Royal College of Paediatrics and Child Health
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EPILEPSY12

Round 3 National Audit, Patient Registration and Clinical audit data entry forms

Introduction

This document contains details of the Epilepsy12 round 3 registration forms and the core clinical audit dataset, effective from **12 July 2018.**For more information on the Epilepsy12 round 3 clinical audit methodology please download the full document from our website: www.rcpch.ac.uk/epilepsy12.

Epilepsy12 Patient registration

Patients can be registered either via health board/trust paediatric epilepsy service staff or by staff within EEG services. The role of EEG services is to register patients who have been referred for a first EEG for a paroxysmal episode or episodes by paediatric epilepsy services. Health board/trust paediatric epilepsy services can register patients onto the Epilepsy12 data platform directly and they will also have to verify any patients that are registered by an EEG service where they are named as the referring health board/trust. See the "How to register" user guides on the downloads section of the Epilepsy12 Submit Data page for further details on the registration process.

The Clinical dataset is split into 10 sections:

1. Trust allocation and Follow up status
2. Diagnostic status
3. Lead epilepsy team
4. Initial referral and examinations
5. Description of episodes
6. Investigations
7. Treatments
8. Care planning
9. Outcome
10. Professional/services involved

Patient Cohorts

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 (i.e. 12 July 2018) and 30 November 2018.
- **Cohort 2** – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2018 to 30 November 2019
- **Cohort 3** – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2019 to 30 November 2020

The **First Paediatric Assessment Form** should be submitted and locked as close to the date of the first assessment as possible and thereafter details of the **First Year of Care** should then be added for each patient. Data should be entered into the **First Year of Care** form and updated throughout the year, but the system will prompt users to complete the form when there is a month remaining of the 12 months post first assessment for each patient.

Epilepsy12 Round 3, Health Board/Trust Initial Patient Registration form:

(All fields are mandatory)

	Question	Type	Answer options	Notes
1.1	NHS patient?	Radio Button	• Yes • No	If the answer to this question is '**No**' then the patient is excluded from the audit.
1.2	Patient's NHS or CHI number?	Text field	Enter 10 alphanumeric characters	A note will appear on screen if the patient has already been registered onto the Epilepsy12 system after checking against the NHS number
1.3	Patient's first name?	Text field	Free text field	
1.4	Patient's surname?	Text field	Free text field	
1.5	Gender	Radio Button	• Male • Female • Not known	'Not known' means that the gender cannot be found on the patient's record.
1.6	Patient's date of birth?	Date Calendar	DD/MM/YYYY	Patients should not be 25 years or over.
1.7	Has this patient been referred for a (first?) EEG	Radio Button	• Yes • No	Still answer 'Yes' if: • The patient has been referred for EEG but has not achieved the EEG (for example 'was not brought' and cancelled by parents etc.) • The patient's first EEG is indicated, but is not requested. For example, diagnosis of epilepsy suspected in a child with autistic spectrum disorder where EEG deemed not appropriate to attempt Please note that first EEG counts: • In EEG services where sleep or sleep deprived EEGs are done as a first EEG If the answer is '**No**' to BOTH this question AND **Q1.9**, then the patient is excluded from the audit.
1.8	What was the date on which the patient was referred for their first EEG?	Date Calendar	DD/MM/YYYY	
1.9	If not referred for a first EEG, was a first EEG indicated although the child was not actually referred?	Radio Button	• Yes • No	If the answer to this question is '**No**' to BOTH this question AND **Q1.7,** then the patient is excluded from the audit.
1.10	Was the first paediatric assessment for the paroxysmal episode or episodes undertaken within this Health Board/Trust?	Dropdown	• Yes • No	This term is chosen in this audit to represent the events causing concern. It includes all epileptic and non-epileptic seizures and also seizures of uncertain origin.

Epilepsy12 Round 3, EEG Initial Patient Registration form:

(All fields are mandatory)

	Question	Type	Answer options	Notes
1.1	NHS patient?	Radio Button	• Yes • No	If the answer to this question is '**No**', then the patient will be excluded from the audit.
1.2	Patient's NHS or CHI number?	Text field	10 alphanumeric characters	A note will appear on screen if the patient has already been registered onto the Epilepsy12 system after checking against the NHS number.
1.3	Was this patient referred from a paediatric service (as opposed to adult service)	Radio Button	• Yes • No	If the answer to this question is '**No**' then presumed adult and excluded from the audit.
1.4	Patient's first name?	Text field	Free text field	
1.5	Patient's surname?	Text field	Free text field	
1.6	Gender	Radio Button	• Male • Female Not known	
1.7	Patient's date of birth?	Date Calendar	DD/MM/YYYY	Patient's should not be 25 years or over.
1.8	Has the child had previous EEGs	Dropdown	1. No this is first referral for EEG 2. Yes previous EEGs for paroxysmal episode(s) 3. Yes previous EEGs but not for paroxysmal episode(s)	If the answer to this question is option **2** the patient will be excluded from the audit.
1.9	What was the date on which the patient was referred for their first EEG?	Date Calendar	DD/MM/YYYY	.
1.10	Who is the referring Trust/Health board?	Dropdown list	Choose the referring Trust/Health board within the drop-down list	**Please ensure you select the correct referring Health Board/Trust when registering your patients.**

Epilepsy12 Round 3, Health Board/Trust Verification form:

(All fields are mandatory)

	Question	Answer options	Notes
2.1	Has the child had a paroxysmal episode or episodes prompting a first paediatric assessment?	• Yes • No	If the answer to this question is '**No**' then the patient is not eligible for inclusion and will be excluded from the audit. If a patient is excluded, you can contact the Epilepsy12 project team (epilepsy12@rcpch.ac.uk) to ask for the patient's registration to be deleted.
2.2	Has the patient had any previous EEG or paediatric assessments for a similar episode or episodes or epilepsy prior to this 'first paediatric assessment'?	• Yes • No	If the answer to this question is '**Yes',** the patient will be excluded from the audit. If a patient is excluded, you can contact the Epilepsy12 project team (epilepsy12@rcpch.ac.uk) to ask for the patient's registration to be deleted.
2.3	What was the date on which the very first paediatric assessment for this episode or these episodes occurred?	DD/MM/YYYY	The date of first assessment must be after the Epilepsy12 clinical audit start date (set at 12 July 2018) or the patient will be excluded. 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. Assessment within an inpatient or outpatient neonatal service may count. Some Paediatric Neurologists see referrals direct from GP or ED and these would count as both a first paediatric assessment and tertiary input.
2.4	Home postcode	Postcode format	Please enter the correct postcode for each patient registration.
2.5	Current General Practice code	Postcode format	To look up your patients GP Practice postcode, please visit: https://fingertips.phe.org.uk/profile/general-practice

Epilepsy12 Round 3, Clinical audit data entry forms (First Paediatric Assessment and ongoing years of care)

To be completed by Health Board/Trust paediatric epilepsy service teams (not EEG services)

