

As at

EPILEPSY12

February 2026

Round 4 Clinical Audit Data Entry Forms

Introduction

This document contains details of the Epilepsy12 round 4 registration forms and the core clinical audit dataset, effective from December 2023. For more information on the Epilepsy12 round 4 clinical audit methodology please download the full document from our website.

Adding Patients to the Audit

Patients can be registered to the audit by staff at the treating Trust/Health Board. This may include staff within paediatric epilepsy services and/or EEG services.

The Clinical dataset is split into 7 sections:

1. Verification and Registration
2. First paediatric assessment
3. Epilepsy Context
4. Multiaxial Diagnosis
5. Milestones
6. Tests
7. Treatment and Care Planning

Patient Cohorts

Clinical audit data entry is prospective, with eligible patients grouped into the following cohorts in round 4:

- Cohort 4 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2020 to 30 November 2021
- Cohort 5 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2021 to 30 November 2022
- Cohort 6 – Patients with a first paediatric assessment for a paroxysmal episode (or episodes) between 1 December 2022 to 30 November 2023

Following a patient being registered and verified by health boards/trusts, the First Year of Care form can be completed throughout the first 12 months of care after the first paediatric assessment. 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, and these must be locked and submitted before the data submission deadline for the cohort.

Add a new child/young person

(All fields are mandatory)

	Label	Question	Answer options	Question Flow/Notes	Help Notes
	first_name	First Name	Free text field		
	surname	Surname	Free text field		
	date_of_birth	Date of Birth	<ul style="list-style-type: none"> • DD/MM/YYYY 	Patients should not be 25 years or over.	Informs performance indicators 3a, 5, 6, 8, and 10
	sex	Sex	<ul style="list-style-type: none"> • Not Known • Male • Female • Not Specified 	'Not known' means that the gender cannot be found on the patient's record.	Informs performance indicator 8
	postcode	Postcode	Free text field	<p>Postcode is validated against https://findthatpostcode.uk/</p> <p>If 'No postcode' selected, choose one of the following options</p> <ul style="list-style-type: none"> • Address unknown • Address unspecified – England <p>No fixed abode</p>	
	nhs_number	NHS Number	10 numeric characters.	NHS number is validated against the NHS number checksum.	
	ethnicity	Ethnicity	<ul style="list-style-type: none"> • African • Any other Asian background • Any other Black background • Any other ethnic group • Any other mixed background 		

			<ul style="list-style-type: none">• Any other White background• Bangladeshi or British Bangladeshi• British, Mixed British• Caribbean• Chinese• Indian or British Indian• Irish• Not Stated• Pakistani or British Pakistani• White and Asian• White and Black African• White and Black Caribbean		
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First Year of Care form

	Label	Question	Answer options	Question Flow/Notes	Help Notes
1. Verification and registration					
1.1		Eligibility criteria	<ul style="list-style-type: none"> I confirm all criteria are present 	If the answer not selected, then it will not be possible to enter any further data into the clinical audit forms for the patient.	
1.2		Primary Centre for Epilepsy12	<p>Automatically populated by the system.</p> <p>If the 'Edit' or 'Transfer' button is pressed, then the user can select from a dropdown list of secondary care NHS trust centres.</p>		
1.3	first_paediatric_assessment_date	First paediatric assessment date	Enter date		<p>Setting the date is an irreversible step. Confirmation will be requested to complete the step.</p> <p>Informs performance indicators 2, 3a, 5, 6, 8, and 10</p>
1.4		Cohort	Automatically populated by the system.		
1.5		Completed First Year	Automatically populated by the system.		
1.6	audit_submission_date	Submission Deadline	Automatically populated by the system.		

	Label	Question	Answer options	Question Flow/Notes	Help Notes
2. First paediatric assessment					
2.1	first_paediatric_assessment_in_acute_or_nonacute_setting	Is the first paediatric assessment in an acute or nonacute setting?	<ul style="list-style-type: none"> • Acute • Non-acute • Don't know 		
2.2	general_examination_performed	General examination	<ul style="list-style-type: none"> • Yes • No 		
2.3	neurological_examination_performed	Neurological examination	<ul style="list-style-type: none"> • Yes • No 		
2.4	developmental_learning_or_schooling_problems	Presence or absence of developmental or educational difficulties	<ul style="list-style-type: none"> • Yes • No 		
2.5	behavioural_or_emotional_problems	Presence or absence of emotional or behavioural problems	<ul style="list-style-type: none"> • Yes • No 		
2.6	has_number_of_episodes_since_first_been_documented	The approximate frequency or number of episodes since the first episode	<ul style="list-style-type: none"> • Yes • No 		Has the approximate frequency or number of episodes since the first recorded episode been documented?
3. Epilepsy Context					
3.1	previous_febrile_seizure	At any point in time has the child had febrile seizure(s)?	<ul style="list-style-type: none"> • Yes • No • Uncertain 		
3.2	previous_acute_symptomatic_seizure	At any point in time has the child had acute symptomatic seizure(s)?	<ul style="list-style-type: none"> • Yes • No • Uncertain 		
3.3	is_there_a_family_history_of_epilepsy	Is there a family history of epilepsy?	<ul style="list-style-type: none"> • Yes • No • Uncertain 		
3.4	previous_neonatal_seizures	Were there seizures in the neonatal period?	<ul style="list-style-type: none"> • Yes • No • Uncertain 		
3.5	were_any_of_the_epileptic_seizures_convulsive	Were any of the epileptic seizures convulsive?	<ul style="list-style-type: none"> • Yes • No 		Informs performance indicator 4.

