SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	E09/S/e
Service	Children's Epilepsy Surgery Service (CESS)
Commissioner Lead	
Provider Lead	*The name of the individual leading on the service for the provider*
Period	*12 months*
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

1.1 National/local context and evidence base

The Children's Epilepsy Surgery Service (CESS) centre is commissioned to provide specialist epilepsy pre-surgical evaluation and surgery to children in specialised CESS centres, for the population of England.

Epilepsy surgery is increasingly recognised as beneficial in selected children. There is also evidence that children should be considered earlier rather than later in view of the consequence of ongoing seizures on brain development. Emerging evidence suggests there are significant advantages with early surgery (especially in children under 5).

When examining the current activity for epilepsy surgery in England against international benchmarks, less than half the numbers of procedures are performed each year that would be considered to be beneficial for the population of children.

Currently there is evidence that children are taking 2 years to move through the clinical and functional assessment and evaluation process to surgery and more urgency is needed where neuro-development can be compromised through delay in operation beyond one year of onset. A recent audit (2008) demonstrated that only 35% of children had surgery within 2 years of the onset of symptoms.[1]

The aim of the service is to improve the uptake and access to epilepsy surgery in those children for whom surgical control or amelioration for their epilepsy is a possibility.

The key roles for the national service is:

- to provide multidisciplinary teams (MDT) review of all children with epilepsy who meet the criteria for evaluation for surgical intervention;
- to provide a comprehensive pre-surgical evaluation for specified children in accordance with section 2;
- to provide and co-ordinate epilepsy surgical procedures for children in line with the specification;
- to identify and support local care within the children's neuroscience network where this is appropriate;
- to provide expert advice to services within the children's neuroscience network;
- to provide leadership for research, audit and training in assessment and management of epilepsy through surgical means.

The service specification covers a national caseload of all residents in England.

This service specification should be read in conjunction with the National Paediatric Neuroscience and Paediatric Neurology service specification.

1.2 Prevalence rate

There is scant data available addressing the number of children who might benefit from surgery. A recent study from Connecticut[2] USA followed children newly diagnosed with epilepsy for 10 years (10). From this it is estimated that in the USA 127/1,000,000 children present with drug resistant epilepsy per year and that 52/1,000,000 children should undergo a pre-surgical evaluation and 27/1,000,000 a resective surgical procedure. This suggests that in the UK 780 children should be evaluated per year and 405 should have a resective surgical procedure. Each regional CESS centre will have an agreed phased plan to meet this level of care for England.

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[1] *Harvey et al., Epilepsia 2008;49:146-155*

	Current UK activity	**Estimated numbers required for UK**	**Estimated numbers required for England**	**Estimated numbers of new procedures For England**
Epilepsy evaluation	392	780	648	322
Resection	106	405	336	248

Source: calculations based on data from *Berg et al 2009, Brain 132; 2785-279*

Taking into account the information in the table above, together with national information on the experience of epilepsy surgery currently, the national caseload is expected to require larger numbers to accommodate this variation.

The service is expected to see a total of 1050 referrals (per year) across 4 epilepsy surgery centres with 350 surgical procedures. Designated CESS providers will agree a phased development of activity across 3 years to meet this expected level.

1.3 Evidence base

All children with a recent onset suspected seizure should be seen urgently by a specialist. The seizure type(s) and epilepsy syndrome, aetiology and co-morbidity should be determined locally by specialist paediatricians and paediatric neurologists following neurological investigations. Epilepsy surgery is considered beneficial in selected children, to relieve the burden of epileptic seizures, in line with international evidence, NICE Clinical Guidelines and International League Against Epilepsy guidelines.

The service is to deliver treatment in line with the NICE guidelines specific to the treatment of epilepsy:

- NICE guidelines for the diagnosis and management of the epilepsies in adults and children in primary and secondary care CG137.

1.4 Waiting times

All CESS referrals are to be managed within 18 weeks, except for patients with actual or suspected malignancy which are reported under the Cancer Waiting Times achievement of two week wait, 31 day wait to first treatment, 31 day wait to subsequent treatment, 62 day wait from referral to first treatment. It is the patient's right to treatment within 18 weeks of referral. Providers are required to report waiting times as part of the standard specialty reporting and the new planning guidance.

The definition of 'treatment' for this service is the relevant surgical intervention following full pre-surgical evaluation and discussion. Waiting times can be suspended where following the full pre-surgical evaluation the MDT recommends 'Watchful waiting' with a planned subsequent review of the child's condition; or where the recommendations of the MDT is that the child would benefit from surgical intervention and the family wish to consider this over a period of time.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	√
Domain 2	**Enhancing quality of life for people with long-term conditions**	√
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	√
Domain 4	**Ensuring people have a positive experience of care**	√
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	√

In line with this specification and standards, the CESS will monitor performance and outcomes using the following measures:

Domain 1: Preventing people from dying prematurely:

- Mortality (peri-surgical and late) with cause
- Peri-operative surgical morbidity (within 30 days)
- Late surgical morbidity (beyond 30 days)
- Post-operative morbidity length of stay, reoperation rates, readmission rates

Domain 2: Enhancing quality of life for people with long term condition:

- Neurological outcome (Better/no change/worse /expected/unexpected)
- Neurodevelopment/cognitive/neurobehavioral outcome at 1, 2 and 5 years (better/no change/deterioration)
- Quality of life

Domain 3: Helping people to recover from episodes of ill health or following injury:

- Seizure outcome 1, 2 and 5 years (related to procedure and pathology)
- Access to support groups and education: Questionnaire survey plus patient/ carer participation

Domain 4: Enduring that people have a positive experience of care:

- Patient/ carer satisfaction: Questionnaire survey
- Re-operation rate
- Waiting times: Time from referral to pre-clinical review, pre-clinical review to surgery

time from referral to surgery from hospital data systems

Domain 5: Treatment and caring for people in a safe environment and protecting them from avoidable harm:

- ‘Near miss’ and adverse events (including CSF leaks, cases postponed or cancelled) in line with the recommendations of the national clinical coordinating group

Other outcomes to include:

- Evidence of programme of joint working with network children’s neurosurgical centres: Shared Care Protocols, Outreach Clinics
- Contribution to surgical data registry
- Collection of standardised and coded activity and outcome data in line with national agreements

The national service will develop common evidence base tools and training programmes:

- Common risk assessment and management approaches and systems
- Training in epilepsy surgery assessment evaluation and treatment
- Clinical information systems, reports to commissioners

Mortality and Morbidity - All CESS centres of paediatric neurosurgery will operate Mortality and Morbidity meetings and these should include Root Cause Analysis investigations of deaths and serious unexpected events which should be shared with commissioners and reviewed by the National Clinical Advisors.