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
1.0	**Trust allocation and Follow up status**			
1.1	**Which form is this? (Automatically populated)**	**(Automatically populated by the data system)**		
1.2	Has this patient requested opt out of inclusion within the Epilepsy12 audit?	• Yes • No	If Yes is answered then it will not be possible to enter any further data into the clinical audit forms for the patient.	Please ensure you clearly record whether your patients have expressed to opt out of their data being processed by Epilepsy12. This will enable the project team to exclude any of their patient data from the audit. Mandatory question
1.2i	What was the date that opt out was requested?	If '**Yes**', is selected for **1.2** enter opt out date	Date format	Mandatory question
1.3	Is the child still having paediatric follow up by this trust for these uncertain, non-epileptic or epileptic episodes?	• Yes • No	If the answer is '**No**', answer question **1.3.1**	This is to identify and confirm that the child requires ongoing inclusion in the audit. Only relevant children will remain in the ongoing ascertainment or audit process. Mandatory question
1.3.1	If the child is no longer having paediatric follow up by this trust for these uncertain, non-epileptic or epileptic episodes, which statement best describes their follow up status?	*1.* Discharged and transferred to another paediatric provider *2.* Transferred to adult services *3.* Discharged to GP because ongoing paediatric follow up not required *4.* Discharged to GP because DNA/was not brought/Cancelled *5.* Followed up by paediatrics but not because of epileptic, non-epileptic or uncertain episodes *6.* No ongoing follow up for other reason *7.* Died	(Choose one of the options and enter a related date for options *1,2,3* and *6* if they are chosen)	This is to identify and confirm that the child requires ongoing inclusion in the audit. Only relevant children will remain in the ongoing ascertainment or audit process Mandatory question
2.0	**Diagnostic status**			
2.1	At any point in time has the child had neonatal seizures(s)	• Yes • No • Uncertain		This refers to any type of seizure in the first month of life. 'Uncertain' means that the neonatal seizures(s) of the patient have not been recorded. Mandatory question
2.2	At any point in time has the child had febrile seizure(s)	• Yes • No • Uncertain		This refers to any seizure that was diagnosed as a febrile seizure or febrile convulsion. (See detailed description in

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
				help notes on the data capture system). 'Uncertain' means that the febrile seizures(s) of the patient have not been recorded. Mandatory question
2.3	At any point in time has the child had acute symptomatic seizure(s)?	• Yes • No • Uncertain		Uncertain' means that the neonatal seizures(s) of the patient has not been recorded. Mandatory question
2.4	Which best describes the patient's diagnostic status:	• The child has had an episode or episodes where one or more are considered epileptic • The child has had an episode or episodes that are considered non-epileptic only • The child has had an episode or episodes where there remains uncertainty whether episodes were epileptic or not.	If the answer is **the first option,**, you must complete question **2.4.i** If the answer is the second option you must answer question **2.4.A**	The user is asked to describe the episodes that have been assessed and indicate whether they are considered to be epileptic. It remains a clinical judgment that this diagnosis of epilepsy is appropriate. If the episode or episodes are considered to be epileptic then the user must describe them via Q2.4i to see if they meet the ILEA 2014 definition of epilepsy. Mandatory question
2.4i	Describe the episode or episodes where one or more were considered epileptic:	• This was a single episode • This was a cluster within 24 hours • These were 2 or more episodes more than 24 hours apart • The patient was diagnosed as having epilepsy for another reason		If there were '2 or more episodes more than 24 hours apart' **or** 'the patient was diagnosed as having epilepsy for another reason' Then this patient is defined as having epilepsy and the rest of clinical audit form (sections 3 to 10) will open up for data entry. **If either of the first two options ('single episode' or 'cluster within 24 hours') are selected the user will not need to complete sections 3 to 10.** Mandatory question

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
2.4.A	Add new non-epileptic episode: Episode Type	• Syncope and Anoxic Seizures • Behavioural, Psychological and Psychiatric Disorders • Sleep Related Conditions • Paroxysmal Movement Disorders • Migraine Associated Disorders • Miscellaneous Events • Other	Only applicable if the second option for question 2.4 is indicated.	
2.5	Notes	Free text field		
3.0	**Lead Epilepsy Team**			
3.1	Home postcode	Details are pulled through from the patient **Trust Verification form**		
3.2	Current General Practice code	Details are pulled through from the patient **Trust Verification form**		This is automatically pulled through from the Trust verification screen. Each practice is identified by a unique code. The general practice code can be found on the hospital electronic record. Mandatory question
3.3	Current epilepsy service within the Trust/Health Board	Answer options can be selected from a drop-down list which is populated from the **Trust Profile.**		Some participating units may have opted to divide their Trust or Health Board into separate services to allow sub analysis at a later stage. If you opted to do this then this allows you to attach the patient to that particular service. Most trusts and health boards will not need to do this. Mandatory question
3.4	Current secondary Paediatric Consultant(s) leading management of the epilepsy	Answer options can be selected from a drop-down list which is populated from the **Trust Profile.**		In some situation's this may be the paediatric neurologist acting in this secondary role. (Data field TP5) Mandatory question
3.5	Current ESN(s)	Answer options can be selected from a drop-down list which is populated from the **Trust Profile.**		Describe the epilepsy nurse allocated to this patient. For services where ESNs share caseloads then nominate a keyworker ESN. (populated by data field TP10) Mandatory question
3.6	Current status of Paediatric Neurology follow-up	• Ongoing input • Previous input • Uncertain • None	If the answer is '**Ongoing** or '**Previous input'**, answer question **3.6.i & 3.6.ii**	Mandatory question
3.6.i	Health Board(s)/Trust(s) involved in tertiary paediatric neurology epilepsy management	Answer options can be selected from a drop-down list which is populated from the **Trust Profile.**		Populated by data field TP3 Mandatory question

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
3.6.ii	Paediatric Neurologist(s)	Answer options can be selected from a drop-down list which is populated from the **Trust Profile.**		Mandatory question
3.7	Current status of Epilepsy Surgery Service	• Ongoing input • Previous input • Uncertain • None	If the answer is '**Ongoing** or '**Previous input'**, answer question **3.7.i**	Mandatory question
3.7.i	Indicate the managing Children's Epilepsy Surgery Service	Answer options can be selected from a drop-down list which is populated from the **Trust Profile.**		Populated by data field TP4 Mandatory question
4.0	**Initial referral and examinations**			
4.1	From which service was the child referred for first paediatric assessment?	• ED • GP • Health Visitor • Outpatient paediatrics • Inpatient paediatrics • PICU • Neonatal care • Other	If the answer is '**Other',** please input the answer in the 4.1.i **'Specify'** field**'.**	Mandatory question
4.2	Date of referral to paediatrics	• Date DD/MM/YYYY • Not Known		This will allow us to track timeliness of first paediatric assessment after the referral date. For some acute situations this may be the same date as the first paediatric assessment. Mandatory question
4.3	Was the first paediatric assessment in an acute or non-acute setting?	• Acute • Non-acute • Don't know		Acute refers to in an ED or inpatient setting. Non-acute refers to a clinic/outpatient setting. Mandatory question
4.4	During the time period from the patient's first paroxysmal episode considered epileptic to the first paediatric assessment was there documentation of the following:	Answer questions **4.4.1 – 4.4.7**		If only one episode then as long as when this occurred is approximately defined then this can be answered yes. Mandatory question
4.4.1	A description of the episode or episodes?	• Yes • No		Mandatory question
4.4.2	Do you know the date the first epileptic episode occurred?	• Approximate date • Exact date • Not known	Enter date in 4.4.2.i where applicable	Mandatory question
4.4.3	The approximate frequency or number of episodes since the first episode?	• Yes • No		Mandatory question
4.4.4	A general examination?	• Yes • No		Any documentation will be accepted. Mandatory question
4.4.5	A neurological examination?	• Yes		Any documentation that suggests that part

