

Epilepsy12 Round 3

2019 Organisational Audit dataset

Section/Question	Answers	(BPC = Best Practice Tariff Criteria)	Notes
1. Workforce			
1.1 How many whole time equivalent (WTE) general paediatric consultants (community or hospital based) are there employed within the Health Board/Trust ?	<ul style="list-style-type: none"> Decimal field (up to 3 decimal points) 		<i>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.</i>
1.2: Of these, how many whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy' are there employed within the Health Board/Trust ? (<i>Paediatric neurologists should not be included in your response.</i>)	<ul style="list-style-type: none"> Decimal field (up to 3 decimal points) 	BPC	<i>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).</i>
1.3: Does the Health Board/Trust have a defined paediatric epilepsy clinical lead?	<ul style="list-style-type: none"> 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		<i>If yes to Q. 1.3</i>
1.4: How many whole time equivalent (WTE) paediatric epilepsy specialist nurses (ESNs) are there employed within the Health Board/Trust?	<ul style="list-style-type: none"> Decimal field (up to 3 decimal points) 	BPC	<i>Paediatric ESN - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies</i>

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<p>1.4i: Which of the following Paediatric ESN functions is the epilepsy service currently able to support?</p>	<p><i>Check box list of the following (multiple choices allowed):</i></p> <ul style="list-style-type: none"> • ED visits • Home visits • 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 		<p><i>For services with at least some (i.e. greater than 0) ESN WTE indicated for Q1.4</i></p>
<p>2. Epilepsy Clinic configuration</p>			
<p>2.1: Does the Health Board/Trust have defined epilepsy clinics seeing patients at a secondary level?</p>	<ul style="list-style-type: none"> • Yes/no 	<p>BPC</p>	<p><i>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.</i></p>
<p>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?</p>	<ul style="list-style-type: none"> • Decimal field 	<p>BPC</p>	<p><i>If yes to Q.2.1 above</i></p>
<p>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?</p> <p>(This might be 20 min with the doctor and nurse at the same time or 20 mins each in succession)</p>	<ul style="list-style-type: none"> • Yes/no 	<p>BPC</p>	<p><i>If yes to Q.2.1 above</i></p>

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<p>2.2: Does the Trust currently run TFC 223 Epilepsy Best Practice Criteria (BPC) clinics?</p> <p>*For Trusts in England only</p>	<p>Choose one from:</p> <ul style="list-style-type: none"> • Not applicable • Yes • No, not at all • No, in development 	BPC	
3. Tertiary provision			
<p>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?</p>	<ul style="list-style-type: none"> • Decimal field (up to 3 decimal points) 		<p><i>This should not include visiting neurologists who are primarily employed by another trust</i></p>
<p>3.2: Does the Health Board/Trust have agreed referral pathways to tertiary paediatric neurology services?</p>	<ul style="list-style-type: none"> • Yes/no 	BPC	
<p>3.3: Can paediatric neurologists receive direct referrals from general practice or emergency services to assess children with possible epilepsy?</p>	<ul style="list-style-type: none"> • Yes/no 		
<p>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)</p>	<ul style="list-style-type: none"> • Yes/no 		<p><i>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.</i></p>
<p>3.5: Which of the following services can be obtained at a location within the Health Board/Trust?</p> <ul style="list-style-type: none"> • i: Commence ketogenic diet • ii: Ongoing dietetic review of ketogenic diet • iii: Vagal Nerve Stimulator (VNS) Insertion • iv: VNS review 	<p>Choose one from the following for each question:</p> <p>Yes/No/Uncertain</p> <p>Yes/No/Uncertain</p> <p>Yes/No/Uncertain</p> <p>Yes/No/Uncertain</p>		<p>If the child would have to travel to a location outside the audit unit to have then service undertaken then answer 'no'</p>

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4. Investigations			
<p>4: Which of the following investigations can be obtained at a location within the Health Board/Trust?</p> <ul style="list-style-type: none"> • i: 12 lead ECG • ii: 'awake' MRI • iii: MRI with sedation • 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 	<p>Choose one from the following for each question:</p> <p>Yes/No/Uncertain</p>		<p>If the child would have to travel to a location outside the audit Health Board/Trust to have then investigation undertaken then answer 'No'</p>
5. Service Contact			
<p>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?</p>	<ul style="list-style-type: none"> • Yes/No 		
<p>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?</p>	<p>Choose one from the following for each question:</p> <ul style="list-style-type: none"> • Yes/no • Yes/no • Yes/no 		<p><i>If yes to Q.5 above</i></p>
<p>5.2: What would your service describe as a typical time for a parent or young person to achieve specialist advice?</p>	<p>Choose one from the following options:</p> <ul style="list-style-type: none"> • Same working day • By next working day • Within 3-4 working days • Within a working week 		<p><i>If yes to Q.5 above</i></p>