	Label	Question	Answer options	Question Flow/Notes	Help Notes
3.6	experienced_prolonged_generalised_convulsive_seizures	Has the child at any point in time experienced prolonged generalised seizures?	<ul style="list-style-type: none"> • Yes • No • Uncertain 		Has the child at any point in time experienced prolonged generalized convulsive seizures >5 min duration (or successive continuing >5 min)?
3.7	experienced_prolonged_focal_seizures	Has the child at any point in time experienced prolonged focal seizures?	<ul style="list-style-type: none"> • Yes • No • Uncertain 		Has the child at any point in time experienced prolonged focal seizures >5 min duration (or successive continuing >5 min)?
3.8	diagnosis_of_epilepsy_withdrawn	Has the diagnosis of epilepsy been withdrawn?	<ul style="list-style-type: none"> • Yes • No 		In the first year after first assessment, has a diagnosis of epilepsy been withdrawn because it has been subsequently deemed incorrect?
4. Multiaxial diagnosis					
4.1		Add a new episode		Answer questions 4.1.1 – 4.1.5.3.6 for each episode type.	
4.1.1	seizure_onset_date	When did the first episode of this type happen?	Enter date		Date the first episode of this type occurred or was witnessed?
4.1.2	seizure_onset_date_confidence	Confidence in reported date of episode	<ul style="list-style-type: none"> • Approximate date • Exact date 		How accurate is the date of episode?
4.1.3	episode_definition	Episode definition	<ul style="list-style-type: none"> • This was a single episode • This was a cluster within 24 hours • These were 2 or more episodes 		

	Label	Question	Answer options	Question Flow/Notes	Help Notes
			more than 24 hours apart		
4.1.4	has_description_of_the_episode_or_episodes_been_gathered	Has a description of the episode or episodes been gathered?	<ul style="list-style-type: none"> • Yes • No 	If yes, write a freehand description of each episode as recorded in the clinical records, using as much detail as you can, to a maximum of 5000 characters. Any key words that have an agreed meaning will automatically be labelled.	
4.1.5	epilepsy_or_nonepilepsy_status	Is a diagnosis of epilepsy definite, or uncertain.	<ul style="list-style-type: none"> • Epileptic • Non-epileptic • Uncertain 	If epileptic, answer 4.1.5.1 If non-epileptic, answer 4.1.5.2 - 4.1.5.3	
4.1.5.1	epileptic_seizure_onset_type	How best would describe the onset of the epileptic episode?	<ul style="list-style-type: none"> • Focal onset • Generalised onset • Unclassified • Unknown onset 	If focal onset, answer 4.1.5.1.1 If generalised onset, answer 4.1.5.1.2	
4.1.5.1.1	laterality, focal_epilepsy_motor_manifestations, focal_epilepsy_nonmotor_manifestations, focal_epilepsy_eeg_manifestations	Focal Onset Epilepsy	Laterality <ul style="list-style-type: none"> • Left • Right Motor manifestations <ul style="list-style-type: none"> • Atonic • Clonic • Spasms • Hyperkinetic 	Drawn from ILAE 2017 Classification of Seizure Types Expanded Version	

	Label	Question	Answer options	Question Flow/Notes	Help Notes
			<ul style="list-style-type: none"> • Myoclonic • Tonic • Tonic-Clonic Non-motor manifestations <ul style="list-style-type: none"> • Automatisms • Impaired Awareness • Gelastic • Autonomic • Behavioural Arrest • Cognitive • Emotional • Sensory EEG Findings <ul style="list-style-type: none"> • Centrotemporal • Temporal • Frontal • Parietal • Occipital 		
4.1.5.1.2	epileptic_generalised_onset	How best describes the generalised nature of the epileptic episode(s)?	<ul style="list-style-type: none"> • Absence with eyelid myoclonia • Atypical absence • Atonic • Clonic • Epileptic spasms • Myoclonic absence • Myoclonic-atonic • Myoclonic-tonic-clonic 	Drawn from ILAE 2017 Classification of Seizure Types Expanded Version	Informs performance indicator 3a.

	Label	Question	Answer options	Question Flow/Notes	Help Notes
			<ul style="list-style-type: none"> • Myoclonic • Other • Typical absence • Tonic-clonic • Tonic 		
4.1.5.2	epileptic_seizure_onset_type	How best would describe the onset of the epileptic episode?	<ul style="list-style-type: none"> • Behaviour arrest • Epileptic spasms • Tonic-clonic • Other 		
4.1.5.3	nonepileptic_seizure_type	How best describes the generalised nature of the nonepileptic episode(s)?	<ul style="list-style-type: none"> • Behavioural Psychological and Psychiatric Disorders • Migraine Associated Disorders • Miscellaneous Events • Other • Paroxysmal Movement Disorders • Sleep Related Conditions • Syncope and Anoxic Seizures 	<p>If behavioural psychological and psychiatric disorders, answer 4.1.5.3.1</p> <p>If migraine associated disorders, answer 4.1.5.3.2</p> <p>If miscellaneous events, answer 4.1.5.3.3</p> <p>If paroxysmal movement disorders, answer 4.1.5.3.4</p> <p>If sleep related conditions, answer 4.1.5.3.5</p> <p>If syncope and anoxic seizures, answer 4.1.5.3.6</p>	

	Label	Question	Answer options	Question Flow/Notes	Help Notes
4.1.5.3 .1	nonepileptic_seizure_behavioural	How best describes the <i>type</i> of behavioural episode?	<ul style="list-style-type: none"> • Daydreaming/Inattention • Dissociative states • Eidetic imagery • Fabricated/factitious illness • Hallucinations in psychiatric disorders • Infantile gratification • Non-epileptic seizures • Out of body experiences • Panic attacks • Tantrums and rage reactions 	Taken from ILAE Epilepsy Imitators List	
4.1.5.3 .2	nonepileptic_seizure_migraine	How best describes the <i>type</i> of migraine?	<ul style="list-style-type: none"> • Benign paroxysmal torticollis • Benign paroxysmal vertigo • Cyclical vomiting • Familial hemiplegic migraine • Migraine with visual aura 	Taken from ILAE Epilepsy Imitators List	

	Label	Question	Answer options	Question Flow/Notes	Help Notes
4.1.5.3.3	nonepileptic_seizure_miscellaneous	How best describes the <i>subtype</i> ?	<ul style="list-style-type: none"> • Benign myoclonus of infancy and shuddering attacks • Jitteriness • Non-epileptic head drops • Paroxysmal extreme pain disorder • Raised intracranial pressure • Sandifer syndrome • Spasmus nutans • Spinal myoclonus 	Taken from ILAE Epilepsy Imitators List	
4.1.5.3.4	nonepileptic_seizure_paroxyssmal	How best describes the <i>type</i> of paroxysmal event?	<ul style="list-style-type: none"> • Alternating hemiplegia • Benign paroxysmal tonic upgaze • Episodic ataxias • Hyperekplexia • Opsoclonus-myoclonus syndrome • Paroxysmal exercise induced dyskinesia 	Taken from ILAE Epilepsy Imitators List	