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		• No		of the neurological system has been formally examined (e.g. mention of reflexes, tone, cranial nerves, fundoscopy or 'neuro'?) should be answered '**yes**'. Mandatory question
4.4.6	The presence or absence of developmental, learning or schooling problems	• Yes • No		Note that this question is determining whether this was assessed not whether there were problems. Mandatory question
4.4.7	The presence or absence of behavioural or emotional problems?	• Yes • No		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. Mandatory question
4.4.8	Comments	Free text field		
5.0	**Description of episodes**			
5.1	Add details of seizure type	Answer questions **5.1 – 5.1.3.1.3**		This tab details your ongoing epilepsy formulation using a DESCRRIBE type approach based on ILAE multi axial classifications and terminology. All children should have this section completed. A new seizure type should be completed for each episode's type including uncertain or non-epileptic episodes. These can be updated and corrected at any time. For example if new information comes to light about a particular episodes the existing seizure type should be amended rather than a new seizure added. (This is not a seizure diary). Mandatory question
5.1.1	Is the date of onset approximate or exact?	• Approximate date • Exact date • Not known	Enter date of onset in 5.1.1.i where applicable	
5.1.2	Description of event	Free text field		
5.1.3	Epileptic, Non-epileptic, Uncertain	• Epileptic • Non-epileptic • Uncertain	If '**Epileptic**' is selected, continue to answer **5.1.3.1** If **'Non-epileptic'** select answer from **'ILAE epilepsy imitators list'** within drop-down shown on **page 29 of this document.**	
5.1.3.1	Epileptic Seizure type	• Focal onset • Generalised onset • Unknown onset	If the answer is '**Focal onset**' answer question **5.1.3.1.1** **If the answer is 'Generalised onset'**	

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		• Unclassified	**answer question 5.1.3.1.2** **If the answer is 'Unknown onset' answer question 5.1.3.1.3**	
5.1.3.1.1	Focal onset	• Impaired awareness • Atonic • Left • Epileptic spasms • Myoclonic • Autonomic • Cognitive • Sensory • Temporal • Parietal • Gelastic • Automatisms • Clonic • Right • Hyperkinetic • Tonic • Behaviour arrest • Emotional • Centro-temporal • Frontal • Occipital • Focal to bilateral tonic clonic • Other	If the answer is '**Other',** please give details in the **available** field**.**	
5.1.3.1.2	Generalised onset	• Tonic-clonic • Clonic • Tonic • Myoclonic • Myoclonic-tonic-clonic • Myoclonic-atonic • Atonic • Epileptic spasms • Typical absence • Atypical absence • Myoclonic absence • Absence with eyelid myoclonia • Other	If the answer is 'Other' please give details in 5.1.3.1.2.i	
5.1.3.1.3	Unknown onset	• Tonic-clonic • Epileptic spasms • Behaviour arrest • Other	If the answer is 'Other' please give details in 5.1.3.1.3.i	
5.2	Add or edit details of electroclinical syndrome if known	Answer questions **5.2.1 – 5.2.1.2**		This tab details your ongoing epilepsy formulation using a DESCRRIBE type

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
				approach based on ILAE multi axial classifications and terminology. Add and describe and epilepsy syndrome diagnosis made. This should be updated as more information comes to light such that this page captures the current best description. Occasionally a child may have 2 epilepsy syndromes for example CAE followed by JAE; Epileptic spasms followed by Lennox Gastaut etc.
5.2.1	Is the date of diagnosis approximate or exact?	• Approximate date • Exact date • Not known	Enter date of onset in 5.2.1.i where applicable	
5.2.2	Electroclinical syndrome	**Select an answer from the drop-down list shown on page 28 of this document.**		
5.3	Add or edit details of a seizure cause if known	Answer questions **5.3.1 – 5.3.2.4**		This tab details your ongoing epilepsy formulation using a DESSCRIBE type approach based on ILAE multi axial classifications and terminology. This should include all possible diagnoses that are associated with the epilepsy and possibly contribute to a cause. This does not need to list every diagnosis the child has but just those associated with the epilepsy.
5.3.1	Is the date of the identification of a seizure cause approximate or exact?	• Approximate date • Exact date • Not known	Enter date of onset in 5.3.1.i where applicable	
5.3.2	Cause	• Structural • Genetic • Infectious • Metabolic • Immune • Not known	If Structural is selected enter a structural type in 5.3.2.3 If Genetic is selected enter a Genetic type in 5.3.2.3	
5.3.2.3	Structural type	• Tuberous Sclerosis • Sturge Weber • Focal cortical dysplasia • Hypothalamic Hamartoma • Low grade tumour • Tumour (other) • Malformations of Cortical Development • Vascular (e.g. arterial ischaemic stroke, venous ischaemia, cerebral haemorrhage) • Traumatic brain injury • Not required		
5.3.2.3	Genetic type	• Dravet syndrome	If '**Chromosomal abnormality**' or	

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		• Glucose Transporter Defect • Angelman Syndrome • Rest Syndrome • Chromosomal abnormality • Gene abnormality	**'Gene abnormality'** is selected, please answer question '**5.3.2.3. i**	
5.3.2.3	Please specify chromosomal abnormality	Free text box		
5.3.2.3 I	Gene abnormality	• UBE3A • GLUT1 • SLC2A1 • MECP2 • SCN1A • STXBP1 • CDKL5 • KCNQ2 • SCN2A • KCNT1 • ARX • FOXG1 • PCDH19 • GRIN2A • Other	If Genetic abnormality is selected enter a Genetic abnormality in 5.3.2.3i	
5.3.2.3	Infectious type	Insert response in free text field		
5.3.2.3	Metabolic type	• Mitochondrial disorder • Neuronal Ceroid Lipofuscinosis (Batten Disease) • Disorder of pyridoxine/pyridoxal phosphate metabolism • Disorder of biotin metabolism • Disorder of creatine metabolism • Disorder of amino acid • Disorder of urea cycle • Disorder of pyrimidine and purine • Disorder of cholesterol • Other neurometabolic disorder		
5.3.2.3	Immune type	• Rasmussen Encephalitis • Antibody mediated	**If '**Antibody mediated' is selected, please select an answer for'**5.3.2.3 Immune type.i'**	
5.3.2.3	Antibody type	• VGKC • NMDAR • GAD • TPO • MOG		

