RCPCH

Royal College of
Paediatrics and Child Health

Leading the way in Children's Health

EPILEPSY12

Round 4 Organisational Audit Data Entry Forms

As of February 2025

Question	Answers	(BPC = Best Practice Tariff Criteria)	Notes
1. Workforce			
1.1 How many whole time equivalent general paediatric consultants does the Health Board/Trust employ?	• Decimal field (up to 3 decimal points)		*Includes general paediatric consultants with 'expertise in epilepsy' (community or hospital based).* *Audit Unit - The audit unit is defined by your audit unit profile. Most audit units will include one or more secondary tier paediatric services grouped together using pragmatic boundaries agreed by the paediatric audit unit lead, the project team and the tertiary link.* *WTE = whole time equivalent. E.g One full time post is 1 WTE; Someone working 3 days a week = 0.6 WTE. 2 people both working 3 days a week = 1.2 WTE*
1.2: Of these, how many have an 'expertise in epilepsy'?	• Decimal field (up to 3 decimal points)	BPC	*Answer using whole time equivalent again. Paediatric neurologists should not be included in your response.* *Paediatrician with expertise - 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).*
1.3: Does the Health Board/Trust have a defined paediatric epilepsy clinical lead?	• Yes/no	BPC	
1.3i: Enter the name of the Health Board/Trust defined paediatric epilepsy clinical lead	**Title, First Name, Surname**, with the ability to edit, delete		*If yes to Q.1.3*
1.4: How many whole time equivalent (WTE) paediatric epilepsy specialist nurses (ESNs)	• Decimal field (up to 3 decimal points)	BPC	*Paediatric ESN - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies*

are there employed within the Health Board/Trust?			
1.4i: *Which of the following Paediatric ESN functions is the epilepsy service currently able to support?*	*Check box list of the following (multiple choices allowed):* • ED visits • Home visits • School Individual Healthcare Plan (IHP) facilitation • Nurse led clinics • Nurse prescribing • Rescue medication training for parents • Rescue medication training for schools • School meetings • Ward visits • *None of the above*		*For services with at least some (i.e. greater than 0) ESN WTE indicated for Q1.4*
1.5 What are the total number of hours per week that the Health Board/Trust has specified towards local epilepsy audit and quality improvement?			*For example in nurse, doctor or allied professionals job plans. You can specify partial hours as a decimal (1.5 would be an hour and a half).*
1.6 What are the total number of hours per week for your Health Board/Trust specified towards local epilepsy service leadership?			*For example in nurse, doctor or allied professionals job plans. As above you can use decimal numbers.*
2. Epilepsy Clinic configuration			
2.1: Does the Health Board/Trust have defined epilepsy clinics seeing patients at a secondary level?	• Yes/no	BPC	*A secondary level 'epilepsy clinic' is a clinic run just for children with seizures or epilepsy that takes referrals direct from GPs or emergency department (decimal*

			answers are allowed). An 'Epilepsy Clinic' is defined as a paediatric clinic where all the children and young people attending have epilepsy or possible epileptic seizures.
2.1i: On average, how many consultant (or associate specialist) led secondary level 'epilepsy clinics' for children or young people take place within your Health Board/Trust per week?	• Decimal field	BPC	*If yes to Q.2.1 above*
2.1ii: Within the epilepsy clinics, does the clinic booking time allow at least 20 minutes of time with a consultant with expertise in epilepsy and an ESN? (This might be 20 min with the doctor and nurse at the same time or 20 mins each in succession)	• Yes/no	BPC	*If yes to Q.2.1 above*
2.2: Does the Trust currently run TFC 223 Epilepsy Best Practice Criteria (BPC) clinics? *For Trusts in England only	Choose one from: • Not applicable • Yes • No, not at all • No, in development	BPC	

3. Tertiary provision

3.1: How many whole-time equivalent (WTE) paediatric neurologists who manage children with epilepsy (acutely and/or non-acutely) are there employed within the Health Board/Trust?	• Decimal field (up to 3 decimal points)		*This should not include visiting neurologists who are primarily employed by another trust*
3.2: Does the Health Board/Trust have agreed referral pathways to tertiary paediatric neurology services?	• Yes/no	BPC	
3.3: Can paediatric neurologists receive direct referrals from general practice or	• Yes/no		

emergency services to assess children with possible epilepsy?			
3.4: Does the trust host satellite paediatric neurology clinics? (e.g. a paediatric neurologist visits a site within the trust to undertake paediatric neurology clinics)	• Yes/no		*e.g. a paediatric neurologist visits a site within the trust to undertake paediatric neurology clinics* *A satellite clinic is where a neurologist supports a clinic outside their base hospital. This might be another hospital or clinic location in their trust or another hospital or clinic location in another trust.*
3.5: Which of the following services can be obtained at a location within the Health Board/Trust? • **i:** Commence ketogenic diet • **ii:** Ongoing dietetic review of ketogenic diet • **iii:** Vagal Nerve Stimulator (VNS) Insertion • **iv:** VNS review	Choose one from the following for each question: Yes/No/Uncertain Yes/No/Uncertain Yes/No/Uncertain Yes/No/Uncertain		If the child would have to travel to a location outside the audit unit to have then service undertaken then answer 'no'
4. Investigations			
4: Which of the following investigations can be obtained at a location within the Health Board/Trust? • **i:** 12 lead ECG • **ii:** 'awake' MRI • **iii:** MRI with sedation	Choose one from the following for each question: Yes/No/Uncertain		If the child would have to travel to a location outside the audit Health Board/Trust to have then investigation undertaken then answer 'No'