	Label	Question	Answer options	Question Flow/Notes	Help Notes
			<ul style="list-style-type: none"> • Paroxysmal kinesigenic dyskinesia • Paroxysmal nonkinesigenic dyskinesia • Stereotypies • Tics 		
4.1.5.3 .5	nonepileptic_seizure_sleep	How best describes the <i>type</i> of sleep event?	<ul style="list-style-type: none"> • Benign neonatal sleep myoclonus • Hypnagogic jerks • Narcolepsy-cataplexy • Parasomnias • Periodic leg movements • REM sleep disorders • Sleep related rhythmic movement disorders 	Taken from ILAE Epilepsy Imitators List	
4.1.5.3 .6	nonepileptic_seizure_sync ope	How best describes the <i>type</i> of syncope?	<ul style="list-style-type: none"> • Breath-holding attacks • Compulsive Valsalva • Hyper-cyanotic spells • Hyperventilation syncope 	Taken from ILAE Epilepsy Imitators List	

	Label	Question	Answer options	Question Flow/Notes	Help Notes
			<ul style="list-style-type: none"> Imposed upper airways obstruction Long QT and cardiac syncope Neurological syncope Orthostatic intolerance Reflex anoxic seizures Vasovagal syncope 		
4.2	syndrome_present	Is there an identifiable epilepsy syndrome?	<ul style="list-style-type: none"> Yes No 	If yes, answer question 4.2.1 – 4.2.2	
4.2.1	syndrome_diagnosis_date	The date the syndrome diagnosis was made.	Enter date		
4.2.2	syndrome	Select an identifiable epilepsy syndrome	See Appendix B	List of epilepsy syndromes drawn from SNOMED	Informs performance indicator 5.
4.3	epilepsy_cause_known	Has a cause for the epilepsy been identified?	<ul style="list-style-type: none"> Yes No 	If yes, answer questions 4.3.1-4.3.2	
4.3.1	epilepsy_cause_categories	Which category/categories best apply to this epilepsy?	<input type="checkbox"/> Genetic <input type="checkbox"/> Immune <input type="checkbox"/> Infectious <input type="checkbox"/> Metabolic <input type="checkbox"/> Structural <input type="checkbox"/> Other		
4.3.2	epilepsy_cause	What is the main identified cause of the epilepsy?	See Appendix C	List of epilepsy causes drawn from SNOMED	

	Label	Question	Answer options	Question Flow/Notes	Help Notes
4.4	relevant_impairments_behavioural_educational	Are there any relevant impairment, behavioural, educational or emotional problems?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer questions 4.4.1-4.4.2 for each comorbidity	
4.4.1	comorbidity_diagnosis_date	What is the date of diagnosis?	Enter date		
4.4.2	comorbidityentity	What is the comorbidity?	See Appendix D	List of epilepsy comorbidities drawn from SNOMED	
4.5	autistic_spectrum_disorder	Has there been a diagnosis of autistic spectrum disorder?	<ul style="list-style-type: none"> • Yes • No 		
4.6	global_developmental_delay_or_learning_difficulties	Has global developmental delay (under 5 years) or learning disability/intellectual disability (over 5 years) been identified?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer 4.6.1	
4.6.1	global_developmental_delay_or_learning_difficulties_severity	Add details on the severity of the neurodevelopmental condition.	<ul style="list-style-type: none"> • Mild • Moderate • Severe • Profound • Uncertain 		
4.7	mental_health_screen	Has a mental health concern been sought?	<ul style="list-style-type: none"> • Yes • No 		Informs performance indicator 6.
4.8	mental_health_issue_identified	Has a mental health issue been identified?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer 4.8.1	Informs performance indicator 7.
4.8.1	mental_health_issues	Add details of any known mental health problem(s)	<input type="checkbox"/> Anxiety disorder <input type="checkbox"/> Emotional/behavioural <input type="checkbox"/> Mood disorder <input type="checkbox"/> Self harm <input type="checkbox"/> Other		

	Label	Question	Answer options	Question Flow/Notes	Help Notes
5. Milestones					
5.1	consultant_paediatrician_referral_made	Has a referral been made to a consultant paediatrician with expertise in epilepsies?	<ul style="list-style-type: none"> Yes No 	If yes, answer 5.1.1 – 5.1.3	Informs performance indicator 1.
5.1.1	consultant_paediatrician_referral_date	Date of referral to a consultant paediatrician with expertise in epilepsies?	Date entry		Informs performance indicator 1.
5.1.2	consultant_paediatrician_input_date	Date seen by a consultant paediatrician with expertise in epilepsies?	Date entry		Informs performance indicator 1.
5.1.3	organisation	Allocate general paediatric organisation	Select from list of organisations	List drawn from NHS Digital	Informs performance indicator 1.
5.2	paediatric_neurologist_referral_made	Has a referral to a consultant paediatric neurologist been made?	<ul style="list-style-type: none"> Yes No 	If yes, answer 5.2.1- 5.2.3	Informs performance indicator 1.
5.2.1	paediatric_neurologist_referral_date	Date of referral to a consultant paediatric neurologist.	Date entry		Informs performance indicator 1.
5.2.2	paediatric_neurologist_input_date	Date seen by consultant paediatric neurologist	Date entry		Informs performance indicators 1 and 3a.
5.2.3	paediatric_neurology_centre	Allocate paediatric neurology centre	Select from list of organisations	List drawn from NHS Digital	
5.3	childrens_epilepsy_surgical_service_referral_criteria_met	Are ANY of these criteria present?	<ul style="list-style-type: none"> Yes No 	Children's Epilepsy Surgery Service referral criteria outlined in Appendix E	Informs performance indicators 3a and 3b.
5.4	childrens_epilepsy_surgical_service_referral_made	Has a referral to a children's epilepsy surgery service been made?	<ul style="list-style-type: none"> Yes No 	If yes, answer 5.4.1 – 5.4.3	Informs performance indicators 3a and 3b.
5.4.1	childrens_epilepsy_surgical_service_referral_date	Date of referral to a children's epilepsy surgery service	Date entry		Informs performance indicators 3a and 3b.
5.4.2	childrens_epilepsy_surgical_service_input_date	Date seen by children's epilepsy surgery service	Date entry		