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		• Other		
5.4	Add or edit details of any known neurodisability or neurodevelopmental problem(s)	Answer questions **5.4.1 – 5.4.2**		This tab details your ongoing epilepsy formulation using a DESSCRIBE type approach based on ILAE multi axial classifications and terminology. This can be added to or edited as time progresses. Some children may have many associated problems and co-morbidities, some will have none.
5.4.1	Is the date of the neurodisability or neurodevelopmental problem approximate or exact?	• Approximate date • Exact date • Not known	Enter date of onset in 5.4.1.i where applicable	
5.4.2	Neurodisability or neurodevelopmental problem(s)	1. Autistic spectrum disorder 2. Cerebral palsy 3. Neurodegenerative disease or condition 4. An identified chromosomal disorder with a neurological or developmental component 5. Attention deficit hyperactivity disorder 6. Intellectual disability/global development delay/'learning disability' 7. Dyspraxia 8. Dyslexia 9. Speech disorder 10. Other learning difficulty	If the answer is '**Other',** please give details in the available field**.** Indicate '**Severity' in 5.4.2.i**: if option 6 "Intellectual disability/global development delay/'learning disability" is chosen for 5.4.2 • Mild, • Moderate, • Severe, • Profound	
5.5	Add or edit details of any known mental health problem(s)	Answer questions **5.5.1– 5.5.2**		This tab details your ongoing epilepsy formulation using a DESSCRIBE type approach based on ILAE multi axial classifications and terminology.
5.5.1	Is the date of the mental health problem(s) approximate or exact?	• Approximate date • Exact date • Not known	Enter date of onset in 5.5.1.i where applicable	
5.5.2	Mental health problem(s)	• Mood Disorder • Anxiety Disorder • Emotional/behaviour • Self-harm • Other	If the answer is '**Other',** please give details in the available field**'.** Select 'Type of emotional / behavioural disorder**' in 5.5.2.i**: for '**Emotional/behavioural**'	
5.6	Were any of the epileptic seizures convulsive?	• Yes • No		An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic). Myoclonic seizures excluded. This question informs the 12 lead ECG performance indicators which tracks the recommendation that all children with a convulsive seizure should

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
				have 12 lead ECG. Mandatory question
5.7	Has the child at any point in time experienced prolonged generalised convulsive seizures > 5 min duration (or successive continuing > 5min)?	• Yes • No • Uncertain		Mandatory question
5.8	Has the child at any point in time experienced prolonged focal seizures > 5 min duration (or successive continuing > 5min)?	• Yes • No • Uncertain		Mandatory question
5.9	Is there a family history of epilepsy?	• Yes • No • Not assessed		Mandatory question
5.9.i	Notes	Free text field		
6.0	**Investigations**			
6.1	Which of the following investigations have been undertaken	Answer questions **6.1.1 – 6.1.5**		Mandatory question
6.1.1	First EEG	1. Not requested 2. Requested and waiting 3. Obtained 4. Requested and did not attend 5. Requested and attempted but not achieved	If **option 3 is** selected, enter a **Date of report.** If **option 5** is selected, enter '**Reasons why not achieved**' in free text field	Mandatory question
6.1.2	12 lead ECG	1. Not requested 2. Requested and waiting 3. Obtained 4. Requested and did not attend 5. Requested and attempted but not achieved	If **option 3 is** selected, enter a **Date of report** and **whether there was evidence that the QTc was calculated.** If **option 5** is selected, enter '**Reasons why not achieved**' in free text field	Mandatory question
6.1.3	CT head scan	1. Not requested 2. Requested and waiting 3. Obtained 4. Requested and did not attend 5. Requested and attempted but not achieved	If **option 3 is** selected, enter a **Date of report.** If **option 5** is selected, enter '**Reasons why not achieved**' in free text field	Mandatory question
6.1.4	MRI brain	• Not requested • Requested and waiting • Obtained • Requested and did not attend • Requested and attempted but not achieved	If **option 3 is** selected, enter a **Date of report.** If **option 5** is selected, enter '**Reasons why not achieved**' in free text field	Mandatory question
6.1.5	Investigation section notes	Enter response in free text field		

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
7.0	**Treatment**			
7.1	Has an AED been given?	• Yes • No	If yes is answered questions 7.1.1, 7.1.2. and 7.1.3 must be answered. If Sodium valproate is indicated and the patient is female then question 7.1.4 "Was there any evidence of consideration and discussion of risk about valproate and pregnancy?" will also need to be answered.	An AED (anti-epileptic drug) is any 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.). This should be kept up to date with all ongoing AEDs that are started or stopped. Doses are not currently included within the Epilespy12 dataset. Mandatory question
7.1.1	Name of drug	**Select AED from drop down menu list shown on page 31 of this document**	Drop-down list of all current AEDs	Mandatory question
7.1.2	Date started	Enter date		Mandatory question
7.1.3	Date stopped	Enter date	Optional choice to select '**Ongoing'** is available	Mandatory question
7.2	Has a rescue medication been prescribed?	• Yes • No	If yes is answered questions 7.2.1, 7.2.2. and 7.2.3 must be answered.	Rescue medication is medication that families or other care settings keep to be given in the event of an ongoing seizure to help stop that seizure. Epilepsy12 will look for evidence that children prescribed a rescue medication has evidence of an emergency plan to support the family understand when and how to administer the chosen medication. Mandatory question
7.2.1	Add name of rescue medication	• Buccal midazolam • Rectal diazepam	If the answer is '**Other',** please input the answer in the **'Specify'** field**'.**	Mandatory question
7.2.2	Date started	Enter date		Mandatory question
7.2.3	Date stopped	Enter date	Optional choice to select '**Ongoing'** is available	Mandatory question
7.2.4	Notes	Optional free text field		

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
7.3	Does the child meet any of the CESS referral criteria below?	• Yes • No	If 'Yes' you will be able to add notes in 7.3.i	Mandatory question
8.0	**Care planning**			
8.1	Is there evidence of a copy clinic letter which includes individualised planning of care?	• Yes • No	If the answer is '**Yes**'. Please '**Add further details**' within the free text field.	Epilepsy12 considers care planning as an ongoing process often comprising many different elements, forms, documents and packages. Different children will require different elements at different times. This tab examines the presence or absence of these components and allows the service to add to this over time. The care planning summary record can be reviewed at any time via the care planning tab Clinic letters are the mainstay for many services to summarise their agreed plan of care for the child. Mandatory question
8.2	Is there evidence of patient held individualised epilepsy documents(s) other than copy clinic letters?	• Yes • No	If the answer is '**Yes**'. Please '**Add further details**' within the free text field.	Some services choose to summarise the ongoing plan of care using proformas separate to or in addition to copy clinic letters. Either approach is considered valid. Mandatory question
8.3	Is there evidence of patient/parent/carer/agreement to the plan of care?	• Yes • No	If the answer is '**Yes**'. Please '**Add further details**' within the free text field.	Ongoing care planning should demonstrate family involvement and agreement in plans made. Different services will demonstrate this in different ways. Mandatory question
8.4	Is there evidence that the care plan is updated when necessary?	• Yes • No	If the answer is '**Yes**', please '**Add further details**' within the free text field.	Children should have ongoing updated plans of care (at least yearly). Mandatory question
8.5	Have details of how to contact the paediatric epilepsy service been provided to the patient/parent/carer?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.5.1 - 8.5.3**	Different services will achieve this in different formats. e.g. information sheets, contact cards, letter headers/footers, passports etc. Mandatory question
8.5.1	Date information provided	Enter date		Mandatory question
8.5.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		Mandatory question
8.5.3	Add further details	Optional free text box		
8.6	Has first aid information been provided to the patient/parent/carer?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.6.1 - 8.6.3**	This may be in the form of verbal or written format or indeed video or other educational formats. Mandatory question
8.6.1	Date information provided	Enter date		Mandatory question