• **iv:** MRI with general anaesthetic • **v:** Standard EEG • **vi:** Sleep-deprived EEG • **vii:** Melatonin induced EEG • **viii:** Sedated EEG • **ix:** 24-48h ambulatory EEG • **x:** Inpatient Video telemetry • **xi:** Outpatient Video Telemetry • **xii:** Home video telemetry • **xiii:** Portable EEG on ward area within trust • Requesting and consenting of Whole Genome Sequencing (WGS)			
5. Service Contact			
5.1: Can patients contact the Epilepsy service for specialist advice (e.g. from a paediatrician with expertise, paediatric neurologist or ESN) between scheduled reviews?	• Yes/No		
5.1.1: Is this available all weekdays? **5.1.2:** Is this available out of hours? **5.1.3:** Is this available 52 weeks per year?	Choose one from the following for each question: • Yes/no • Yes/no • Yes/no		*If yes to Q.5 above*
5.2: What would your service describe as a typical time for a parent or young person to achieve specialist advice?	Choose one from the following options: • Same working day • By next working day • Within 3-4 working days • Within a working week		*If yes to Q.5 above*
5.3: Who typically provides the initial 'specialist advice'?	Choose one from the following options: • ESN		*If yes to Q.5 above*

	• Consultant Paediatrician with expertise in epilepsy • Paediatric neurologist • Trainee paediatric neurologist • Other (please specify)		
5.4: Is there evidence of a clear point of contact within the Health Board/Trust for non-paediatric professionals seeking paediatric epilepsy support? (e.g. school, social care, CAMHS, adult services)	Yes/No		
6. Young People and Transition			
6.1: Does your Health Board/Trust have agreed referral pathways to adult services?	Yes/no	BPC	
6.2: Does your Health Board/Trust have a specific outpatient clinic for 'young people' with epilepsies that supports transition?	Yes/no	BPC	Young people typically could be teenage or secondary school age
6.2.i: From what age does this young persons clinic that supports transition typically accept young people?	Number		*If yes to Q.2 above*
6.3: Does your Health Board/Trust have an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals?	Yes/no		
6.3.i: Is this usually:	Choose one from the following options: • A single joint appointment • A series of several joint appointments • A flexible approach including mixture of joint or individual reviews • Other (please specify)		*If yes to Q.3 above*
6.3.ii: As an estimate, what percentage of young people transferred to adult services	Enter a percentage value		*If yes to Q.3 above*

are transitioned through this joint professional process?			
6.4: Which adult professionals are routinely involved in transition or transfer to adult services?	*Check box list of the following (multiple choices allowed).* • Adult ESN • Adult Learning difficulty ESN • Adult Neurologist • Youth worker • Other (please specify)		
6.5: Does your paediatric service use structured resources to support transition? (e.g. Ready Steady Go)	• Yes/No		
7. Mental health			
7.1: Does your Health Board/Trust paediatric epilepsy service routinely, formally screen for mental health disorders?	Yes/No		
7.1i: Are any particular mental health screening questionnaires used?	*Check box list of the following (multiple choices allowed):* • BDI – Beck Depression Inventory • Connor's Questionnaire • Emotional Thermometers Tool • GAD – Generalised Anxiety Disorder • GAD 2 – Generalised Anxiety Disorder 2 • GAD 7 – Generalised Anxiety Disorder GAD 7 • HADS – Hospital Anxiety and Depression Scale • MFQ – Mood and Feelings Questionnaire (Child, Parent, Adult versions)		*If yes to Q.1*

	• NDDI -E Neurological Disorders Depression Inventory for Epilepsy • PHQ – Patient Health Questionnaire, PHQ 2, PHQ 9 • SDQ (Strength and Difficulties Questionnaire) • Other (please specify)		
7.2: Does your Health Board/Trust have agreed referral pathways for children with any of the following mental health concerns?	*Check box list of the following (multiple choices allowed):* • Anxiety • • Mood Disorders • Non-epileptic attack disorders • Other (please specify)	BPC	
7.3: Does your Health Board/Trust facilitate mental health provision within epilepsy clinics?	• Yes/no	BPC	
7.3.1: Does this comprise:	*Check box list of the following (multiple choices allowed):* • Epilepsy Clinics where mental health professionals can provide direct co-located clinical care • MDT meetings where epilepsy and mental health professionals discuss individual patients • Other (please specify)	BPC	*If yes to Q.3 above*
7.3.2: Is there a current trust action plan describing steps towards co-located mental health provision within epilepsy clinics?	• Yes/No	**BPC**	*If No to Q.3 above*
7.4: Can your Health Board/Trust refer to any of the following where required, either within or outside of your trust?	*Check box list of the following (multiple choices allowed – OTHER than "Cannot achieve any of the above" which excludes other options if chosen):* • Clinical psychology assessment		

	• Educational psychology assessment • Formal developmental assessment • Neuropsychology assessment • Psychiatric assessment • Cannot achieve any of the above		
8. Neurodevelopmental support			
8.1 Does your Health Board/Trust paediatric epilepsy service routinely formally screen for neurodevelopmental conditions?	• Yes/No		
8.1: Does your Health Board/Trust have agreed referral criteria for children with any of the following neurodevelopmental conditions?	*Check box list of the following (multiple choices allowed – OTHER than "None of the above" which excludes other options if chosen):* • ADHD • ASD • Behaviour difficulties • Developmental Coordination Disorder • Intellectual disability/Global developmental delay • Learning disabilities • Other (please specify) • None of the above	BPC	
9. Care Planning			
9.1: Does the Health Board/Trust routinely undertake comprehensive care planning for children with epilepsy?	• Yes/No	BPC	
10. Patient Database/Register			
10.1: Other than Epilepsy12, does the trust maintain a database or register of children with epilepsies?	Choose one from the following options: • Yes, for all children • Yes, for some children • No		