	Label	Question	Answer options	Question Flow/Notes	Help Notes
5.4.3		Allocate Children's Surgical Centre	Select from list of organisations	List drawn from NHS Digital	
5.5	epilepsy_specialist_nurse_referral_made	Has a referral to an epilepsy nurse specialist been made?	<ul style="list-style-type: none"> Yes No 	If yes, answer 5.5.1–5.5.3	Informs performance indicator 2.
5.5.1	epilepsy_specialist_nurse_referral_date	Date of referral to an epilepsy nurse specialist	<ul style="list-style-type: none"> Date entry 		Informs performance indicator 2.
5.5.2	epilepsy_specialist_nurse_input_date	Date seen by epilepsy nurse specialist	<ul style="list-style-type: none"> Date entry 		
6. Tests					
6.1	eeg_indicated	Has a first EEG been requested?	<ul style="list-style-type: none"> Yes No 	If yes, answer 6.1.1-6.1.2	If a diagnosis of epilepsy is suspected, a routine EEG should be carried out to support the diagnosis. CYP undergoing initial investigations for epilepsy should have tests within 4 weeks of being requested.
6.1.1	eeg_request_date	Date EEG requested	Date entry		Even if the EEG was not performed, a request date is still required.
6.1.2	eeg_performed_date	Date EEG performed	Date entry Select 'EEG declined' if EEG could not be performed		
6.2	twelve_lead_ecg_status	Has a 12-Lead ECG been performed?	<ul style="list-style-type: none"> Yes No 		The Epilepsy12 standard is that all children with a convulsive episode should have a 12 lead

	Label	Question	Answer options	Question Flow/Notes	Help Notes
					ECG. Informs performance indicator 4.
6.3	ct_head_scan_status	Has a CT head been performed?	<ul style="list-style-type: none"> • Yes • No 		NICE states if MRI is contraindicated, consider a CT scan for children, young people and adults with epilepsy.
6.4	mri_indicated	Has a brain MRI been requested?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer 6.4.1-6.4.2	NICE recommends that an MRI scan should be offered to children, young people and adults diagnosed with epilepsy, unless they have idiopathic generalized epilepsy or self-limited epilepsy with centrotemporal spikes. The MRI should be carried out within 6 weeks of the MRI referral. Informs performance indicator 5.
6.4.1	mri_brain_requested_date	MRI brain requested date	Date entry		Informs performance indicator 5.
6.4.2	mri_brain_reported_date	Date MRI brain reported	Date entry Select 'MRI Brain declined' if MRI brain could not be performed		Informs performance indicator 5.

7. Treatment and care planning

	Label	Question	Answer options	Question Flow/Notes	Help Notes
7.1	has_an_aed_been_given	Has antiseizure medication been given?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer 7.1.1 – 7.1.4 for each antiseizure medication	
7.1.1	antiepilepsy_medicine_start_date	Medicine start date	Date entry	If medicine discontinued, answer 7.1.2	
7.1.2	antiepilepsy_medicine_stopped_date	Medicine discontinued date	Date entry		
7.1.3	medicine_entity	Medicine name	See Appendix F	If Sodium Valproate selected and patient is female, answer 7.1.5-7.1.6	Informs performance indicator 3a.
7.1.4	antiepilepsy_medicine_risks_discussed	Medication risks discussed?	<ul style="list-style-type: none"> • Yes • No 		Have the risks related to the anti-seizure medicine been discussed with the child/young person and their family?
7.1.5	has_a_valproate_annual_risk_acknowledgement_form_been_completed	Has a Valproate – Annual Risk Acknowledgement Form been completed?	<ul style="list-style-type: none"> • Yes • No 		<p>For girls and young women who are prescribed sodium valproate, it is recommended that an annual Valproate Annual Risk Acknowledgement form is completed.</p> <p>Informs performance indicator 8.</p>
7.1.6	is_a_pregnancy_prevention_programme_in_place	Is the Valproate Pregnancy Prevention Programme in place?	<ul style="list-style-type: none"> • Yes • No 		For girls and young women who are prescribed sodium valproate, it is

	Label	Question	Answer options	Question Flow/Notes	Help Notes
					recommended that pregnancy prevention is actively discussed and documented. Informs performance indicator 8.
7.2	has_rescue_medication_been_prescribed	Has rescue medication been prescribed?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer 7.2.1-7.2.4 for each rescue medication	Informs performance indicator 9b and 9b. i.
7.2.1	antiepilepsy_medicine_start_date	Medicine start date	Date entry	If medicine discontinued, answer 7.1.2	
7.2.2	antiepilepsy_medicine_stop_date	Medicine discontinued date	Date entry		
7.2.3	medicine_entity	Medicine name	<ul style="list-style-type: none"> • Buccal midazolam (Midazolam only product) • Lorazepam (Lorazepam only product) • Other • Rectal diazepam (Diazepam only product) 		
7.2.4	antiepilepsy_medicine_risks_discussed	Medication risks discussed?	<ul style="list-style-type: none"> • Yes • No 		Have the risks related to the anti-seizure medicine been discussed with the child/young person and their family?