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
8.6.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		Mandatory question
8.6.3	Add further details	Optional free text box		
8.7	Is there evidence of planning of care that encompasses a parental or carer prolonged seizure care plan?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.7.1 - 8.7.3**	This is a proforma +/- a training package that evidences that the family has been trained to administer rescue medication appropriately. A prescription alone is not evidence of appropriate planning of care.
8.7.1	Date information provided	Enter date		Mandatory question
8.7.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		Mandatory question
8.7.3	Add further details	Optional free text box		
8.8	Is there evidence of planning of care that encompasses provision of information on General participation and risk?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.8.1 - 8.8.3**	Evidence may exist within clinic letters or within patient information shared with the family. As an example SUDEP Action have produced a specific information resource to introduce consideration of relevant risks for children and young people with epilepsy. Mandatory question
8.8.1	Date information provided	Enter date		Mandatory question
8.8.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		Mandatory question
8.8.3	Add further details	Optional free text box		
8.9	Is there evidence of planning of care that encompasses provision of information on Water Safety?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.9.1 - 8.9.3**	Seizure related Drowning should be considered as an avoidable cause of death and morbidity in epilepsy. This is highlighted as a risk that warrants specific evidence of discussion and documentation with the family. Mandatory question
8.9.1	Date information provided	Enter date		Mandatory question
8.9.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		Mandatory question
8.9.3	Add further details	Optional free text box		
8.10	Is there evidence of planning of care that encompasses provision of information on SUDEP?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.10.1 - 8.10.3**	Currently Epilepsy12 does not define which children should have SUDEP information when. As an example, SUDEP ACTION have produced an information leaflet specifically for children and young people with epilepsy suitable for use for any child with epilepsy early after diagnosis. Mandatory question

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
8.10.1	Date information provided	Enter date		Mandatory question
8.10.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		Mandatory question
8.10.3	Add further details	Optional free text box		
8.11	Is there evidence of planning of care that encompasses provision of information on Road Safety?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.11.1 - 8.11.3**	This will be relevant for some children but not all.
8.11.1	Date information provided	Enter date		
8.11.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		
8.11.3	Add further details	Optional free text box		
8.12	Is there evidence of planning of care that encompasses provision of information on Heights?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.12.1 - 8.12.3**	For example, climbing trees and climbing frames. This will be relevant for some children but not all
8.12.1	Date information provided	Enter date		
8.12.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		
8.12.3	Add further details	Optional free text box		
8.13	Is there evidence of planning of care that encompasses provision of information on Sleep monitoring?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.13.1 - 8.13.3**	This will be relevant for some children but not all.
8.13.1	Date information provided	Enter date		
8.13.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		
8.13.3	Add further details	Optional free text box		
8.14	Is there evidence of planning of care that encompasses provision of information on Photosensitivity?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.14.1 - 8.14.3**	This will be relevant for some children but not all.
8.14.1	Date information provided	Enter date		
8.14.2	Information provided by	Select answer within drop-down box that is populated from the **Trust Profile**		
8.14.3	Add further details	Optional free text box		
8.15	Add details of provision of information on epilepsy treatments	Answer questions **8.15.1 – 8.15.4**		Medicines for children (www.medicinesforchildren.org.uk) produce a comprehensive set of printable patient information resources
8.15.1	Type of information	• Treatment goals • Drug Information leaflet • Sodium Valproate Risks & Benefits		

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		• VNS Option • Surgery option • Ketogenic option • Other		
8.15.2	Date information provided	Enter date		
8.15.3	Information provided by	Select answer from the drop-down box options which are populated from the **Trust Profile.**		
8.15.4	Add further details	Optional free text box		
8.16	Add details of provision of information on Transition and Teenage lifestyle (Contraception, Driving, Self-Management etc.)	Answer questions **8.16.1 – 8.16.4**		This will be relevant for some children but not all. 'Ready Steady Go' is the transition resource established by Southampton Children's Hospital. Progress through this resource can be tracked via the Epilepsy12 care planning tool.
8.16.1	Type of information	• Driving • Contraception • Pregnancy • Adherence • Sleep hygiene • Alcohol • Recreational Drugs • Career • Bus pass • Seen on own • Self-management • Goal Setting • Ready • Steady • Go • Hello • Other		
8.16.2	Date information provided	Enter date		
8.16.3	Information provided by	Select answer from the drop-down box options which are populated from the **Trust Profile.**		
8.16.4	Add further details	Optional free text box		
8.17	Add new epilepsy details	Answer questions **8.17.1 – 8.17.4**		Elements of this will be relevant for some children but not all
8.17.1	Type of information	• Seizure diary • Seizure types • Syndrome type • Prognosis • Co-morbidities		

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		• National Support Groups • Other		
8.17.2	Date information provided	Enter date		
8.17.3	Information provided by	Select answer from the drop-down box options which are populated from the **Trust Profile.**		
8.17.4	Add further details	Optional free text box		
8.18	Has there been a review of the patient's/parent's seizure diary?	• Yes • No	If the answer is '**Yes**, please 'add further information' for questions **8.14.1 - 8.14.3**	
8.18.1	Date information provided	Enter date		
8.18.2	Information provided by	Select answer from the drop-down box options which are populated from the **Trust Profile.**		
8.19	Is there evidence of a School Individual Healthcare plan (IHP)?	• No evidence • Requested but no other evidence • Possibly in place but uncertain • Documented as in place but no copy of IHP • Copy of the IHP within trust health record	If **option five** is selected, please complete 8.19.i '**Date of agreement of the IHP**'.	A written plan of care regarding health needs coordinated and held by school with input and agreement from parents and relevant healthcare professionals. All children with epilepsy should have an IHP. Children with an EHCP should also have an individual plan regarding their health (IHP) within that. *Supporting pupils at school with medical conditions*. *Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*, *December 2015.* Mandatory question
8.20	Is there evidence of an EHCP?	• No evidence • Requested but no other evidence • Possibly in place but uncertain • Documented as in place but no copy of EHCP • Copy of the EHCP within trust health record • Not applicable to this patient	If **option five** is selected, please complete 8.20.i '**Date of agreement of the EHCP**'.	EHCP (School Education **and** HealthCare Plan). Mandatory question
8.21	Add details of provision of information relating to education and school	Answer questions **8.21.1 – 8.21.4**		
8.21.1	Type of information	• Consent to share health information with school • Teacher generic epilepsy awareness • IEP (Individual Education Plan) • Exam Provision • School rescue medication plan • School rescue medication training • Other		
8.21.2	Date information provided	Enter date		
8.21.3	Information provided by	Select answer from the drop-down box options which		