Mortality and Morbidity meetings aim to improve standards of surgical care:

- All in-hospital deaths will be reviewed and a standardised format for review followed.
- Deaths of recently discharged patients will be reviewed.
- Cases are presented at meetings for the purpose of:
    - Identifying opportunities to improve patient safety and quality of care.
    - Providing a learning opportunity focused on system thinking.
    - Discussing management decisions.
- Issues will be identified and, where appropriate, recommendations for system change made.
- Progress with implementation of recommendations will be reviewed at subsequent meetings.
- A centre may consider that an independent review would be beneficial.
- Meetings will be recorded.
- Local multiagency child protection policies will be adhered to.

The commissioners and CESS network will conduct a formal Joint Service Review at least every six months.

3. Scope

3.1 Aims and objectives of service

Strategic objectives:

- To improve seizure control and quality of life in drug resistant epilepsy
- To improve the quality of life in children with drug resistant epilepsy.
- To raise awareness of the benefits of epilepsy surgery in children who meet the criteria
- To reduce the risk of inappropriate and or inadequate surgical interventions
- To improve access to clinical and functional assessment and evaluation before surgery
- To increase the amount of appropriate epilepsy surgery undertaken
- To reduce epilepsy related deaths, including Sudden Unexpected Death in Epilepsy
- (SUDEP), in children

Ultimately, successful Epilepsy Surgical intervention may lead to improved developmental and psychosocial outcomes for these children.

Objectives:

- To provide a comprehensive MDT review and assessment for all children eligible for consideration of surgical management of their epilepsy and advise on the appropriate course of treatment and care in the centre and/or local services
- To provide expert pre-surgical evaluation utilising the most up to date, validated assessment / diagnostic tools and knowledge, including Positron emission tomography (PET) / Magnetoencephalography (MEG) / Single-photon emission computed tomography (SPECT) scans/functional Magnetic resonance imaging (MRI) scans and invasive Electroencephalography (EEG) monitoring
- To provide expert management of epilepsy surgery through the use of the most up-to-date clinical protocols for therapeutic interventions and surgical management
- To support the effective ongoing monitoring of children's development in local services where appropriate, including assessing educational progress in children
- To provide diagnosis and treatment of neuropsychological problems and psychiatric disorders including an assessment of educational deficits, in children assessed as benefitting from epilepsy surgery
- To operate a rolling programme of clinical audit to test current practice and inform the evolution of care and therapeutic intervention for the range of procedures
- To provide therapeutic support and care with a patient and family centred focus to maximise the child and family experience of care within the nationally designated providers
- To be seen as the leading clinical services and a source of expert advice for the diagnosis and management of children requiring epilepsy surgery
- To provide high quality information for patients, families and carers in appropriate and accessible formats and media
- To develop the experience, knowledge and skills of the MDT to ensure high quality sustainable provision to include the development of specific skills required to undertake assessment for and conduct of epilepsy surgery
- To support the development of continual professional development through career pathways and training opportunities for professionals within the service

Outcomes:

- To reduce seizures in children with epilepsy
- To optimise developmental potential and improve educational progress in children with epilepsy
- To improve quality of life in children with epilepsy

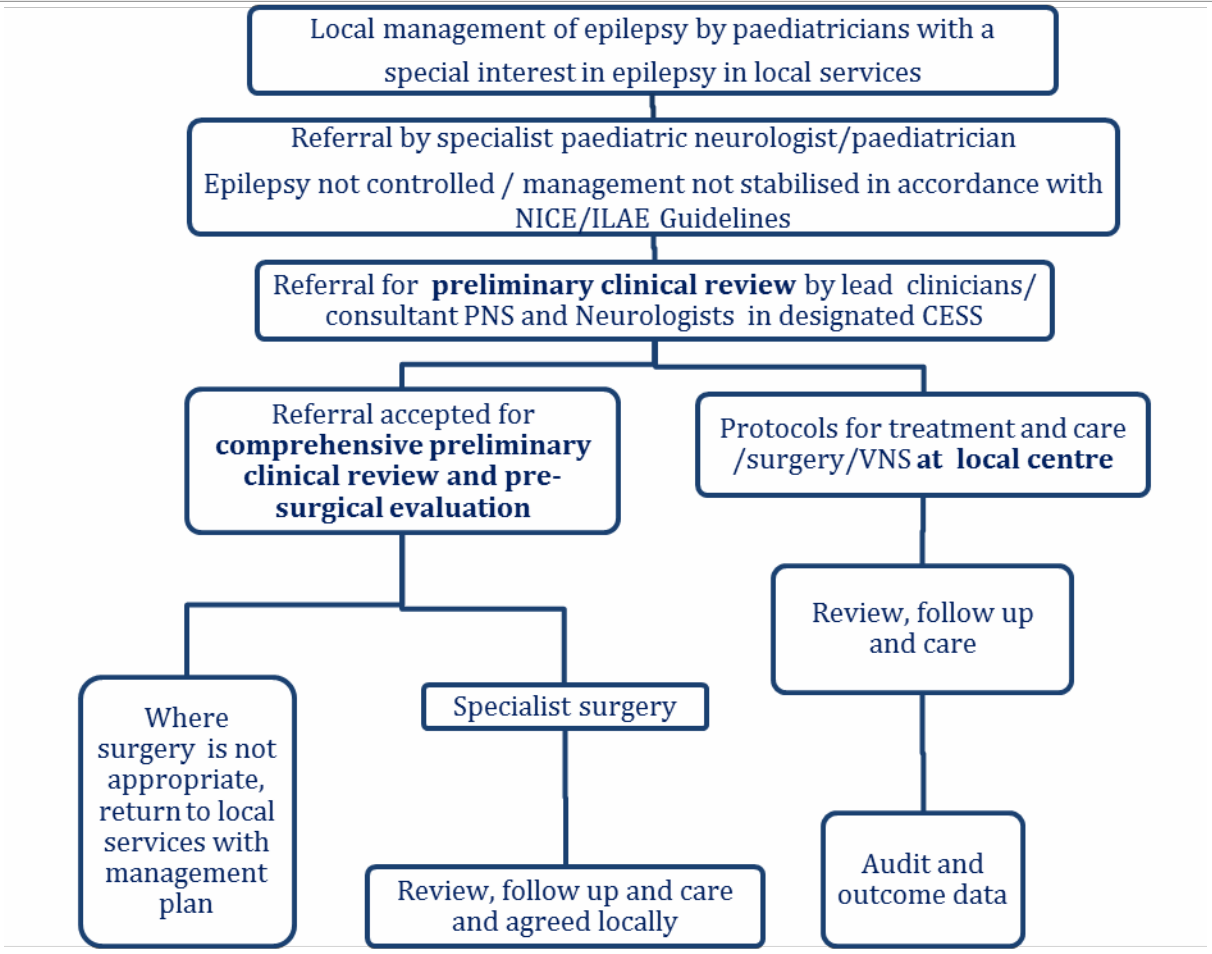
3.2 Service description/care pathway

The service model and pathways have been developed as part of the Safe & Sustainable Children's Neurosurgical Services review and set out in Children's Neuroscience Networks (for the neurosurgical child) - Framework and Standards for services in England (May 2013). The designated CESS centres will be part of the networks for Children's Neurosurgical Services and will play a key part in delivering the network standards, audit, development and improvement plans. It should be noted that not every Children's Neuroscience Network will have its own CESS centre.

