learning difficulty or global development delay, Cerebral palsy, Neurodegenerative disease or condition, An identified chromosomal disorder with a neurological or developmental component, Attention deficit hyperactivity disorder (ADHD), Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties</i>
17. If yes, were any of the following diagnoses documented?	<ul style="list-style-type: none"> <li>- Autistic spectrum disorder</li> <li>- Moderate, severe (or profound) learning difficulty or global development delay</li> <li>- Cerebral palsy</li> <li>- Neurodegenerative disease or condition</li> <li>- An identified chromosomal disorder with a neurological or developmental component</li> <li>- Attention deficit hyperactivity disorder (ADHD)</li> <li>- other</li> </ul>	<b>Only if answered yes to Q16</b>

Comments		Please add any comments you would like to be taken into account based on your response above
<b>SECTION E: PROFESSIONAL INVOLVEMENT</b>		
18. By 12 months after first paediatric assessment:		
a. Was there any evidence of <u>input</u> from a <u>Consultant Paediatrician with expertise in epilepsy</u>	Yes   No	<p><b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</b>  <b>AND</b>  <b>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b></p> <p>Consultant Paediatrician with expertise in epilepsy- A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: training and continuing education in epilepsies AND peer review of practice AND regular audit of diagnosis (e.g. participation in Epilepsy12)</p>
b. Was there any evidence of <u>input</u> from a Consultant Paediatric Neurologist?	Yes   No	<p><b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</b>  <b>AND</b>  <b>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b></p> <p>Input - Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact</p>
c. Was there any evidence the child had a referral to or <u>input</u> from an <u>epilepsy specialist nurse?</u>	Yes   No	<p><b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</b>  <b>AND</b>  <b>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b></p> <p>Epilepsy specialist nurse - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies. Copy clinic letter to ESN or documented phone call would count as evidence</p>
Comments		Please add any comments you would like to be taken into account based on your response above
<b>SECTION F: INVESTIGATIONS</b>		
19. By 12 months after first paediatric assessment, is there an MRI head result documented?	Yes   No	

20. By 12 months after first paediatric assessment, is there a CT head scan result documented?	Yes   No	
21. By 12 months after first paediatric assessment, is there a 12 lead ECG result documented or contained within notes?	Yes   No	
Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>
<b>SECTION G: TREATMENT</b>		
22. By 12 months after first paediatric assessment, what number of different (maintenance) <u>antiepileptic drugs</u> had been used?	Number	<i>Antiepileptic drugs - Regular daily drug treatment for reduction of risk of epileptic seizures in epilepsy. Not including drug treatment given for during a prolonged seizure (e.g. rectal diazepam/paraldehyde, buccal midazolam, IV lorazepam/phenytoin) or clusters of seizures (e.g. intermittent clobazam). Not including drugs where the purpose of treatment is for something other than epilepsy treatment (e.g. CBZ for behaviour, topiramate for migraine etc). If no maintenance AED then answer 0.</i>
23. By 12 months after first paediatric assessment, was Carbamazepine prescribed at any time?	Yes   No	<b>Only asked if above 1 or more answered to Q22</b>
Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>
<b>SECTION H: COMMUNICATION</b>		
24. By 12 months after first paediatric assessment was there any evidence of discussion with the parent and/or patient about issues relating to contraception, preconception or pregnancy?	Yes   No	<b>Only asked for females</b>  <i>Any documented evidence of discussion is acceptable. This discussion may not be indicated for many female individuals in this audit but a yes or no answer is still required. Indications for this discussion be taken into account during data analysis.</i>
Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>

<b>SECTION I: OUTCOME</b>		
25. Was there documentation to suggest that seizures occurred between 6 months after first paediatric assessment to 12 months after first paediatric assessment?	<ul style="list-style-type: none"> <li>- Documentation suggests no seizure occurred</li> <li>- Documentation suggests seizure(s) occurred</li> <li>- No documentation or documentation unclear</li> </ul>	<b>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 <u>AND</u> [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</b>
26. Was there documentation to suggest that seizures occurred between 9 months after first paediatric assessment to 12 months after first paediatric assessment?	Yes   No	<b>Only available if Q25 answered as Documentation suggests seizures occurred.</b>
27. Is there any evidence that the child has died?	<ul style="list-style-type: none"> <li>- Died</li> <li>- Presumed alive</li> </ul>	<i>Children who have died will be excluded from the user experience questionnaire</i>
Comments		<i>Please add any comments you would like to be taken into account based on your response above</i>

## Dataset 5 – data completeness

This form is completed when the clinical audit is closed. Successfully completing this form opens the user experience domain.