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		are populated from the **Trust Profile.**		
8.21.4	Add further details	Optional free text box		
9.0	**Outcome**			
9.1	Do you know the date of the last epileptic seizure?	• Approximate date • Exact date • Not known		Mandatory question
9.i	When was the last epileptic seizure?	Date - DD/MM/YYYY		This applies to any epileptic seizure type. It may be years or days or minutes since the child and young person's last seizure. This should be updated each time child is reviewed so as to show those children with ongoing seizure freedom. Mandatory question
9.ii	Date of update	Date - DD/MM/YYYY		This date should be updated even if the date of the last seizure is unchanged. The difference between the date of last seizure and date of update documents the currently achieved seizure freedom. Mandatory question
10.	**Professionals/Services involved**			
10.1	Is there evidence the child has current or previous evidence of input from a • Consultant Paediatrician with expertise in epilepsies	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date**'**.** If **option 4** is selected, please '**Input requested date' & 'Reasons**'**.** If **option 5** is selected, please '**Input requested date'.**	Consultants with this expertise should be named within your trust and health board's profile. 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) (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'. Mandatory question
10.2	Is there evidence the child has current or previous evidence of input from • ESN	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date**'**.**	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies. Mandatory question

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
			If **option 4** is selected, please '**Input requested date' & 'Reasons**'. If **option 5** is selected, please '**Input requested date'.**	
10.3	Is there evidence the child has current or previous evidence of input from • Paediatric neurologist	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date**'. If **option 4** is selected, please '**Input requested date' & 'Reasons**'. If **option 5** is selected, please '**Input requested date'.**	Mandatory question
10.4	Is there evidence the child has current or previous evidence of input from • CESS	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date**'. If **option 4** is selected, please '**Input requested date' & 'Reasons**'. If **option 5** is selected, please '**Input requested date'.**	Children's Epilepsy Surgical Service. Mandatory question
10.5	Is there evidence the child has current or previous evidence of input from • Ketogenic dietician	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date**'. If **option 4** is selected, please '**Input requested date' & 'Reasons**'. If **option 5** is selected, please '**Input requested date'.**	
10.6	Is there evidence the child has current or previous evidence of input from	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input**	

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
	• VNS service	5. Input requested and non-attended	**requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.7	Is there evidence the child has current or previous evidence of input from • Genetic service	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.8	Is there evidence the child has current or previous evidence of input from • Clinical psychologist	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.9	Is there evidence the child has current or previous evidence of input from • Educational psychologist	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'**	
10.10	Is there evidence the child has current or previous evidence of input from • Psychiatrist	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input**	

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		5. Input requested and non-attended	**requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.11	Is there evidence the child has current or previous evidence of input from • Neuropyschologist	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.12	Is there evidence the child has current or previous evidence of input from • Counselling service	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.13	Is there evidence the child has current or previous evidence of input from • Other mental health professional	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'**	
10.14	Is there evidence the child has current or previous evidence of input from • Youth worker	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input**	

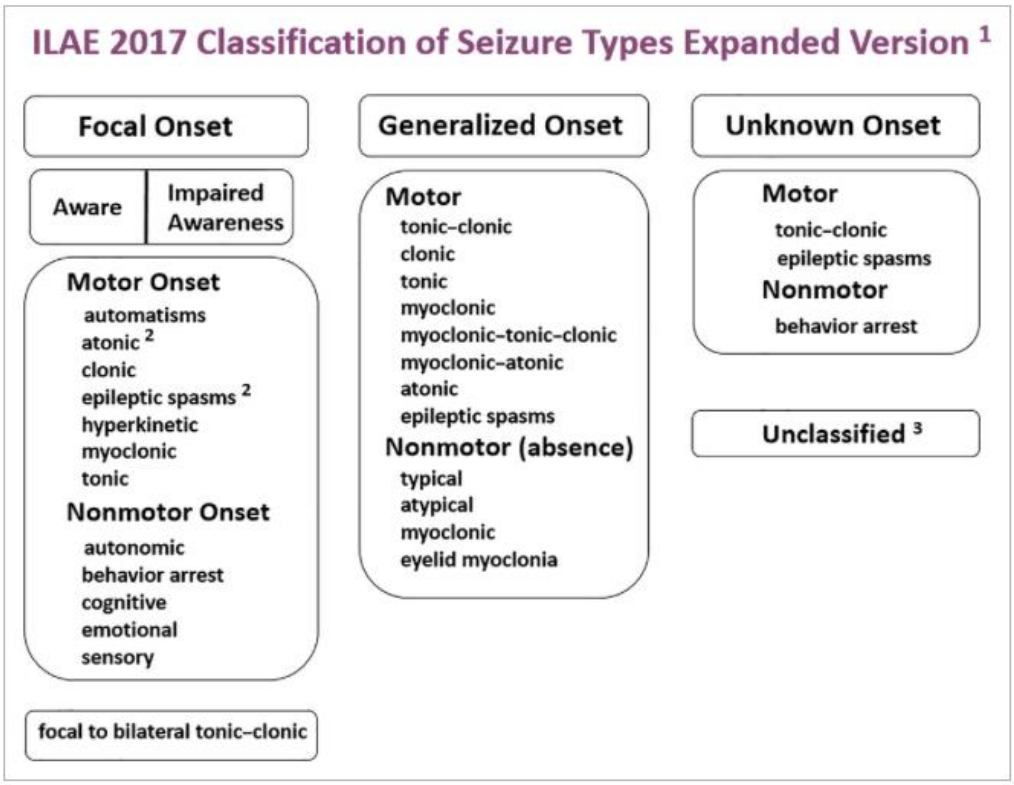
	Round 3+ Question	Answer options	Question Flow/Notes	Validation
		5. Input requested and non-attended	**requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.15	Is there evidence the child has current or previous evidence of input from • Other	1. Input not requested 2. Input requested and waiting for input 3. Input requested and input achieved 4. Input requested and rejected 5. Input requested and non-attended	If **option 2** is selected, please '**Input requested date'.** If **option 3** is selected, please '**Input requested date' & 'Input achieved date'.** If **option 4** is selected, please '**Input requested date' & 'Reasons'.** If **option 5** is selected, please '**Input requested date'.**	
10.16	At any point in time has there been a formal developmental assessment?	• Yes • No	If the answer to this question is '**Yes**', please answer questions **10.16.1** & **10.16.2**	This does not form part of any current Epilespy12 standards. Mandatory question
10.16.1	Date of formal developmental assessment	Enter date DD/MM/YYYY		Mandatory question
10.16.2	Further details	Free text box		Mandatory question
10.17	At any point in time has there been a formal cognitive assessment?	• Yes • No		This does not form part of any current Epilespy12 standards. Mandatory question
10.17.1	Date of formal cognitive assessment	Enter date DD/MM/YYYY		Mandatory question
10.17.2	Further details	Free text box		
10.18	Has there been a clinical review by a paediatrician with expertise in epilepsy or paediatric neurologist in the past 12 months?	• Yes • No		All children should have evidence of ongoing involvement of a consultant (or associate specialist) paediatrician with expertise in epilepsies. Mandatory question
10.18.1	Date of clinical review	Enter date DD/MM/YYYY		Mandatory question
10.18.2	Further details	Free text box		
10.19	Has the diagnosis of epilepsy been withdrawn because it has been subsequently deemed incorrect?	• Yes • No		If a child was given a diagnosis of epilepsy (with or without children) and it was later determined that this was an incorrect diagnosis then this should be checked. This may happen at any time after diagnosis. Epilepsy12 will use this to track ongoing

	Round 3+ Question	Answer options	Question Flow/Notes	Validation
				misdiagnosis rates. Mandatory question
10.19.1	Date diagnosis of epilepsy been withdrawn	Enter date DD/MM/YYYY		Mandatory question
10.19.2	Further details	Free text box		