	Label	Question	Answer options	Question Flow/Notes	Help Notes
7.3	individualised_care_plan_in_place	Has care planning (either an individualized epilepsy document or copy clinic letter including care planning information) commenced?	<ul style="list-style-type: none"> • Yes • No 	If yes, answer 7.3.1-7.3.10	Informs performance indicator 9a and 9a.i
7.3.1	individualised_care_plan_date	On what date was the individualized care plan put in place?	Date entry		
7.3.2	individualised_care_plan_has_parent_carer_child_agreement	Does ongoing individualised care planning include: Parent or carer and child agreement	<ul style="list-style-type: none"> • Yes • No 		<p>Has the parent or carer and child agreement to an individualised care plan been documented?</p> <p>Informs performance indicator 9a and 9a.ii.</p>
7.3.3	individualised_care_plan_include_first_aid	First aid advice	<ul style="list-style-type: none"> • Yes • No 		<p>Does the individualised care plan include first aid advice?</p> <p>Informs performance indicator 9b and 9b.iii.</p>
7.3.4	individualised_care_plan_includes_general_participation_risk	General participation and risk assessment	<ul style="list-style-type: none"> • Yes • No 		<p>Does the individualised care plan include general participation and risk assessment?</p> <p>Informs performance indicator 9b and 9b.iv.</p>
7.3.5	individualised_care_plan_addresses_sudep	Sudden unexpected death in epilepsy (SUDEP)	<ul style="list-style-type: none"> • Yes • No 		<p>Does the individualised care plan address sudden unexpected death in epilepsy?</p> <p>Informs performance indicator 9b and 9b.v.</p>
7.3.6	has_individualised_care_plan_been_updated_in_the_last_year	Being updated as necessary	<ul style="list-style-type: none"> • Yes • No 		Has the individualised care plan been updated in the last

	Label	Question	Answer options	Question Flow/Notes	Help Notes
					year? Informs performance indicator 9a and 9a.iii.
7.3.7	individualised_care_plan_includes_service_contact_details	Service contact details	<ul style="list-style-type: none"> • Yes • No 		Does the individualised care plan include service contact details? Informs performance indicator 9b and 9b.vi.
7.3.8	individualised_care_plan_parental_prolonged_seizure_care	Parental advice on managing prolonged seizures	<ul style="list-style-type: none"> • Yes • No 		Does the individualised care plan include parental advice on managing prolonged seizures? Informs performance indicator 9b and 9b.i.
7.3.9	individualised_care_plan_addresses_water_safety	Water safety	<ul style="list-style-type: none"> • Yes • No 		Does the individualised care plan address water safety? Informs performance indicator 9b and 9b.ii.
7.3.10	individualised_care_plan_includes_ehcp	An educational health care plan (EHCP)	<ul style="list-style-type: none"> • Yes • No 		Does the individualised care plan include an educational health care plan (EHCP)? Informs performance indicator 10.
7.4	has_been_referred_for_mental_health_support	Has a referral for mental health support been made?	<ul style="list-style-type: none"> • Yes • No 		Has the child been referred for support with their mental health?

	Label	Question	Answer options	Question Flow/Notes	Help Notes
7.5	has_support_for_mental_health_support	Is mental health support in place?	<ul style="list-style-type: none"> • Yes • No 		<p>Is there evidence of the child receiving support for their mental health?</p> <p>Informs performance indicator 7.</p>

Appendix A – Key Performance Indicators

No.	Brief Title	Calculation	Relevant variables
1	Paediatrician with expertise	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> who had input from a paediatrician with expertise in epilepsy OR a paediatric neurologist within 2 weeks of initial referral.</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year</p>	consultant_paediatrician_referral_made consultant_paediatrician_referral_date consultant_paediatrician_input_date paediatric_neurologist_referral_made paediatric_neurologist_referral_date paediatric_neurologist_input_date
2	Epilepsy Specialist Nurse	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> who had input from an epilepsy specialist nurse within the first year of care</p> <p>Denominator = Number of children diagnosed with epilepsy at first year</p>	childrens_epilepsy_surgical_service_referral_made childrens_epilepsy_surgical_service_input_date first_paediatric_assessment_date
3a	Tertiary input	<p>Numerator = Number of children less than 3 years old at first paediatric assessment <u>OR</u> less than 4 years old with myoclonic seizures [including both focal and generalised seizures that are solely myoclonic] <u>OR</u> who had 3 or more maintenance AEDs at first year <u>OR</u> have ongoing seizures and meet CESS criteria <u>AND</u> had evidence of involvement of a paediatric neurologist or referral to CESS within the first year of care</p> <p>Denominator = Number of children less than 3 years old at first paediatric assessment with epilepsy <u>OR</u> less than 4 years old with myoclonic seizures [including both focal and generalised seizures that are solely myoclonic] <u>OR</u> who had 3 or more maintenance AEDs at first year <u>OR</u> who have ongoing seizures and meet CESS criteria with epilepsy at first year</p>	date_of_birth first_paediatric_assessment_date epileptic_generalised_onset focal_epilepsy_motor_manifestations epileptic medicine_entity childrens_epilepsy_surgical_service_referral_criteria_met paediatric_neurologist_input_date childrens_epilepsy_surgical_service_referral_made
3b	Epilepsy surgery referral	<p>Numerator = Number of children and young people diagnosed with epilepsy <u>AND</u> meet CESS criteria <u>AND</u> have evidence of referral or involvement of Epilepsy Surgery Service</p> <p>Denominator = Number of children and young people diagnosed with epilepsy <u>AND</u> meet CESS criteria at first year</p>	childrens_epilepsy_surgical_service_referral_criteria_met childrens_epilepsy_surgical_service_referral_made