The national CESS will provide evidence-based pre-surgical evaluation and surgical treatment for children with uncontrolled epilepsy, in designated inpatient services and ensures that there is an effective, safe, and timely discharge to local services, giving specialist professional advice to referrers and other agencies where needed.

The service provides high quality clinical care in the following ways: the summary pathway is set out below (the full pathway is set out in Appendix 1):

Summary Pathway:



I. Referrals to the CESS must also include a minimum of:
   - Clinical history, including perinatal history, seizure onset, seizure types, medication history / treatment history, neurodevelopmental progress, family history, other medical problems, investigation history, neurological examination
   - MRI using specified protocols in line with national protocols
   - EEG including period of sleep in line with national protocols

II. Preliminary clinical review: This review provides the initial clinical assessment of the children with epilepsy in line with one or more of the parameters outlined in the acceptance criteria in section 2.4.

    For the avoidance of doubt, the purpose of this stage is to provide a case review (with scans and results from preliminary investigations) which will take place between the lead clinician, comprising of Epileptologist (Consultant Paediatric Neurologist with recognised knowledge skills and experience in the management of epilepsy) and Paediatric Neurosurgeon) at the CESS and the local children's neuroscience centre as a virtual outpatient appointment.

    The preliminary clinical review should also include the neuro-imaging and EEG report.

    Following the preliminary clinical review, a management plan is agreed between the CESS and the local Children's Neurosurgical Centre (CNC). This includes agreement on the patient care pathway/ management plan, including the pre-surgical assessment at the CESS and any appropriate procedures to be carried out within defined protocols.

Some patients may be fast tracked from pre-clinical review straight to stage 2 – this depends on the clinical presentation and the amount of information provided by the referrer.

III. For urgent referrals the preliminary clinical review at the CESS should be undertaken by the named lead paediatric neurologist and paediatric neurosurgeon (PNS), completed within 5 working days from receipt of the case details and scans, reviewing the child as an outpatient.
Pre-surgical assessment: For children where specialist treatment is indicated, a comprehensive specialist in-patient assessment and pre–surgical evaluation will be required following preliminary review. The pre-surgical assessment will incorporate:

- Interictal sleep EEG recording
- Video EEG recording of seizures
- MRI with specified protocol including serial scans if appropriate
- Functional imaging as required
- Age appropriate neuropsychology or neurodevelopmental assessment, diagnosis and advice on educational interventions/treatment
- Neuropsychiatry assessment and treatment

The data resulting from the above evaluation will be discussed by the Epilepsy MDT and a clinical decision made for the appropriate surgical treatment.

The exact scope of investigation will vary according to the needs of the child but in addition <u>access</u> to the following is required 3T MRI, SPECT, PET, fMRI, MEG, tractography.

The Area Team and CESS are to determine and agree with local Children's Neurosurgery Centres (CNCs) which of the above tests can be undertaken in accordance with the principle for care of children; as much care provided local as possible and specialised when needed.

IV. Cases that should have epilepsy surgery in a CESS centre

Hemispheric procedures
Invasive EEG monitoring
Surgery for Rasmussens
Tuberous sclerosis
Hypothalamic hamartoma
Sturge Weber syndrome
Peri-central lesions
Peri-insular lesions
All temporal lobe resections
Multilobular resections or disconnections
Lobar resections

Cortical resections for malformations of cortical development (e.g. focal cortical dysplasia, polymicrogyria)
Callosotomy

The only cases that may be considered for surgery outside a CESS centre are: lesionectomies for glioneuronal tumours, cavernomas or AVMs where the lesion is in non-eloquent cortex.

V. Post-operative care and follow-up

VI. A comprehensive multi-disciplinary team comprising wide ranging skills and professional expertise:

Paediatric Epileptologist*, Neurosurgeon with expertise in paediatric epilepsy, Neurophysiologist with an expertise in Paediatric Neurophysiology, Neuroradiologist with expertise in paediatric Neuroradiology, Paediatric Neuropsychology, Paediatric Neuropsychiatrist, Specialist Epilepsy Nurse, Therapy: Paediatric OT, SLT, Physiotherapy, Paediatric Neuroanaesthetist, Neuropathologist and Paediatric Ophthalmologist, EEG physiologists.

*a paediatric epileptologist is a paediatric neurologist who had done an epilepsy fellowship, or spent a period of training in an epilepsy surgery centre.

VII. Family support for the period of the inpatient stay is provided in a child friendly environment.

VIII. Support and advice is provided to other professionals to enable timely transfer to local services.

Tele-link facilities (including the ability to share imaging) are used to link different geographic parts of the National Service for clinical management meetings.

IX. The CESS should demonstrate clear working relationships with an adult epilepsy surgery unit with the existence of services for adolescents and transitional arrangements to adult epilepsy services.

X. Post- surgical care to include HDU and/or PICU care, paediatric neurosurgery nursing.

XI. The Management Plan needs to be agreed with the family and discussed with them on an ongoing basis. This will include the details on follow up care, monitoring and review and should be shared with the key clinicians in more local CNC services. This should be facilitated by support from a designated Epilepsy Nurse Specialist.

XII. Planning the transition from children's to adult services should be initiated at least by the age of 16 years of age. There should not be a fixed age for transition from children's to adult services which will vary according to the needs of the child and their family.

CESS will be responsible for developing a transition plan that will include the close involvement of the adult epileptologist in the local network.

XIII. The CESS is part of the Children's Neuroscience Network Operational Delivery Network and its collaborations with other CNCs is to be determined by the NHS England Area Teams, in line with the national mandated standards outlined in this specification.

The Area Team and CESS Centre are required to assess any care and treatment outlined in this specification that is provided outside a CESS Centre. This will be through assessing local Children Neurosurgery Centre against the clinical standards detailed in Appendix 3.

Core standard:
Specialist epilepsy surgery for children of all ages as specified in section IV above will only be provided at a designated CESS centre.

Surgical facilities and equipment forms an integral part of this specification and are detailed in Appendix 3.

Self-care and education
Every patient and family / carer must receive information about their condition in an appropriate format. The information must cover:

- description of the disease;
- management of the disease within the scope of the commissioned service as described in the specification, clinical pathways and service standards including importance of drugs and other treatments commissioned in the clinical pathway;
- self-management and care;
- psychological support;
- access to appropriate patient support group;
- contact details of the patient are allocated named nurse;
- contact details for patient groups and charities.