Epilepsy12 audit, Round 3
Appendix of data items within clinical audit dataset tables

Seizure types tables set up within the '**Description of episodes'** follow sub-content and that aim to pick up parent terms automatically. For example for question **5.1.3.1, Epileptic Seizure type** the data entered might look like the following:

- Focal onset, clonic
- Generalised onset, tonic clonic (picked up parent term)
- Typical absence (not picked up parent term)
- Generalised onset (no motor or non-motor seizure selected)
- Unknown onset motor (picked up parent term but not Tonic clonic or epileptic spasms)
- Focal onset, impaired awareness emotional



Epilepsy electroclinical syndrome types – drop down list for questions 5.2.1.2

1.	No epilepsy syndrome stated
2.	Other – [free text]
3.	Unclassified syndrome
4.	(Benign) childhood epilepsy with centrotemporal spikes (BECTS) (benign rolandic epilepsy)
5.	Epilepsy with myoclonic astatic seizures (Doose syndrome) (Myoclonic astatic epilepsy)
6.	Panayiotopoulos syndrome (Early onset (benign) childhood occipital epilepsy)
7.	Occipital lobe epilepsy
8.	Parietal lobe epilepsy
9.	Temporal lobe epilepsy
10.	Frontal lobe epilepsy
11.	Juvenile myoclonic epilepsy (JME)

12.	Juvenile absence epilepsy (JAE)
13.	Childhood absence epilepsy (CAE)
14.	Dravet syndrome (severe myoclonic epilepsy of/in infancy or SMEI)
15.	West syndrome
16.	Defined as ‘unclassified’
17.	Benign familial neonatal seizures
18.	Idiopathic focal epilepsy of childhood
19.	Visual sensitive epilepsies
20.	Primary reading epilepsy
21.	Startle epilepsy
22.	Benign neonatal seizures Benign non-familial neonatal seizures
23.	Rasmussen’s encephalitis (chronic progressive epilepsia partialis continua) (Kozhevnikov syndrome)
24.	Gelastic seizures due to hypothalamic hamartoma
25.	Eyelid myoclonia with absences
26.	Perioral myoclonia with absences
27.	Phantom absences
28.	Childhood epilepsy with occipital paroxysms
29.	Hemiconvulsion-hemiplegia syndrome
30.	Hot water epilepsy
31.	Bathing epilepsy
32.	Classical petit mal
33.	Reflex epilepsies
34.	Familial focal epilepsy with variable foci
35.	Generalized Epilepsies with Febrile seizures plus (FS+)
36.	Early myoclonic encephalopathy
37.	Ohtahara syndrome
38.	Migrating partial (focal) seizures of infancy
39.	(Benign) Myoclonic epilepsy in infancy
40.	Benign infantile seizures
41.	Myoclonic encephalopathy in non-progressive disorders {myoclonic status in non-progressive encephalopathies}
42.	Late onset childhood occipital epilepsy (Gastaut type) (idiopathic childhood occipital epilepsy)
43.	Epilepsy with myoclonic absences
44.	Lennox-Gastaut syndrome
45.	Landau-Kleffner syndrome
46.	Epilepsy with generalized tonic-clonic seizures only (Epilepsy with generalised tonic clonic seizures on awakening)
47.	Progressive myoclonus (myoclonic) epilepsies (PME)
48.	Autosomal-dominant nocturnal frontal lobe epilepsy (ADNFLE)
49.	Familial temporal lobe epilepsies
50.	Autosomal dominant partial epilepsy with auditory features

ILAE epilepsy imitators list - drop down list for question 5.1.3, Epileptic, Non-epileptic, Uncertain

1	**Syncope And Anoxic Seizures**
a	Vasovagal syncope
b	Reflex anoxic seizures
c	Breath-holding attacks
d	Hyperventilation syncope
e	Compulsive valsalva
f	Neurological syncope
g	Imposed upper airways obstruction
h	Orthostatic intolerance
i	Long QT and cardiac syncope
j	Hyper-cyanotic spells
2	**Behavioral, Psychological And Psychiatric Disorders**
a	Daydreaming /inattention
b	Infantile gratification
c	Eidetic imagery
d	Tantrums and rage reactions
e	Out of body experiences

f	Panic attacks
g	Dissociative states
h	Non-epileptic seizures
i	Hallucinations in psychiatric disorders
j	Fabricated / factitious illness
3	**Sleep Related Conditions**
a	Sleep related rhythmic movement disorders
b	Hypnogogic jerks
c	Parasomnias
d	REM sleep disorders
e	Benign neonatal sleep myoclonus
f	Periodic leg movements
g	Narcolepsy-cataplexy
4	**Paroxysmal Movement Disorders**
a	Tics
b	Stereotypies
c	Paroxysmal kinesigenic dyskinesia
d	Paroxysmal nonkinesigenic dyskinesia
e	Paroxysmal exercise induced dyskinesia
f	Benign paroxysmal tonic upgaze
g	Episodic ataxias
h	Alternating hemiplegia
i	Hyperekplexia
j	Opsoclonus-myoclonus syndrome
5	**Migraine Associated Disorders**
a	Migraine with visual aura
b	Familial hemiplegic migraine
c	Benign paroxysmal torticollis
d	Benign paroxysmal vertigo
e	Cyclical vomiting
6	**Miscellaneous Events**
a	Benign myoclonus of infancy and shuddering attacks
b	Jitteriness
c	Sandifer syndrome
d	Non-epileptic head drops
e	Spasmus nutans
f	Raised intracranial pressure
g	Paroxysmal extreme pain disorder
h	Spinal myoclonus
7	**Other** (Free Text)

Epilepsy Aetiologies - drop down list for question 5.3.2 Cause

1.	**Structural**
	• Tuberous Sclerosis
	• Sturge Weber
	• Focal cortical dysplasia
	• Hypothalamic Hamartoma
	• Low grade tumour
	• Tumour (other)
	• Malformations of Cortical Development
	• Vascular (eg arterial ischaemic stroke, venous ischaemia, cerebral haemorrhage)
	• Traumatic brain injury
2.	**Genetic**
	• Dravet syndrome
	• Glucose Transporter Defect)
	• Angelman Syndrome
	• Rett Syndrome
	• Chromosomal abnormality
	○ Free text box

• Gene abnormality
○ UBE3A
○ GLUT1
○ SLC2A1
○ MECP2
○ SCN1A
○ STXBP1
○ CDKL5
○ KCNQ2
○ SCN2A
○ KCNT1
○ ARX
○ FOXG1
○ PCDH19
○ GRIN2A
○ Other (free text)
3. Infectious
• Open free text
4. Metabolic
• Mitochondrial disorder
• Neuronal Ceroid Lipofuscinosis (Batten Disease)
• Disorder of pyridoxine/pyridoxal phosphate metabolism
• Disorder of biotin metabolism
• Disorder of creatine metabolism
• Disorder of amino acid
• Disorder of urea cycle
• Disorder of pyrimidine and purine
• Disorder of cholersterol
• other neurometabolic disorder [free text]
5. Immune
• Rasmussen Encephalitis
• Antibody mediated
○ VGKC
○ NMDAR
○ GAD
○ TPO
○ MOG
○ Other [free text]