4	ECG	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year AND with convulsive episodes at first year <u>AND</u> who obtained 12 lead ECG</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with convulsive episodes at first year</p>	<p>were_any_of_the_epileptic_seizures_convulsive twelve_lead_ecg_status</p>
5	MRI	<p>Numerator= Number of children and young people diagnosed with epilepsy at first year AND who are NOT (JME OR JAE OR CAE OR Epilepsy with generalised tonic clonic seizures alone OR self-limited epilepsy with centrotemporal spikes ~(SELECT)) AND who had an MRI within 6 weeks of referral.</p> <p>Denominator= Number of children and young people diagnosed with epilepsy at first year AND who are NOT (JME OR JAE OR CAE OR Epilepsy with generalised tonic clonic seizures alone OR self-limited epilepsy with centrotemporal spikes ~(SELECT))</p>	<p>syndrome date_of_birth first_paediatric_assessment_date mri_brain_requested_date mri_brain_reported_date</p>
6	Assessment of mental health issues	<p>Numerator = Number of children and young people over 5 years diagnosed with epilepsy <u>AND</u> who had documented evidence of enquiry or screening for their mental health</p> <p>Denominator = Number of children and young people over 5 years diagnosed with epilepsy</p>	<p>date_of_birth first_paediatric_assessment_date mental_health_screen</p>
7	Mental health support	<p>Numerator = Number of children and young people diagnosed with epilepsy <u>AND</u> had a mental health issue identified <u>AND</u> had evidence of mental health support received</p> <p>Denominator = Number of children and young people diagnosed with epilepsy <u>AND</u> had a mental health issue identified</p>	<p>mental_health_issue_identified has_support_for_mental_health_support</p>
8	Sodium Valproate	<p>Numerator = All females 12 years and over with epilepsy on valproate in defined audit year <u>AND</u> evidence of Valproate annual risk acknowledgement form completed OR Pregnancy Prevention Programme in place</p>	<p>medicine_entity has_a_valproate_annual_risk_acknowledgement_form_been_completed is_a_pregnancy_prevention_programme_in_place date_of_birth first_paediatric_assessment_date</p>

		Denominator = All females 12 years and over with epilepsy on valproate at first year	sex
9a	Care planning agreement	Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> (with an individualised epilepsy document or copy clinic letter that includes care planning information) <u>AND</u> evidence of agreement <u>AND</u> care plan is up to date including elements where appropriate as below Denominator = Number of children and young people diagnosed with epilepsy at first year	individualised_care_plan_in_place individualised_care_plan_has_parent_carer_child_agreement has_individualised_care_plan_been_updated_in_the_last_year
	i. Patient held individualised epilepsy document	Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> (with individualised epilepsy document or copy clinic letter that includes care planning information) Denominator = Number of children and young people diagnosed with epilepsy at first year	individualised_care_plan_in_place
	ii. Patient/carer/parent agreement	Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with evidence of agreement Denominator = Number of children and young people diagnosed with epilepsy at first year	individualised_care_plan_has_parent_carer_child_agreement
	iii. Updated when necessary	Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with care plan which is updated where necessary Denominator = Number of children and young people diagnosed with epilepsy at first year	has_individualised_care_plan_been_updated_in_the_last_year
9b	Care planning content	Numerator= Number of children and young people diagnosed with epilepsy at first year <u>AND</u> evidence of written prolonged seizures plan if prescribed rescue medication <u>AND</u> evidence of discussion regarding water safety <u>AND</u> first aid <u>AND</u> participation and risk <u>AND</u> service contact details <u>AND</u> evidence of discussions regarding SUDEP Denominator= Number of children and young people diagnosed with epilepsy at first year	individualised_care_plan_parental_prolonged_seizure_care has_rescue_medication_been_prescribed individualised_care_plan_addresses_water_safety individualised_care_plan_include_first_aid individualised_care_plan_includes_general_participation_risk individualised_care_plan_includes_service_contact_details individualised_care_plan_addresses_sudep

i. Parental prolonged seizures care plan	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> prescribed rescue medication <u>AND</u> evidence of a written prolonged seizures plan</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> prescribed rescue medication</p>	has_rescue_medication_been_prescribed individualised_care_plan_parental_prolonged_seizure_care
ii. Water safety	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with evidence of discussion regarding water safety</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year</p>	individualised_care_plan_addresses_water_safety
iii. First aid	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with evidence of discussion regarding first aid</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year</p>	individualised_care_plan_include_first_aid
iv. General participation and risk	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with evidence of discussion regarding general participation and risk</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year</p>	individualised_care_plan_includes_general_participation_risk
v. SUDEP	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with evidence of discussions regarding SUDEP <u>AND</u> evidence of a written prolonged seizures plan</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year</p>	individualised_care_plan_addresses_sudep
vi. Service contact details	<p>Numerator = Number of children and young people diagnosed with epilepsy at first year <u>AND</u> with evidence of discussion of been given service contact details</p> <p>Denominator = Number of children and young people diagnosed with epilepsy at first year</p>	individualised_care_plan_includes_service_contact_details

10	School Individual health care plan	Numerator = Number of children and young people aged 5 years and above diagnosed with epilepsy at first year <u>AND</u> with evidence of IHP Denominator = Number of children and young people aged 5 years and above diagnosed with epilepsy at first year	has_support_for_mental_health_support date_of_birth first_paediatric_assessment_date
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Appendix B - List of Identifiable Epilepsy Syndromes (Question 4.2.2)

List drawn from SNOMED CT, as at September 2023.

CDKL5-DEE
Childhood absence epilepsy
Childhood occipital visual epilepsy
DEE or EE with spike-and-wave activation in sleep
Dravet syndrome
Early infantile DEE
Epilepsy of infancy with migrating focal seizures
Epilepsy with auditory features
Epilepsy with eyelid myoclonia
Epilepsy with generalized tonic-clonic seizures alone
Epilepsy with myoclonic absences
Epilepsy with myoclonic-atonic seizures
Epilepsy with reading-induced seizures
Etiology-specific DEEs
Familial focal epilepsy with variable foci
Familial mesial temporal lobe epilepsy
Febrile infection-related epilepsy syndrome
Gelastic seizures with HH
Genetic epilepsy with febrile seizures plus
GLUT1DS-DEE
Hemiconvulsion-hemiplegia-epilepsy
Infantile epileptic spasms syndrome
Juvenile absence epilepsy
Juvenile myoclonic epilepsy
KCNQ2-DEE
Lennox-Gastaut syndrome
Mesial temporal lobe epilepsy with hippocampal sclerosis
Myoclonic epilepsy in infancy
PCDH19 clustering epilepsy
Photosensitive occipital lobe epilepsy
Progressive myoclonus epilepsies
Pyridoxine-dependent and pyridox(am)ine 5' phosphate deficiency DEE
Rasmussen syndrome
Self-limited epilepsy with autonomic seizures
Self-limited epilepsy with centrotemporal spikes
Self-limited (familial) infantile epilepsy
Self-limited (familial) neonatal epilepsy
Self-limited familial neonatal-infantile epilepsy
Sleep-related hypermotor (hyperkinetic) epilepsy
Sturge-Weber syndrome

Appendix C - List of Epilepsy Causes (Question 4.3.2)

List drawn from SNOMED CT, as at September 2023.