3.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

*Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

The national service will provide consultation on a discretionary basis to Wales, Scotland and Northern Ireland. And will only carry out direct clinical work with children or families in Scotland, Wales or Northern Ireland if the child is either resident or in school in

England. We will support the development of new services in other countries.

The CESS is accessible to children and their families at the centre of choice. The service is sensitive to the total physical and cultural needs of the child and their family taking into account the complex needs (including learning disabilities) that some children have.

Providers require staff to attend mandatory training on equality and diversity and the facilities provided offer appropriate disabled access for patients, family and carers. When required the providers will use translators and printed information will be available in multiple languages and in a format that is suitable.

The Provider has a duty to co-operate with the commissioner in undertaking Equality Impact Assessments as a requirement of race, gender, sexual orientation, and religion and disability equality legislation.

The CESS centres are commissioned to provide and deliver high quality medical and surgical treatment for children who meet the criteria for pre- surgical evaluation outlined in section 2.4.

3.4 Any acceptance and exclusion criteria and thresholds

Referrals can be made by patient's GP, Paediatrician or Paediatric Neurology or Neurosurgeon from the CESS network.

Acceptance criteria:

- A recognised unilateral lesion
- All children <24m, with evidence of focality or lateralisation
- All children with epilepsy associated with congenital hemiplegia who has failed two Anti-epileptic Drugs (AEDs)
- All children with ongoing seizures of suspected focal onset, who have failed two AEDs with or without evidence of a lesion on MRI
- Specific syndromes requiring special consideration including Tuberous sclerosis, Sturge Weber, Rasmussens Syndrome; Hypothalamic Hamartoma

All children with a recent onset suspected seizure should be seen urgently by a specialist. The seizure type(s) and epilepsy syndrome, aetiology and co-morbidity should be determined locally by specialist paediatricians and paediatric neurologists following neurological investigations. Epilepsy surgery is considered beneficial in selected children, to relieve the burden of epileptic seizures, in line with international evidence and NICE Clinical Guidelines.

Referrals are accepted from any core member of the MDT where the patient has confirmed or suspected drug resistant epilepsy. The receiving clinician at one of the CESS centres may request the referrer to carry out further investigations to aid the proper diagnosis of the patient's condition. Referrals will be accepted by the nationally designated providers via the on-call Consultant Paediatric Neurologist (with recognised knowledge skills and experience in the management of epilepsy) or Paediatric Neurosurgeon who are part of the CESS MDT.

Response time & detail and prioritisation

- Initial telephone contacts from referrers are to be dealt with immediately by the senior clinical lead / surgeon for urgent cases. The referral may be accepted over the phone immediately and / or the CESS service provider may request the referrer to carry out further investigations. Advice on optimal management will be given and on-going support will be provided until the patient is transferred.

- Transfer of patients to a nationally designated CESS centre will be prioritised according to the needs of individual patients but in all cases where a transfer to the CESS centre has been agreed that transfer will take place as soon as is practicable. If necessary the nationally designated CESS centre will communicate with each other to coordinate appropriate care for patients at times when capacity at one or the other providers is under pressure.

Exclusion criteria:

- Vagal Nerve Stimulation (VNS) is excluded from this service specification. However VNS should not normally be considered unless the case had been discussed at CESS centre to ensure it is part of an appropriate management plan for the child.
- Long-term follow-up care is not included in the specification and will be provided in services local to the child and their family. This is particularly necessary where children have complex needs which are more appropriately provided for locally to the child and their family. In all cases ongoing reviews and monitoring will be agreed as part of the management plan shared with other services.

3.5 Interdependencies with other services/providers

The Children's Epilepsy Surgical Service (CESS) centres will hold annual co-ordinating meetings to include the clinical lead, operational and finance manager from each of the 4 designated centres, PPI representatives, and senior clinicians from other disciplinary groups. This meeting will afford an opportunity for additional national service co-ordination and planning supporting the work of the National Clinical Co-ordinating Group and the Clinical Reference Group.

The nationally designated CESS's are the leaders in the NHS for patient care in this area. They provide a direct source of advice and support when other clinicians refer patients into the nationally designated providers. The providers are also required to provide education within the NHS, and the wider Children's Neuroscience Network(s) to raise and maintain awareness of epilepsy and its surgical management, improving uptake and access to services.

The national services will undertake:

- a yearly national audit meeting to include mapping of provision and review (involving commissioners and the national epilepsy clinical advisers);
- a yearly national away day to discuss service development;
- regional telephone conference clinical meetings;
- contract review meetings with local NHS England Area Teams;
- national Clinical Coordinating Meetings.

Co-located Services

The CESS centre providers are leaders in the NHS for patient care in this area. They provide a direct source of advice and support when other clinicians in the full pathway of the child. This support will continue until the patient is transferred into the regional

Specialist centre or it becomes apparent that the child does not have epilepsy that requires surgical interventions.

Interdependent Services

The standards in Appendix 3 (Section D) set out the critical services interdependencies in line with Department of Health, Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies, August 2008.

- Each CESS and Children's Neurosurgical Centre will be co-located with a paediatric intensive care unit and there must be access to a defined neurosurgical high dependency care area.
- Each CESS and Children's Neurosurgical Centre will have paediatric anaesthesia co-located with paediatric neurosurgery.
- Each CESS and Children's Neurosurgical Centre will be co-located with 24/7 paediatric neurology services) and must include appropriate early rehabilitation services.
- Other specialist services must be provided in accordance with this Department of Health guidance.

The CESS will form a relationship with local Children's Neurosurgical Centres (CNCs) and relevant health providers in the Children's Neuroscience Network and help optimise any care for epilepsy surgery which is provided locally for the patient.

The specialist services will work together to provide tele-linked services (including the ability to share imaging), supporting teleconferencing facilities that will be used for the provision of consultation, liaison, and clinical managerial discussions.

The service is required to work in partnership with Paediatric Neurosciences and Paediatric Rehabilitation services.

The national services will work together with other regional and national organisations to improve and facilitate appropriate high quality training for professionals in both specialist and generic services.

Related Services

The service is required:

- to provide education within the NHS to raise and maintain awareness of paediatric epilepsies and their management;
- to work in collaboratively with local health and social care providers to help optimise any care for children with epilepsy provided locally. This may include liaison with consultants, GPs, community nurses, social workers or professionals from third sector organisation etc.

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

Please refer to section 1.3 and service standards for Epilepsy Surgery (Appendix 3).

4.2 Applicable standards set out in Guidance and/or issued by a competent body (E.g. Royal Colleges)

As above

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

See appendices

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

These are in the process of being developed and will be inserted once agreed.