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<p>5.3: Who typically provides the initial 'specialist advice'?</p>	<p>Choose one from the following options:</p> <ul style="list-style-type: none"> • ESN • Consultant Paediatrician with expertise in epilepsy • Paediatric neurologist • Trainee paediatric neurologist • Other (please specify) 		<p><i>If yes to Q.5 above</i></p>
<p>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)</p>	<p>Yes/No</p>		
<p>6. Young People and Transition</p>			
<p>6.1: Does your Health Board/Trust have agreed referral pathways to adult services?</p>	<p>Yes/no</p>	<p>BPC</p>	
<p>6.2: Does your Health Board/Trust have a specific outpatient clinic specifically for 'young people' with epilepsies?</p>	<p>Yes/no</p>	<p>BPC</p>	<p>Young people typically could be teenage or secondary school age</p>
<p>6.2.i: From what age does this young people's clinic typically accept young people?</p>	<p>Number</p>		<p><i>If yes to Q.2 above</i></p>
<p>6.3: Does your Health Board/Trust have an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals?</p>	<p>Yes/no</p>		
<p>6.3.i: Is this usually:</p>	<p>Choose one from the following options:</p> <ul style="list-style-type: none"> • A single joint appointment • A series of several joint appointments • A flexible approach including mixture of joint or individual reviews • Other (please specify) 		<p><i>If yes to Q.3 above</i></p>

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<p>6.3.ii: As an estimate, what percentage of young people transferred to adult services are transitioned through this joint professional process?</p>	<p>Enter a percentage value</p>		<p><i>If yes to Q.3 above</i></p>
<p>6.4: Which adult professionals are routinely involved in transition or transfer to adult services?</p>	<p><i>Check box list of the following (multiple choices allowed).</i></p> <ul style="list-style-type: none"> • Adult ESN • Adult Learning difficulty ESN • Adult Neurologist • Youth worker • Other (please specify) 		
<p>6.5: Does your paediatric service use structured resources to support transition? (e.g. Ready Steady Go)</p>	<ul style="list-style-type: none"> • Yes/No 		
<p>7. Mental health</p>			
<p>7.1: Does your Health Board/Trust paediatric epilepsy service routinely, formally screen for any of the listed diagnoses related to epilepsy?</p>	<p><i>Check box list of the following (multiple choices allowed):</i></p> <ul style="list-style-type: none"> • ADHD • ASD • Mental health disorders • None of the above 		
<p>7.1i: Are any particular mental health screening questionnaires used?</p>	<p><i>Check box list of the following (multiple choices allowed):</i></p> <ul style="list-style-type: none"> • 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 		<p><i>If yes to Q. 1</i></p>

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	<ul style="list-style-type: none"> • MFQ – Mood and Feelings Questionnaire (Child, Parent, Adult versions) • 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?	<p><i>Check box list of the following (multiple choices allowed):</i></p> <ul style="list-style-type: none"> • Anxiety • Depression • Mood Disorders • Non-epileptic attack disorders • Other (please specify) 	BPC	
7.3: Does your Health Board/Trust facilitate mental health provision within epilepsy clinics?	<ul style="list-style-type: none"> • Yes/no 	BPC	
7.3.1: Does this comprise:	<p><i>Check box list of the following (multiple choices allowed):</i></p> <ul style="list-style-type: none"> • 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	<i>If yes to Q.3 above</i>
7.3.2: Is there a current trust action plan describing steps towards co-located mental health provision within epilepsy clinics?	<ul style="list-style-type: none"> • Yes/No 	BPC	<i>If No to Q.3 above</i>

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<p>7.4: Can your Health Board/Trust refer to any of the following where required, either within or outside of your trust?</p>	<p><i>Check box list of the following (multiple choices allowed – OTHER than “Cannot achieve any of the above” which excludes other options if chosen):</i></p> <ul style="list-style-type: none"> • Clinical psychology assessment • Educational psychology assessment • Formal developmental assessment • Neuropsychology assessment • Psychiatric assessment • Cannot achieve any of the above 		
8. Neurodevelopmental support			
<p>8.1: Does your Health Board/Trust have agreed referral criteria for children with any of the following neurodevelopmental problems?</p>	<p><i>Check box list of the following (multiple choices allowed – OTHER than “None of the above” which excludes other options if chosen):</i></p> <ul style="list-style-type: none"> • ADHD • ASD • Behaviour difficulties • Developmental Coordination Disorder • Intellectual disability • Other (please specify) • None of the above 	BPC	
9. Care Planning			
<p>9.1: Does the Health Board/Trust routinely undertake comprehensive care planning for children with epilepsy?</p>	<ul style="list-style-type: none"> • Yes/No 	BPC	
10. Patient Database/Register			
<p>10.1: Other than Epilepsy12, does the trust maintain a database or register of children with epilepsies?</p>	<p>Choose one from the following options:</p> <ul style="list-style-type: none"> • Yes, for all children • Yes, for some children • No 		