17q11 deletion syndrome
2-methyl-3-hydroxybutyric aciduria
3-methylglutaconic aciduria type IV with sensorineural deafness, encephalopathy and Leigh-like syndrome
ABri amyloidosis
ADan amyloidosis
Adult neuronal ceroid lipofuscinosis
Adult-onset cervical dystonia DYT23 type
AGel amyloidosis
Agenesis of corpus callosum and abnormal genitalia syndrome
Aicardi's syndrome
Alexander's disease
Alopecia, epilepsy, intellectual disability syndrome Moynahan type
Alopecia, progressive neurological defect, endocrinopathy syndrome
Alpha-N-acetylgalactosaminidase deficiency
Amyloid polyneuropathy type I
Andermann syndrome
Arginase deficiency
Arts syndrome
Ataxia-telangiectasia syndrome
ATPase cation transporting 13A2 related juvenile neuronal ceroid lipofuscinosis
Autosomal dominant adult-onset proximal spinal muscular atrophy
Autosomal dominant optic atrophy classic form
Autosomal dominant sensory neuropathy
Autosomal dominant spastic paraplegia type 17
Autosomal dominant spastic paraplegia type 3
Autosomal recessive cerebellar ataxia, epilepsy, intellectual disability syndrome due to RUBCN deficiency
Autosomal recessive spastic paraplegia type 15
Autosomal recessive spastic paraplegia type 21
Autosomal recessive spastic paraplegia type 23
Azorean disease
Borjeson-Forssman-Lehmann syndrome
Brain calcification Rajab type
Brunner syndrome
Bulbospinal neuronopathy
CAMOS syndrome
CEDNIK syndrome
Cerebellar ataxia Cayman type
Cerebral lipidosis
Charcot-Marie-Tooth disease, type I
Cockayne syndrome
Cold-induced sweating syndrome
Combined deficiency of sialidase AND beta galactosidase
Congenital pontocerebellar hypoplasia type 1
Congenital sensory neuropathy with selective loss of small myelinated fibres
Cranio-cervical dystonia with laryngeal and upper limb involvement
Crisponi syndrome
Crome syndrome

Dandy-Walker malformation with postaxial polydactyly syndrome
Déjérine-Sottas disease
Dentatorubropallidoluysian degeneration
Diabetes mellitus AND insipidus with optic atrophy AND deafness
Dysmorphic sialidosis
Dysmorphic sialidosis with renal involvement
Dystonia 16
Dystonia 6
Early onset parkinsonism and intellectual disability syndrome
Endocrine-cerebro-osteodysplasia syndrome
Episodic ataxia
Facial onset sensory and motor neuropathy syndrome
Familial dysautonomia
Familial hemiplegic migraine
Fibrous skin tumour of tuberous sclerosis
Foveal hypoplasia, optic nerve decussation defect, anterior segment dysgenesis syndrome
FOXP1 syndrome
Fryns macrocephaly
Galactosylceramide beta-galactosidase deficiency
Galloway Mowat syndrome
Gangliosidosis
GAPD syndrome
Gemignani syndrome
Glucose transporter protein type 1 deficiency syndrome
GM1 gangliosidosis
Hereditary ataxia
Hereditary cerebral amyloid angiopathy, Icelandic type
Hereditary hyperekplexia
Hereditary insensitivity to pain with anhidrosis
Hereditary motor and sensory neuropathy
Hereditary motor and sensory neuropathy with optic atrophy
Hereditary motor and sensory neuropathy with retinitis pigmentosa
Hereditary oculoleptomeningeal amyloid angiopathy
Hereditary sensory and autonomic neuropathy
Hereditary spastic paraplegia
Huntington's chorea
Hypogonadism with anosmia
Hypomyelination, hypogonadotropic hypogonadism, hypodontia syndrome
Hypoxic ischaemic encephalopathy
Infantile neuronal ceroid lipofuscinosis
Infantile onset spinocerebellar ataxia
Intellectual disability, hypoplastic corpus callosum, preauricular tag syndrome
Isotretinoin-like syndrome
Joubert syndrome
Joubert syndrome with congenital hepatic fibrosis
Joubert syndrome with oculorenal defect
Joubert syndrome with orofaciocigital defect
Kugelberg-Welander disease
L1 syndrome
L-2(OH) glutaric aciduria
Leber plus disease
Leigh's disease
Lowe syndrome

Maroteaux-Lamy syndrome
Martsolf syndrome
MASA syndrome
Menkes kinky-hair syndrome
Moebius syndrome
Myosclerosis
Navajo neurohepatopathy
Neonatal cerebral haemorrhage
Neonatal hypoglycaemia
Neuroectodermal melanolyosomal disease
Neurofibromatosis type 1
Neurofibromatosis type 2
Neuronal ceroid lipofuscinosis 8
Non-accidental injury
NPHP3-related Meckel-like syndrome
Pachygyria, intellectual disability, epilepsy syndrome
Paroxysmal dystonic choreoathetosis with episodic ataxia and spasticity
Pelizaeus-Merzbacher disease null syndrome
Perinatal stroke
Periventricular leukomalacia
Pettigrew syndrome
Photomyoclonus, diabetes mellitus, deafness, nephropathy and cerebral dysfunction
Phytanic acid storage disease
Polyneuropathy, hearing loss, ataxia, retinitis pigmentosa, cataract syndrome
PPM-X syndrome
Progressive encephalopathy with oedema, hypersarrhythmia, and optic atrophy-like syndrome
Progressive encephalopathy with oedema, hypersarrhythmia and optic atrophy syndrome
Progressive sclerosing poliodystrophy
Proteus syndrome
Ptosis and vocal cord paralysis syndrome
RAB18 deficiency
Rapid onset dystonia parkinsonism
Retinal detachment and occipital encephalocoele
RHYNS syndrome
Rud's syndrome
Saldino-Mainzer dysplasia
Sandhoff disease
Schwartz-Jampel syndrome
Seizure, sensorineural deafness, ataxia, intellectual disability, electrolyte imbalance syndrome
Sialidosis
Sialidosis type 1
Sotos' syndrome
Spinal muscular atrophy, type II
Spinocerebellar ataxia type 36
Tay-Sachs disease
Tay-Sachs disease, variant AB
Temtamy syndrome
Tuberous sclerosis syndrome
Vici syndrome
Von Hippel-Lindau syndrome
Warburg micro syndrome
Wilson's disease
X-linked Charcot-Marie-Tooth disease type 4