6. Location of Provider Premises

The Provider's Premises are located at:

In line with the manual of prescribed specialised services, epilepsy surgery will:

- be regionally located and provided on a collaborative model to ensure there is consistent and equitable national coverage.
- provide outreach across each network and ensure that there is appropriate coverage to meet the population needs according to clinical need

The CESS will be based at:

- Birmingham Children's Hospital NHS Foundation Trust.
- Great Ormond Street Hospital for Children NHS Foundation Trust and Kings College Hospital NHS Foundation Trust (surgery for children aged 5 years and under will be undertaken at Great Ormond Street Hospital for Children NHS Foundation Trust).
- Alder Hey Children's NHS Foundation Trust and Central Manchester University Hospitals NHS Foundation Trust (surgery for children aged 5 years and under will be undertaken at Central Manchester University Hospitals NHS Foundation Trust).
- University Hospitals Bristol NHS Foundation Trust

Days/Hours of operation:

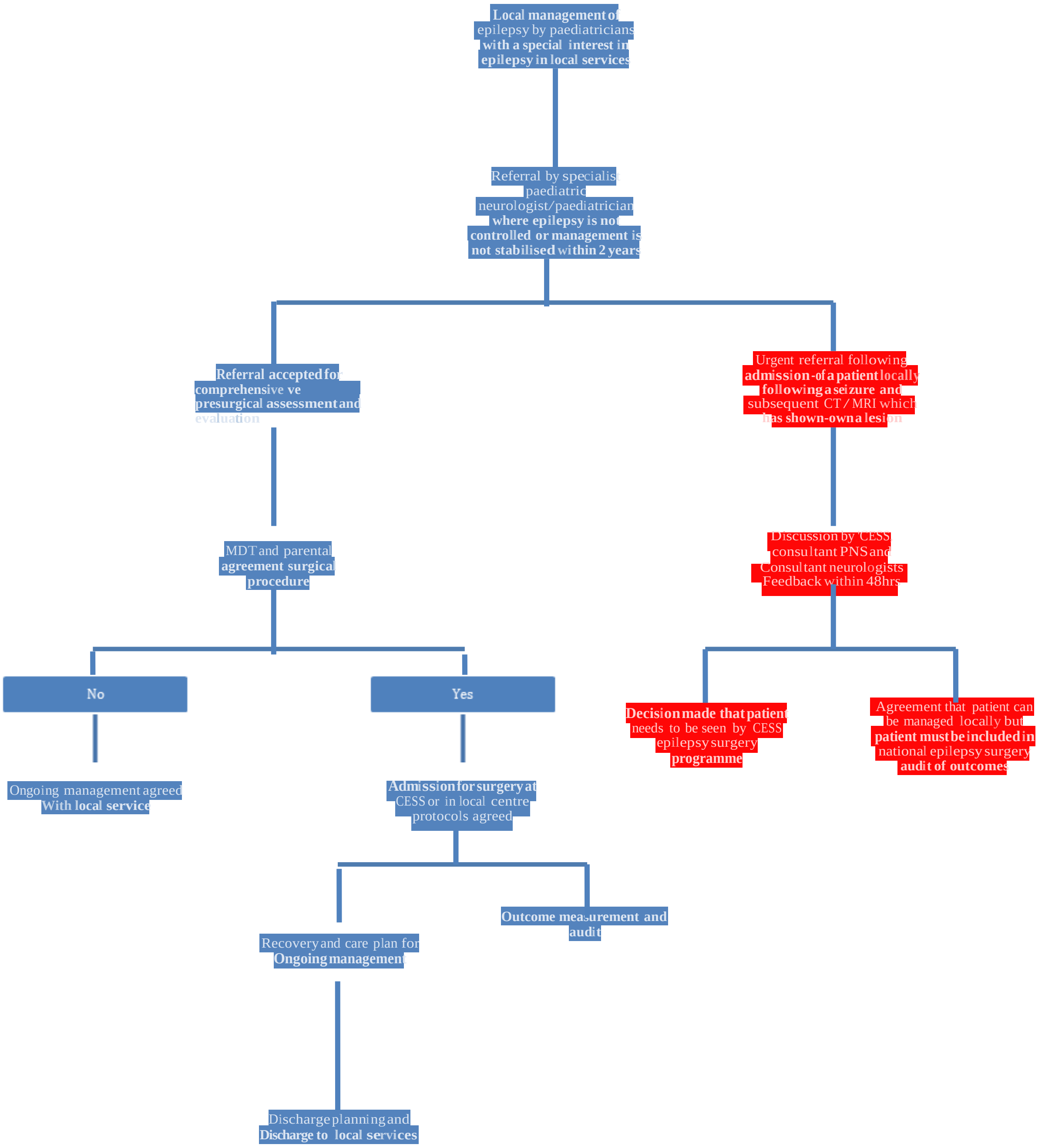
- Inpatient care will be provided 24 hours a day, 365 days a year.
- Outpatient care and home visits will be provided through the normal working day. MDT clinics will be on a specified day of the week and run at least monthly.

7. Individual Service User Placement

Quality standards specific to the service:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
Mortality (peri-surgical and late) with cause.	Zero	Orion	Investigation
Peri-operative surgical morbidity (within 30 days).	Zero	Orion	Investigation
Late surgical morbidity (beyond 30 days).	Zero	Orion	Investigation
Post-operative length of stay, reoperation rates, readmission rates.	Peer review	Orion	National audit
Domain 2: Enhancing the quality of life of people with long-term conditions			
Neurological outcome (Better/no change/worse /expected/unexpected).	Worse	Orion	National audit
Neurodevelopment/cognitive/neurobehavioral outcome at 1, 2 and 5 years (better/no change/deterioration).	Deterioration	Orion	National audit
Quality of life.	Worse	Orion	National audit
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Seizure outcome 1, 2 and 5 years (related to procedure and pathology).	Worse	Engel criteria	National audit
Access to support groups and education: Questionnaire survey plus patient/ carer participation	No Not done	Orion Report to commissioners	National audit Review by commissioners
Domain 4: Ensuring that people have a positive experience of care			
Patient/ carer satisfaction: Questionnaire Survey.	Not done	Report to commissioners	Review by commissioners
Waiting times: Time from referral to pre-clinical review, pre-clinical review to surgery, time from referral to surgery from hospital data systems.	Peer review	Orion	National audit
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
‘near miss’ and adverse events (including CSF leaks, cases postponed or cancelled)	None	Orion	Investigation

Appendix 1 – Care Pathway Overview



Appendix 2 – Local tariff and surgical codes

1. Local Tariff structure and coding

Stages in the pathway

1	Pre-clinical review
2	Pre-surgical assessment – video telemetry
3	Pre-surgical assessment – complex diagnostics
4	Pre-surgical assessment – intercranial telemetry
5	Surgery

Week	Step (Path 1)	Tasks	Staffing	Technology	Settings	Activity / Coding
1	Pre-clinical review referral	Standardised referral form completed and sent to CESS (passed to Co-ordinator as single point of contact) Preclinical review meeting – Neurosurgeon, Neurologist and Radiologist (if available) review referral and make plan (accept / reject / redirect referral).	Consultant paediatrician / referring agent/ Co-ordinator		Admin Seminar room	Record referral and decision (new currency) – coding to be determined
2	Telephone review	Requesting missing data Data base updated	Coordinator	Teleconference Data base	Virtual event (telephone)	

