

Dataset 2 - Service Description Questionnaire for Secondary Services

Online web form completed via web tool by registered audit unit link person after census day. All questions must be answered.

- I understand that in answering these questions I am referring to all paediatric services contained within 'audit unit' as defined within the 'audit unit' profile.
- I understand that I am referring to services as they were on 'census day'.

<p>1. How many whole time equivalent (WTE) general paediatric consultants (community or hospital based) are there employed within the 'audit unit'?</p>	<ul style="list-style-type: none"> • Decimal field 	<p><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></p>
<p>2. How many whole time equivalent (WTE) general paediatric consultants with 'expertise in epilepsy' are there employed within the 'audit unit'?</p>	<ul style="list-style-type: none"> • Decimal field 	<p><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). Paediatric neurologists should not be included in your response.</i></p>
<p>3. What are the names of the consultant paediatricians defined by the audit unit as having 'expertise in epilepsy'?</p>	<ul style="list-style-type: none"> • Free text 	<p><i>This field is referred to in the clinical dataset when the user is asked whether evidence of input from a 'paediatrician with expertise'</i></p> <p><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). Paediatric neurologists should not be included in your response.</i></p>
<p>4. How many whole time equivalent (WTE) epilepsy specialist nurses (ESNs) are there employed within the 'audit unit'?</p>	<ul style="list-style-type: none"> • Decimal field 	<p><i>ESN - A children's nurse with a defined role and specific qualification and/or training in children's epilepsies</i></p>

<p>5. On average, how many consultant (or associate specialist) led secondary level 'epilepsy clinics' for children or young people take place within your audit unit per week?</p>	<ul style="list-style-type: none"> • Decimal field 	<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>6. Do any of the paediatric services within the 'audit unit' maintain a database or register of children with epilepsies?</p>	<ul style="list-style-type: none"> • Yes for all children • Yes for some children • No 	
<p>7. Which of the following investigations can be obtained at a location within the 'audit unit'?</p> <ul style="list-style-type: none"> • 12 lead ECG • 'awake' MRI • MRI with sedation • MRI with general anaesthetic • Routine EEG • Sleep-deprived EEG • Melatonin induced EEG • Sedated EEG • 24-48h ambulatory EEG • Video telemetry • Portable EEG on paediatric ward within audit unit 	<ul style="list-style-type: none"> • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain 	
<p>8. Does the 'audit unit' host paediatric neurology clinics? (e.g. a paediatric neurologist visits a site within the audit unit or is based within that 'audit unit')</p>	<ul style="list-style-type: none"> • Yes • No 	

<p>9. Which of the following 'transition services' are available within the 'audit unit'?</p> <ul style="list-style-type: none"> • A specific clinic for 'young people' or 'teenagers' with epilepsies • a 'Handover clinic' • Other defined handover or referral process • Local adult specialist epilepsy nurse • Youth worker • From what age do 'outpatient' adult services within your audit unit begin to accept referrals from General Practitioners (GPs) for young people with a seizure or seizures? 	<ul style="list-style-type: none"> • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Yes/No/Uncertain • Number 	<p><i>Handover Clinic - A clinic where a young person 'leaves the paediatric service and joins an adult service' and comprises both adult and paediatric health professionals</i></p>
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Glossary & Definitions

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 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)
'Audit Unit'	One or more secondary tier paediatric services grouped together using pragmatic boundaries agreed by the paediatric audit unit link, the project team and the tertiary link
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. Neonatologists would not be included in this definition unless they also fulfill general paediatric roles.
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	A chronic neurological condition characterised by two or more epileptic seizures (ILAE). A pragmatic definition for epilepsy in this audit is 2 or more epileptic seizures more than 24 hours apart that are not acute symptomatic seizures or febrile seizures.
Epilepsy Syndrome	A complex of clinical features, signs and symptoms that together define a distinctive, recognizable clinical disorder (ILAE)
'Epilepsy Syndrome Category'	A group of epilepsies described using the terms idiopathic primary, symptomatic, probably symptomatic and cryptogenic AND focal, partial, multifocal or generalized
Epileptic seizure	Clinical manifestation(s) of epileptic (excessive and/or hypersynchronous), usually self-limited activity of neurons in the brain. (ILAE)
Febrile seizure	An episode diagnosed by the assessing team as a 'febrile seizure' or 'febrile convulsion' or 'febrile fit'
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. Some paediatric neurologists see referrals direct from 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 where a young person '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
Neurodisability	Documented diagnosis including any of the following phrases indicating the diagnosis made by the assessing team: <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	A paediatric consultant (or associate specialist) defined by themselves, their employer and tertiary service/network as having: <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) (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.
'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)
Single Cluster	A number of 'paroxysmal episodes' confined to a single 24 hour period (SIGN)
Syncope	Synonymous with 'Faints' or 'vasovagal episodes'