X-linked dystonia parkinsonism
X-linked intellectual disability with cerebellar hypoplasia syndrome

Appendix D - List of Epilepsy Comorbidities (Question 4.4.2)

Attention deficit hyperactivity disorder (MBD - Minimal brain dysfunction)
Cerebral palsy (Cerebral palsy)
Conductive hearing loss (Conductive deafness)
DCD - developmental coordination disorder (Developmental dyspraxia)
Developmental language disorder (Developmental language disorder)
Developmental speech disorder (Developmental speech disorder, NOS)
Disorder of fluency (Disorder of fluency)
Dyscalculia (Dyscalculia)
Dysgraphia (Dysgraphia)
Dyslexia (Specific reading difficulty)
Hereditary spastic paraplegia (Strumpell disease)
Hydrocephalus (Hydrocephalus)
Migraine (Migraine)
Moderate binocular visual impairment (Moderate visual impairment, binocular)
Movement disorder (Movement disorder)
Oppositional defiant disorder (Oppositional defiant disorder)
Sensorineural hearing loss (Perceptive deafness, NOS)
Sleep disorder (Sleep disorder, NOS)
Speech and language developmental delay (Speech and language developmental delay)
Tic disorder (Habit disorder)

Appendix E – Children’s Epilepsy Surgical Service (CESS) Referral Criteria

1. Children with catastrophic early onset epilepsy with evidence of lateralisation of the seizure onset
2. All children under 24 months old with evidence of focality of seizure onset, with or without an MRI evident lesion
3. Children of any age with evident focal epilepsy, or lateralised seizures associated with congenital hemiplegia, resistant to two appropriate anti-epileptic drugs (AEDs)
4. Children who have epilepsy associated with a lateralised abnormality seen on a brain scan
5. Children with epilepsy associated with Sturge Weber syndrome, benign tumours with developmental issues and/or ongoing seizures, or Rasmussen’s syndrome
6. 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)
7. Children who have ‘drop attacks’ as part of a more complex epilepsy
8. Children with epilepsy associated with hypothalamic hamartoma

Appendix F - List of Antiseizure Medications (Question 7.1.3)

Acetazolamide (Acetazolamide only product)
ACTH (Corticotropin)
Carbamazepine (Carbamazepine only product)
Clobazam (Clobazam only product)
Clonazepam (Clonazepam only product)
Eslicarbazepine acetate (Eslicarbazepine only product)
Ethosuximide (Ethosuximide only product)
Gabapentin (Gabapentin only product)
Lacosamide (Lacosamide only product)
Lamotrigine (Lamotrigine only product)
Levetiracetam (Levetiracetam only product)
Methylprednisolone (Methylprednisolone only product)
Nitrazepam (Nitrazepam only product)
Other
Oxcarbazepine (Oxcarbazepine only product)
Perampanel (Perampanel only product)
Phenobarbital (Phenobarbital only product)
Phenytoin (Phenytoin only product)
Piracetam (Piracetam only product)
Prednisolone (Prednisolone only product)
Pregabalin (Pregabalin only product)
Primidone (Primidone only product)
Rufinamide (Rufinamide only product)
Stiripentol (Stiripentol only product)
Sulthiame (Sultiame)
Tiagabine (Tiagabine only product)
Topiramate (Topiramate only product)
Vigabatrin (Vigabatrin only product)
Zonisamide (Zonisamide only product)

Appendix G - Glossary

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	<p>ILAE 2014 definition</p> <p>Epilepsy is a disease of the brain defined by any of the following conditions</p> <ol style="list-style-type: none"> 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 diagnoses of an epilepsy syndrome <p>Operationally for epilepsy¹², epilepsy will be considered for 2 or more epileptic episodes' or 'considered as having epilepsy for other reason' including:</p> <ul style="list-style-type: none"> • Single epileptic seizure and significant risk of further epileptic seizure • Single epileptic seizure and epilepsy syndrome diagnosis
EHCP	School Education and Healthcare Plan.
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	<p>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.</p> <p>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. <i>Epilepsia</i>, 50: 2–6.</p>
First paediatric assessment	<p>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.</p> <p>Assessment within emergency department counts if performed by paediatric team rather than an emergency department team.</p> <p>Some paediatric neurologists see referrals direct from the GP or ED and these would count as both a first paediatric assessment and tertiary input</p>
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)	<p>A written plan of care regarding health needs coordinated and held by school with input and agreement from parents and relevant healthcare professionals.</p> <p><i>Supporting pupils at school with medical conditions Statutory guidance for governing bodies of maintained schools and proprietors of academies in England December 2015</i></p>

Neurodisability	<p>Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team:</p> <ul style="list-style-type: none"> • 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	<p>A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having:</p> <ul style="list-style-type: none"> • Training and continuing education in epilepsies • And peer review of practice • And regular audit of diagnosis (e.g. Participation in epilepsy12) <p>(consensus conference on better care for children and adults with epilepsy - final statement, royal college of physicians of Edinburgh, 2002)</p> <p>A paediatric neurologist is also defined as a 'paediatrician with expertise'.</p>
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 5 th 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'

Appendix H – Version history

Version	Date	Description of changes
1.0	28/11/2023	V1.0 created.
1.1	12/19/2023	Added the following options to the list of epilepsy causes in question 4.3.2 (appendix C): <ul style="list-style-type: none">• Neonaatal hypoglycaemia• Hypoxic ischaemic encephalopathy (HIE)• Perinatal stroke• Non-accidental injury• Periventricular leukomalacia• Neonatal cerebral haemorrhage