Week	Step (Path 1)	Tasks	Staffing	Technology	Settings	Activity / Coding
5	Patient seen in outpatients	Information letter sent to patient / carer Detailed physical examination and detailed history Decision to continue confirmed (consent) Correspondence with local paediatrician confirming plan	Epileptologist & Epilepsy nurse Coordinator		Outpatient department	Outpatient attendance (TFC) – national tariff
7	Patient admitted for investigations Video EEG, GA MRI and Neuropsychology	Investigations booked Supporting investigations (physio, speech, visual assessments). Neuropsychology review referral assess need for neuropsychology or developmental assessment	Coordinator	Database	Admin	Included as on cost the admission
		Pre admission tasks – discuss plans for medication reduction, plus any potential language, family safeguarding desensitisation issues assessed Risk assessment	Epilepsy nurse		Telephone conversation/ telephone clinic	
		Admission clerking Ancillary investigations (Bloods, LP)	Ward staff Diagnostic support	Theatre Video telemetry	Inpatient for 5 days (ward and theatre and	Admission coded and submitted to HES / SUS If to be a local currency

Week	Step (Path 1)	Tasks	Staffing	Technology	Settings	Activity / Coding
		Investigations undertaken Results collected for discussion and events recorded Ward round review of admission – immediate medication changes or plans made NB: A small but significant group may not come in for VT – they may be assessed on NICU/PICU or have a day case assessment with prolonged EEG	departments and Coordinator Epileptologist + neurophysiologist	MRI	imaging department)	linked to the Coordinator Record this will need to be excluded from SUS.
10	1st MDT	Decision to progress to next stage or repeat investigations or refer elsewhere	Epileptologist / Neurophysiologist / neurosurgeon / neuropsychologist t / radiologist Coordinator		1st Epilepsy Surgery MDT – seminar room + virtual attendees	
15	Further diagnostic testing	Investigations requested and could include: SPECT Scan; fMRI; PET; MEG, Wada; Stealth MRI; Tractography; Neuropsychology; Neuropsychiatry	Epileptologist Neuropsychology Neuropsychiatry Radiology	Diagnostic technology as described	Range of outpatient and inpatient events depending on tests used. In the hospital and at other centres	Coordinator

Week	Step (Path 1)	Tasks	Staffing	Technology	Settings	Activity / Coding
17	2nd MDT	Decision to progress to next stage, repeat investigations or discuss at National CESS MDT Patient prioritised and recommendations made to proceed to invasive monitoring	MDT including coordinator		2nd Epilepsy Surgery MDT – seminar room + virtual attendees	
	Agreement to proceed to invasive monitoring	Patient /carers contacted prior to admission and coordinates admission / AEDS risk assessment	Epilepsy Nurse		Telephone	Admission coded and submitted to HES / SUS If to be a local currency linked to the Coordinator record this will need to be excluded from SUS.
18	Surgical planning meeting	GRID or Stereo EEG: Target selection and planning, hardware selection, and ordering. Record decision	Epileptologist, Neurosurgeon, Neurophysiologist and/or Neuroradiologist Coordinator	EEG, VEEG, MRI +/- PET, MEG, SPECT	Admin	
21	Neurosurgery OPA pre-operative	Patient / Carer counselled MRSA, pre op bloods, anaesthetic review, risk assessment HDU bed booked NB: The neurosurgery pre-operative OPA could happen after stage 1 admission, or after stage 2, or both	Neurosurgeon Anaesthetist Pathology Epilepsy Nurse	Pathology	Outpatient department	

Week	Step (Path 1)	Tasks	Staffing	Technology	Settings	Activity / Coding
		For some patients.				
	Surgical intervention	Patient admitted (includes HDU for 24 hours) Insert intra-cranial electrodes	Neurosurgeon Neurophysiologist Theatre staff Ward staff including HDU	Operating theatre Intra-cranial electrodes Medical Photography	Theatre	
	Cortical mapping	Patient / carer counselled	Neurophysiologist ; Neuropsychologis t t; Epileptologist; Epilepsy Nurse; Neurosurgeon	Monitoring tools including Video EEG and Cortical Stimulator	Ward / HDU	
26	Resection - Surgery	Removal of monitoring and resection HDU 24 hours Post-op recovery and assessment by therapy staff on the ward	Neurosurgeon Theatre staff Ward staff including HDU	Operating theatre	Theatre Ward HDU	HRG for episode of care – National tariff– OPCS codes to be mapped against various scenarios (HRGs to be determined but potentially AA08).

ASSUMPTIONS

- Stages 2-4 are currently all part of the bundled package of care known as pre-surgical assessment. If the commissioners maintain a bundled package of care then payment should be triggered at the first admission for assessment.

Key additional points:

- Post-surgery discharge follow-up is:
    - 10-14 days – telephone clinic with nurse specialist
    - 6 weeks - Epilepsy surgery clinic review
    - 3-6 months – epilepsy clinic review
    - 1 year – epilepsy surgery clinic review with MRI and EEG.
    - Re-evaluations – there will be some patients for whom surgery does not work the first time round, and these may be re- evaluated and then recommended for further surgery.
    - Some patients will skip steps (i.e. initial outpatient review, or telemetry admission) others will repeat steps (have 2 initial telemetry admissions)

GLOSSARY OF TERMS

Neurosurgeon	In this case a Paediatric Neurosurgeon
Epileptologist	Neurologist with a specialist role in the management of epilepsy
Epilepsy Nurse	Specialist nurse with an interest in epilepsy disorder
Neuropsychology	In this case a paediatric neuropsychologist
Neuropsychiatry	In this case a paediatric consultant neuropsychiatrist
Neurophysiology	In this case a Consultant Clinical Neurophysiologist and Clinical Physiologist
Coordinator	Administrative role for the co-ordination of all patient activity through the Programme
AEDS	Anti-epileptic drugs
MRI	Magnetic resonance imaging
F-MRI	Functional magnetic resonance imaging or functional MRI (fMRI) is an MRI procedure that measures brain activity by detecting associated changes in blood flow
Video EEG	Concomitant long term Video and Electroencephalogram recording
SPECT	Single Photon Emission Computed Tomography
PET	Positron Emission Tomography
MEG	Magnetoencephalography (MEG) is an imaging technique used to measure the magnetic fields produced by electrical activity in the brain via extremely sensitive devices such as superconducting quantum interference devices
Stealth MRI	MRI brain scan performed to allow utilisation of image guidance systems during surgery
Tractography	A procedure to demonstrate the neural tracts. It uses special techniques of magnetic resonance imaging (MRI), and computer-based image analysis.
WADA	Also known as the "intracarotid sodium amobarbital procedure" (ISAP), is used to establish cerebral language and memory representation of each hemisphere
Intracranial telemetry	The concomitant recording of video and Intracranial EEG by grid, strip and depth (Stereo EEG) electrodes
Cortical Mapping	The identification of areas of the cortex which are functionally eloquent (e.g. speech, motor, sensory and visual function) or that may relate to the epileptogenic zone (i.e. irritative zone by eliciting ‘after’ discharges)
HDU	High dependency Unit