What is the total number of children whose names appeared on the list received from the EEG department?	Number Not determinable
What is the total number of children who were defined as 'excluded' on the ascertainment tracking form?	Number Not determinable

## Glossary & Definitions

<b>Acute</b>	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
<b>Acute Symptomatic Seizures</b>	Seizures occurring at the time of a diagnosis of an acute disorder e.g. meningitis, encephalitis, electrolyte disturbance etc)
<b>AED (Anti epileptic drug)</b>	Regular daily drug treatment for reduction of risk of epileptic seizures in epilepsy. Not including drug treatment given for during a prolonged seizure (e.g. rectal diazepam/paraldehyde, buccal midazolam, IV lorazepam/phenytoin) or clusters of seizures (e.g. intermittent clobazam). Not including drugs where the purpose of treatment is for something other than epilepsy treatment (e.g. CBZ for behaviour, topiramate for migraine etc)
<b>'Audit Unit'</b>	One or more secondary tier paediatric services grouped together using pragmatic boundaries agreed by the paediatric audit unit link, the project team and the tertiary link
<b>Cardiovascular Examination</b>	Examination of the cardiovascular system to at least include cardiac auscultation
<b>Children's Epilepsy Specialist Nurse</b>	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies
<b>Consultant General Paediatrician</b>	A paediatric consultant (or associate specialist) with a role that includes seeing children or young people in a general outpatient or community clinic setting. They may or may not have other specialty or acute roles. They are likely to receive referrals directly from primary care. Neonatologists would not be included in this definition unless they also fulfill general paediatric roles.
<b>Convulsive episode</b>	An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic) Myoclonic seizures excluded.
<b>Date of first paediatric assessment</b>	Date of acute or non-acute assessment. For children admitted as part of first assessment then the date of admission is the date of first paediatric assessment
<b>Epilepsy</b>	A chronic neurological condition characterised by two or more epileptic seizures (ILAE). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
<b>Epilepsy Syndrome</b>	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
<b>'Epilepsy Syndrome Category'</b>	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic AND focal, partial, multifocal or generalized
<b>Epileptic seizure</b>	Clinical manifestation(s) of epileptic (excessive and/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)
<b>Febrile seizure</b>	An episode diagnosed by the assessing team as a 'febrile seizure' or 'febrile convulsion' or 'febrile fit'
<b>First paediatric assessment</b>	A 'face to face' assessment by a secondary level/tier doctor in a paediatric service occurring in any non-acute or acute setting.

	Assessment within emergency department counts if performed by paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input
<b>First year</b>	Time period from 'date of first paediatric assessment' to 12 months following that date
<b>General examination</b>	Any evidence of a multisystem examination of the child other than neurological examination
<b>Handover clinic</b>	A clinic where a young person 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals
<b>Input</b>	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact
<b>Neurodisability</b>	Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team: <ul style="list-style-type: none"> <li>• Autistic spectrum disorder</li> <li>• Moderate, severe (or profound) learning difficulty or global development delay</li> <li>• Cerebral palsy</li> <li>• Neurodegenerative disease or condition</li> <li>• An identified chromosomal disorder with a neurological or developmental component</li> <li>• Attention deficit hyperactivity disorder (ADHD)</li> <li>• Exclusions e.g. hypermobility, dyspraxia, specific learning difficulties e.g. (dyslexia, dyscalculia)</li> </ul>
<b>Neurological examination</b>	Any evidence of a neurological examination of the child
<b>Non acute</b>	Paediatric outpatients or clinic
<b>Paediatrician with expertise</b>	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: <ul style="list-style-type: none"> <li>• training and continuing education in epilepsies</li> <li>• AND peer review of practice</li> <li>• AND regular audit of diagnosis (e.g. participation in Epilepsy12)</li> </ul> (Consensus Conference on Better care for children and adults with epilepsy - Final Statement Royal College of Physicians of Edinburgh, 2002) A paediatric neurologist is also defined as a 'paediatrician with expertise'.
<b>Paroxysmal episodes</b>	This is the term chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain origin.
<b>'School age'</b>	Child 5 years and older (past their 5 <sup>th</sup> birthday)
<b>Seizure</b>	Paroxysmal disturbance of brain function that may be epileptic, syncopal (anoxic) or due to other mechanisms (SIGN)
<b>Single Cluster</b>	A number of 'paroxysmal episodes' confined to a single 24 hour period (SIGN)
<b>Syncope</b>	Synonymous with 'Faints' or 'vasovagal episodes'