Neurodisability and neurodevelopmental co-morbidities - drop down list for question 5.4.2

1	Autistic spectrum disorder
2	Cerebral palsy
3	Neurodegenerative disease or condition
4	An identified chromosomal disorder with a neurological or developmental component
5	Attention deficit hyperactivity disorder
6	Intellectual disability/global development delay/'learning disability'
7	Dyspraxia
8	Dyslexia
9	Speech disorder
10	Other learning difficulty
Severity (optional subheadings)	
• Mild	
• Moderate	
• Severe	

• Profound

Mental Health Co-morbidities - drop down list for question 5.5.2, Mental health problem(s)

1.	Mood disorder
2.	Anxiety disorder
3.	Emotional/ behavioural
	a. conduct disorder
	b. Oppositional Defiant Disorder (ODD)
4.	Self-harm
5.	Other

CESS referral criteria

i.	Children with catastrophic early onset epilepsy with evidence of lateralisation of the seizure onset
ii.	All children under 24 months old with evidence of focality of seizure onset, with or without an MRI evident lesion
iii.	Children of any age with evident focal epilepsy, or lateralised seizures associated with congenital hemiplegia, resistant to two appropriate anti-epileptic drugs (AEDs)
iv.	Children who have epilepsy associated with a lateralised abnormality seen on a brain scan
v.	Children with epilepsy associated with Sturge Weber syndrome, benign tumours with developmental issues and/or ongoing seizures, or Rasmussen's syndrome
vi.	Children of any age with epilepsy associated with tuberous sclerosis resistant to two AEDs where seizures may arise from a single focus (probably from a single tuber)
vii.	Children who have 'drop attacks' as part of a more complex epilepsy
viii.	Children with epilepsy associated with hypothalamic hamartoma]

AEDS - drop down list for question 7.1.1, Name of drug

1.	Acetazolamide
2.	ACTH
3.	Carbamazepine
4.	Clobazam
5.	Clonazepam
6.	Eslicarbazepine acetate
7.	Ethosuximide
8.	Gabapentin
9.	Lacosamide
10.	Lamotrigine
11.	Levetiracetam
12.	Methylprednisolone
13.	Nitrazepam
14.	Oxcarbazepine
15.	Perampanel
16.	Piracetam
17.	Phenobarbital
18.	Phenytoin
19.	Pregabalin
20.	Prednisolone
21.	Primidone
22.	Rufinamide
23.	Sodium valproate
24.	Stiripentol
25.	Sulthiame
26.	Tiagabine
27.	Topiramate

28. Vigabatrin
29. Zonisamide
30. Other

Glossary & Definitions of clinical audit dataset

Acute	Inpatient review, or paediatric review in emergency department, or other clinical assessment in an acute paediatric setting
Acute symptomatic seizures	Seizures occurring at the time of a diagnosis of an acute disorder e.g. Meningitis, encephalitis, electrolyte disturbance, head injury, hypoxic ischemic injury etc)
AED (anti-epileptic drug)	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)
Trust/health board	For children where there is paediatric neurology involvement this will be considered as in addition to secondary care involvement. For some situations this will be a different trust/health board for some the same trust/health board.
Cardiovascular examination	Examination of the cardiovascular system to at least include cardiac auscultation
Children's epilepsy specialist nurse	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies
Consultant general paediatrician	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.
Convulsive episode	An episode where there is symmetrical or asymmetrical limb motor involvement (tonic, clonic, tonic-clonic). Myoclonic seizures excluded.
Date of first paediatric assessment	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
Epilepsy	ILAE 2014 definition Epilepsy is a disease of the brain defined by any of the following conditions 1. At least two unprovoked (or reflex) seizures occurring >24 h apart 2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two diagnosis of an epilepsy syndrome Operationally for epilepsy12, epilepsy will be considered for 2 or more epileptic episodes' or 'considered as having epilepsy for other reason' including: • Single epileptic seizure and significant risk of further

	epileptic seizure • Single epileptic seizure and epilepsy syndrome diagnosis
EHCP	School Education and Healthcare pPan.
Epilepsy clinic	An 'epilepsy clinic' is defined as a paediatric clinic where all the children and young people attending have epilepsy or possible epileptic seizures.
Epilepsy (electroclinical) syndrome	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
Epileptic seizure	Clinical manifestation(s) of epileptic (excessive and/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)
Febrile seizure	**Simple febrile seizure** A short generalized seizure, of a duration of <15 min, not recurring within 24 h, occurring during a febrile episode1 not caused by an acute disease of the nervous system, in a child aged 6 months to 5 years, with no neurologic deficits (i.e., with no pre-, peri-, or postnatal brain damage, with normal psychomotor development, and with no previous afebrile seizures) fever may not be detected before the seizure, but it must be present at least in the immediate post-acute period and be the symptom of a paediatric disease. **Complex febrile seizure** A focal, or generalized and prolonged seizure, of a duration of greater than 15 min, recurring more than once in 24 h, and/or associated with postictal neurologic abnormalities, more frequently a postictal palsy (todd's palsy), or with previous neurologic deficits Capovilla, g., mastrangelo, m., romeo, a. And vigevano, f. (2009), recommendations for the management of "febrile seizures" ad hoc task force of NICE guidelines commission. Epilepsia, 50: 2–6.
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. From round 3 this might also include neonatal settings. Assessment within emergency department counts if performed by paediatric team rather than an emergency department team. Some paediatric neurologists see referrals direct from the GP or ED and these would count as both a first paediatric assessment and tertiary input
First year	Time period from 'date of first paediatric assessment' to 12 months following that date
General examination	Any evidence of a multisystem examination of the child other than neurological examination
Handover clinic	A clinic consultation where a young people 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals
Input	Any form of documented clinical contact including face to face clinical, written, electronic or telephone contact

Secondary level clinic	A secondary level clinic is a clinic that takes referrals direct from GPs or emergency department. In most situations this will be led by a general or community paediatrician. Some paediatric neurology services fulfil secondary level functions in addition to tertiary functions
School individual healthcare plan (IHCP)	A written plan of care regarding health needs coordinated and held by school with input and agreement from parents and relevant healthcare professionals. *Supporting pupils at school with medical conditions* *Statutory guidance for governing bodies of maintained schools and proprietors of academies in England* *December 2015*
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 e.g. (dyslexia, dyscalculia)
Neurological examination	Any evidence of a neurological examination of the child
Non-acute	Paediatric outpatients or clinic
Paediatrician with expertise	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) (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'.
Paroxysmal episodes	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.
Prolonged convulsive seizures	A convulsive epileptic seizure with duration of 5 minutes or above. One seizure continuing into another counts as an ongoing seizure.
Parental prolonged seizures care plan	A written plan of care held by the parent's that describes and individualised emergency plan including rescue medication
'school age'	Child 5 years and older (past their 5th birthday)
Seizure	Paroxysmal disturbance of brain function that may be epileptic,

	syncopal (anoxic) or due to other mechanisms (sign 2004)
Single cluster	A number of ‘paroxysmal episodes’ confined to a single 24 hour period (sign 2004)
Syncope	Synonymous with ‘faints’ or ‘vasovagal episodes’