2. Surgery Procedure Codes

Age	DIAG1	Diag Description	Total
5 and under	B018	Varicella with other complications	1
	G401	Locl-rel(roc)prt)symp epilep/epileptic syn simple part seiz	1
	G403	Generalized idiopathic epilepsy and epileptic syndromes	1
	G404	Other generalized epilepsy and epileptic syndromes	1
	G408	Other epilepsy	3
	G409	Epilepsy, unspecified	2
	Q049	Congenital malformation of brain, unspecified	2
	Z090	Follow-up examination after surgery for other conditions	2
	Z480	Attention to surgical dressings and sutures	1
6 and over			1
	C712	Malignant neoplasm of cerebrum, temporal lobe	2
	D713	Malignant neoplasm of cerebrum, parietal lobe	1
	F432	Neoplasm uncert / unkn behave brain, unspecified	2
	G799	Unspec mental retard without mention of impairment of behave	1
	G379	Demyelinating disease of central nervous system, unspecified	1
	G401	Locl-rel(foc)part)symp epilep/ epileptic syn simple part seiz	9
	G402	Locl-rel(foc)part)symp epilep/ epileptic syn complex part seiz	1
	G403	Generalized idiopathic epilepsy and epileptic syndromes	1
	G408	Other epilepsy	8
	G409	Epilepsy, unspecified	32
	G809	Cerebral palsy, unspecified	2
	G819	Hemiplegia, unspecified	1
	J690	Pneumonitis due to food and vomit	1
	L511	Bullous erythema multiforme	1
	Q02X	Microcephaly	1
	Q046	Congential cerebral cysts	1
	R298	Other spec symptoms signs involve nervous/musculoskel systs	1
	R568	Other and unspecified convulsions	1
	S099	Unspecified injury of head	1
	Z080	Follow-up examination after surgery for malignant neoplasm	1
		Grand total	84

OPCS	**Label (shaded area = codes used by GOSH)**
A011	**Hemispherectomy, Functional Hemispherectomy or Hemispherotomy?**
A012	**Total lobectomy of brain**

OPCS	Label (shaded area = codes used by GOSH)
A013	**Partial lobectomy of brain**
A018	Other specified major excision of tissue of brain
A019	Unspecified major excision of tissue of brain
A021	Excision of lesion of tissue of frontal lobe of brain
A022	Excision of lesion of tissue of temporal lobe of brain
A023	Excision of lesion of tissue of parietal lobe of brain
A028	Other specified excision of lesion of tissue of brain
A029	Unspecified excision of lesion of tissue of brain
A041	Open biopsy of lesion of tissue of frontal lobe of brain
A042	Open biopsy of lesion of tissue of temporal lobe of brain
A043	Open biopsy of lesion of tissue of parietal lobe of brain
A071	Open division of tissue of brain
A075	**Multiple subpial transections**
A076	**Complete callosotomy**
A077	**Partial callosotomy**
A078	Other specified other open operations on tissue of brain
A079	Unspecified other open operations on tissue of brain
A091	Implantation of neurostimulator into brain
A092	Maintenance of neurostimulator in brain
A093	Removal of neurostimulator from brain
A094	Operation on neurostimulator in brain NEC
A095	Insertion of neurostimulator electrodes into the brain
A098	Other specified neurostimulation of brain
A099	Unspecified neurostimulation of brain
A108	Other specified other operations on tissue of brain
A109	Unspecified other operations on tissue of brain
A111	Placement of depth electrodes for electroencephalography
A112	Placement of surface electrodes for electroencephalography
A118	Other specified operations on tissue of brain
A119	Unspecified operations on tissue of brain
A201	Drainage of ventricle of brain NEC
A208	Other specified other operations on ventricle of brain
A209	Unspecified other operations on ventricle of brain
A841	Electroencephalography NEC

3. Algorithm

At the planning stage the following algorithm was used to identify the baseline activity however the identification rules and tariff structure is define above.
The criteria required to identify paediatric epilepsy from APC SUS 2011/12 should be:

- Any provider
- Age on admission <=18
- Procedure codes A01, A02, A03 in any position
- Diagnosis codes G400-G419 inclusive in any position

SQL CODE THAT MAY/MAY NOT BE USEFUL

```
/*
Query:  Paediatric Epilepsy
```

```
Source: West Midlands SUS APC 2011/12
Base:   Registrant
Author: Martin Hart
Date:   31/07/2012
*/

USE [SUS IP]
GO
/* DELETE ANY PRE-EXISTING TABLES */
IF EXISTS (SELECT * FROM sysobjects WHERE id = object_id ('TEMP'))
  DROP TABLE TEMP
GO
IF EXISTS (SELECT * FROM sysobjects WHERE id = object_id ('SCRATCH'))
  DROP TABLE SCRATCH
GO

/* CREATE A TEMPORARY TABLE (TEMP) WITH A FLAG FIELDS FOR THE
RESULT SET */
SELECT
EpisodeID,
CommissionerCode,
CommissionerName,
ResponsiblePCT,
ProviderCode,
ProviderName,
NHSNumber,
AdmissionMethodCode,
PatientClassificationCode,
MonthEndOfSpell,
Diagnosis1,
Diagnosis2,
Diagnosis3,
Diagnosis4,
Diagnosis5,
Diagnosis6,
Diagnosis7,
Diagnosis8,
Diagnosis9,
Diagnosis10,
Procedure1,
Procedure2,
Procedure3,
Procedure4,
Procedure5,
Procedure6,
Procedure7,
Procedure8,
Procedure9,
Procedure10,
Cost,
```

```
PointOfDeliveryRS,
AgeOnAdmission,
CBSADerivedSpellHRGCode,
CBSADerivedSpellHRGDescription
INTO TEMP
FROM dbo.WMREG_IP_GEN_FCE_1112
GO

ALTER TABLE TEMP
ADD DIAGFLAG varchar (1) NOT NULL DEFAULT 'N'
ALTER TABLE TEMP
ADD PROCFLAG varchar (1) NOT NULL DEFAULT 'N'
ALTER TABLE TEMP
ADD AGEBAND varchar (5) NULL
GO

/* POPULATE THE FLAG FIELDS WHERE THE CONDITION(S) ARE TRUE */
UPDATE TEMP
SET DIAGFLAG = 'Y'
WHERE
LEFT (Diagnosis1,3) IN ('G40','G41') OR
LEFT (Diagnosis2,3) IN ('G40','G41') OR
LEFT (Diagnosis3,3) IN ('G40','G41') OR
LEFT (Diagnosis4,3) IN ('G40','G41') OR
LEFT (Diagnosis5,3) IN ('G40','G41') OR
LEFT (Diagnosis6,3) IN ('G40','G41') OR
LEFT (Diagnosis7,3) IN ('G40','G41') OR
LEFT (Diagnosis8,3) IN ('G40','G41') OR
LEFT (Diagnosis9,3) IN ('G40','G41') OR
LEFT (Diagnosis10,3) IN ('G40','G41')

UPDATE TEMP
SET PROCFLAG = 'Y'
WHERE
LEFT (Procedure1,3) IN ('A01','A02','A07') OR
LEFT (Procedure2,3) IN ('A01','A02','A07') OR
LEFT (Procedure3,3) IN ('A01','A02','A07') OR
LEFT (Procedure4,3) IN ('A01','A02','A07') OR
LEFT (Procedure5,3) IN ('A01','A02','A07') OR
LEFT (Procedure6,3) IN ('A01','A02','A07') OR
LEFT (Procedure7,3) IN ('A01','A02','A07') OR
LEFT (Procedure8,3) IN ('A01','A02','A07') OR
LEFT (Procedure9,3) IN ('A01','A02','A07') OR
LEFT (Procedure10,3) IN ('A01','A02','A07')

UPDATE TEMP
SET AGEBAND = CASE
WHEN (AgeOnAdmission <=5) THEN '0-5'
WHEN (AgeOnAdmission >=6 and AgeOnAdmission <=18) THEN '6-18'
WHEN (AgeOnAdmission >=19) THEN '19+'
```

```
END

/* COPY THE RESULT SET FROM THE TEMPORARY TABLE INTO A TABLE
(SCRATCH) WHERE THE FLAG(S) IS/ARE TRUE */
SELECT * INTO SCRATCH
FROM dbo.TEMP
WHERE (DIAGFLAG='Y' AND PROCFLAG='Y') and AgeOnAdmission <=18
GO

/* DELETE THE TEMPORARY TABLE */
IF EXISTS (SELECT * FROM sysobjects WHERE id = object_id ('TEMP'))
  DROP TABLE TEMP
GO
```