## **Epilepsy seizure types for matrix**

- (generalised) tonic-clonic seizures
- Clonic seizures
- absence seizures (including typical or atypical)
- Myoclonic absence seizures
- Tonic seizures
- Spasms
- Infantile spasms
- Myoclonic seizures
- Massive bilateral myoclonus
- Eyelid myoclonia
- Myoclonic atonic seizures
- Negative myoclonus
- Atonic seizures
- Reflex seizures
- Focal seizures
- Focal sensory seizures
- Focal motor seizures
- Temporal seizure
- Parietal seizures
- Occipital seizures
- Frontal seizures
- Gelastic seizures
- Hemiclonic seizures
- Secondarily generalized seizures
- Reflex seizures
- Defined as “unclassified” seizure
- Grand mal seizures
- Petit mal seizures
- Other seizure stated
- No seizure type stated

## List of Epilepsy syndrome types

- Benign familial neonatal seizures
- Early myoclonic encephalopathy
- Ohtahara syndrome
- Migrating partial (focal) seizures of infancy
- West syndrome(of infantile spasms)
- (Benign) Myoclonic epilepsy in infancy
- Benign infantile seizures
- Dravet syndrome (severe myoclonic epilepsy of/in infancy or SMEI)
- Myoclonic encephalopathy in nonprogressive disorders {myoclonic status in non-progressive encephalopathies}
- Panayiotopoulos syndrome (Early onset (benign) childhood occipital epilepsy)
- Epilepsy with myoclonic astatic seizures (Doose syndrome) (Myoclonic astatic epilepsy)
- (Benign) childhood epilepsy with centrotemporal spikes (BECTS) (benign rolandic epilepsy)
- Late onset childhood occipital epilepsy (Gastaut type) (idiopathic childhood occipital epilepsy)
- Epilepsy with myoclonic absences
- Lennox-Gastaut syndrome
- Landau-Kleffner syndrome
- Childhood absence epilepsy(CAE)
- Juvenile absence epilepsy (JAE)
- Juvenile myoclonic epilepsy (JME)
- Epilepsy with generalized tonic-clonic seizures only (Epilepsy with generalised tonic clonic seizures on awakening)
- Progressive myoclonus (myoclonic) epilepsies (PME)
- Autosomal-dominant nocturnal frontal lobe epilepsy (ADNFLE)
- Familial temporal lobe epilepsies
- Autosomal dominant partial epilepsy with auditory features
- Generalized Epilepsies with Febrile seizures plus (FS+)
- Familial focal epilepsy with variable foci
- Reflex epilepsies
- Idiopathic photosensitive occipital lobe epilepsy
- Visual sensitive epilepsies
- Primary reading epilepsy

- Startle epilepsy
- Benign neonatal seizures Benign non-familial neonatal seizures {fifth day fits
- frontal lobe epilepsy
- temporal lobe epilepsy
- parietal lobe epilepsy
- occipital lobe epilepsy
- Rasmussen's encephalitis (chronic progressive epilepsia partialis continua)  
(Kozhevnikov syndrome)
- Gelastic seizures due to hypothalamic hamartoma
- Eyelid myoclonia with absences
- Perioral myoclonia with absences
- Phantom absences
- Idiopathic focal epilepsy of childhood
- Benign focal epilepsy of childhood
- Childhood epilepsy with occipital paroxysms
- Hemicconvulsion-hemiplegia syndrome
- Hot water epilepsy
- Bathing epilepsy
- Classical petit mal
- Defined as "unclassified"
- Grand mal epilepsy
- Petit mal epilepsy
- Other epilepsy syndrome stated
- No epilepsy syndrome stated