

## 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	Validation Rules
1. What is the NHS, CHI or H&C number?	10 alphanumeric characters	<i>Web tool will check not already submitted and has correct number of integers</i>
2. Patient's date of birth?	dd/mm/yyyy	<i>If patient accepted to audit then this DOB encrypted and an [age at first paediatric assessment derived]</i>
3. What was the date on which the <u>first paediatric assessment</u> for the <u>episode</u> or <u>episodes</u> occurred?	dd/mm/yyyy	<i>This date must fall within (census date-12 months to census date – 18 months) AND The patient must be before their 16th birthday and after 1 month of age on this date</i>
4. How old was the patient at first paediatric assessment (decimal age)?	System generated	
5. Is the patient male or female	Male Female	<i>Must be answered but doesn't matter whether male or female</i>
6. What was the date on which the patient received their first EEG?	dd/mm/yyyy	<i>If this falls outside (census date-6 months to census date – 18 months) then not accepted.</i>
7. Is the patient male or female	Male Female	<i>Must be answered but doesn't matter whether male or female</i>
8. Does the child have any of the following exclusion criteria?  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') 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) c. The patient has had a paediatric assessment previously for similar episode or episodes or epilepsy prior to first paediatric assessment 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	No to all Yes to one or more	<i>If yes then this child's data should not be entered The user should be prompted to record the patient as excluded the ascertainment tracking form If no to all then can proceed</i>

## 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.

Question	Answer	Rules determining whether question asked	Other	User help
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. GP practice code	Number Unknown	All		<i>Each GP practice is identified by a unique GP practice code. The GP 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			
<b>Section 1: First paediatric assessment</b>				
2. Was the <u>first paediatric assessment</u> in an <u>acute</u> or <u>non-acute</u> setting?	Acute Non-acute Don't know	All		<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:				<i>If relevant data is included in the referral letter then this can be recorded as positive evidence. If acute assessment results in acute admission then the whole admission can contribute to the questions in this section.</i>
a. A description of the <u>episode</u> or <u>episodes</u> ?	Yes   No	All		
b. Approximately when the first episode was, or how old the child was at that time?	Yes   No	All		
c. The approximate frequency or number of episodes since the first episode?	Yes   No	All		<i>If only one episode then as long as when this occurred is approximately defined then this can be answered yes</i>
d. A <u>general examination</u> ?	Yes   No	All		<i>Any documentation accepted</i>
e. A <u>neurological examination</u> ?	Yes   No	All		<i>Any documentation that suggests that part of the neurological system has been formally examined (e.g. mention of</i>

				<i>reflexes, tone, cranial nerves, fundoscopy 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	All		<i>Note that this question is determining whether this was assessed not whether there were problems. Any documentation suggesting development assessed accepted. Any documentation suggesting schooling assessed accepted</i>
g. The presence or absence of behavioural or emotional problems	Yes, this issue was assessed No, this issue was not assessed	Only asked if child [age at first paediatric assessment] is 36 months or greater		<i>Note that this question is determining whether this was assessed not whether there were problems. Any documentation accepted</i>
<b>Section 2: 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)	All		<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)	All		<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	Only for those where Q5 answered "non-epileptic episode(s)" at first assessment		
7. Was a diagnosis of probable tics made?	Yes   No	Only for those where Q5 answered "non-epileptic episode(s)" at first assessment		
<b>Section 3: 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?	-A single episode -A cluster of episodes (confined to a 24 hour period) -2 or more episodes (occurring over a time period greater than 24 hours)	All		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
9. Which statement best describes the diagnosis made by the paediatric team by the end of the 12 months after <u>first paediatric assessment</u> ?	-Epileptic or probably epileptic episode(s) -Non-epileptic episode(s) -Uncertain or unclear episode(s)	All		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
10. Was there any evidence that a diagnosis of epilepsy	Yes   No	All		

(two or more epileptic seizures) was made and then later withdrawn at any time during 12 months after <u>first paediatric assessment?</u>				
11. Were any afebrile episodes documented as <u>convulsive?</u>	Yes   No	All		Convulsive episode - An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic) Myoclonic seizures excluded.
12. Which of the listed <u>epileptic seizure type(s)</u> were identified?	Drop down list of epilepsy seizures	<i>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</i> <b>AND</b> <i>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</i>	Can select more than one option	
13. Which of the listed <u>epilepsy syndromes</u> were diagnosed?	Drop down list of epilepsy syndromes	<i>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</i> <b>AND</b> <i>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</i>	"Other" dropdown menu only available if "Common" drop down selected as "Other"	
14. Were there any of the listed <u>epilepsy syndrome categories</u> identifiers used?	-Idiopathic (or primary) -Symptomatic -Probably symptomatic (or cryptogenic) -Genetic -Structural/Metabolic -Unknown -None of above	<i>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</i> <b>AND</b> <i>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</i>		
15. Were there any of the listed <u>epilepsy syndrome categories</u> identifiers used?	-Focal (or partial) -Multifocal -Generalised -Uncertain	<i>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8</i> <b>AND</b> <i>[Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</i>		

16. Was there evidence of a <u>neurodisability</u> diagnosis recorded by professionals involved?	Yes   No	All		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
17. If yes, were any of the following diagnoses documented?	-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) -other	Only if yes to Q16		
<b>Section 4: 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	Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 <b>AND</b> [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9	List of [paediatricians with expertise] derived from service descriptor form	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)
b. Was there any evidence of <u>input</u> from a Consultant Paediatric Neurologist?	Yes   No	Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 <b>AND</b> [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9		Input - Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact
c. Was there any evidence the child had a referral to or <u>input</u> from an <u>epilepsy specialist nurse</u> ?	Yes   No	Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 <b>AND</b> [Epileptic or probably epileptic		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

		<i>episode(s)] at 12 months answered for Q9</i>		
<b>Section 5: Investigations</b>				
19. By 12 months after first paediatric assessment, is there an MRI head result documented?	Yes   No	All		
20. By 12 months after first paediatric assessment, is there a CT head result documented?	Yes   No	All		
21. By 12 months after first paediatric assessment, is there a 12 lead ECG result documented or contained within notes?	Yes   No	All		
<b>Section 6: Treatment</b>				
22. By 12 months after first paediatric assessment, what number of different (maintenance) antiepileptic drugs had been used?	Number	All	Must be whole number - 0 accepted	If no maintenance antiepileptic drugs then answer '0'  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.
23. By 12 months after first paediatric assessment, was Carbamazepine prescribed at any time?	Yes   No	Only asked if above 1 or more answered to Q22		
<b>Section 7: 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	Only asked for females		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.
<b>Section 8: 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?	Documentation suggests no seizure occurred Documentation suggests seizure(s) occurred No documentation or documentation unclear	<i>Only if 2 or more episodes (diagnosis at 12 months) answered for Q8 <b>AND</b> [Epileptic or probably epileptic episode(s)] at 12 months answered for Q9</i>		

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	Only available if Q25 answered as Documentation suggests seizures occurred.		
27. Is there any evidence that the child has died?	Died Presumed alive	All		Children who have died will be excluded from the user experience questionnaire

## 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