ICD 10 codes for Epilepsy

G400	Locl-rel(foc)(part)idiop epilep/ epilptic syn seiz locl ons
G401	Locl-rel(foc)part)symp epilep/ epilptic syn simple part seiz
G402	Locl-rel(foc)part)symp epilep/epilptic syn complex part seiz
G403	Generalized idiopathic epilepsy and epileptic syndromes
G404	Other generalized epilepsy and epileptic syndromes
G405	Special epileptic syndromes
G406	Grand mal seizures, unspecified (with or without petit mal)
G407	Petit mal, unspecified, without grand mal seizures
G408	Other epilepsy
G409	Epilepsy, unspecified
G410	Grand mal status epilepticus
G411	Petit mal status epilepticus
G412	Complex partial status epilepticus
G418	Other status epilepticus
G419	Status epilepticus, unspecified

Appendix 3

SERVICE SPECIFICATION STANDARDS FOR EPILEPSY SURGERY

To be read in conjunction with Children's Neuroscience Network (for the neurosurgical child) – Framework and Standards for services in England - May 2013

Mandatory	These will be reviewed at 6 months to assess the effectiveness of implementation
Mandatory Orange	These will be reviewed at the end of the first year to assess progress
Yellow	These will be reviewed at the end of the second year
Green	Core NHS standards

Please note the following regarding the definition of a child:

1) When defining the appropriate age of children for these services, the Steering group decided to adopt the same approach as the National Service Framework for Children Young People and Maternity Services 2003:

   > Actual age is less important than the needs and preferences of the individual child or young person. In particular, the needs of adolescents require careful consideration. In general, adolescents prefer to be located alongside other people of their age who are more likely to meet their need for social interaction and this makes it is easier for staff to meet their needs for different forms of entertainment, education and additional privacy.

   The Steering Group recognised the particular challenges posed by young people who are developmentally delayed but agreed that local services should take account of the total needs of that young person and their family.

2) The Specialised Services National Definitions set (3rd Edition) Specialised Services for Children - Definition No. 23, page 4 describes codes for specialised paediatric services, with a child as 18years and below. This guidance is used for agreeing the payment by results tariff for specialised children's services. It goes on to say,

   "The age when it is appropriate for an adolescent to move from specialised paediatric services to adult services (whether specialised or non-specialised) will vary according to the individual and the circumstances of their illness, with most children being ready to move by the time they reach 17."

   The list of providers eligible for the additional top up payment for children's services is listed in the guidance spreadsheet.

   http://www.specialisedservices.nhs.uk/library/21/Specialised_Services_for_Children.pdf
   PBR guidance: Download 2011-12 tariff information spreadsheet - revised on 23 March (XLS, 3063K)

THE NETWORK APPROACH

In summary the model of care which is set out in the service specification describes the following:

- All epilepsy surgery for children as specified in Section 3.2 IV of this document will be performed at the new CESS centres and initially (during the development of the service) epilepsy surgery in children aged 5 years and under will only be performed in CESS centres outside Great Ormond Street after case discussion with Great Ormond Street Hospital CESS MDT.
- Where epilepsy surgery in children is being considered, all cases will have an initial Preliminary Clinical Review performed by the consultant paediatric neurosurgeons and paediatric neurologists at the CESS centres. They will review the clinical information and scans to advise the management of the child.
  - Further assessment and investigations, as a Pre-Surgical Review, may need to be undertaken at the CESS centres or at local
  - Children’s neurosurgical centres where expertise is available.
  - The results will be discussed by the CESS centre multi-disciplinary teams, involving local clinicians to agree the management plan.

A2	All National Children’s Epilepsy Surgery Service (CESS) centres will provide clear leadership for epilepsy surgery and Participate in their children’s neurosurgical clinical networks, with a formally nominated Clinical Lead and Lead Nurse in order to manage and develop further referral, care and treatment pathways, policies, procedures, performance monitoring and audit for epilepsy surgery, including relevant professional training and development in referring hospitals and primary care.
A3	All National Children’s Epilepsy Surgery Service (CESS) centres will be co-ordinated and reviewed nationally by NHS Commissioners; this will include comparative outcomes and measures as set out in this document, job plans and CPD activity of all consultant paediatric neurosurgeons and neurologists (involved in the CESS centres) including the number of annual surgical procedures undertaken by each consultant in each centre.
A4	The National Children’s Epilepsy Surgery Service (CESS) centres clinical leaders will develop and coordinate the formal Pathways for epilepsy. They will provide leadership and support for the work of the multi-disciplinary teams and ensure that the key processes appropriate to the local CESS network are established that cover the critical transition points along the pathway of care.
A5	All National Children’s Epilepsy Surgery Service (CESS) centres must provide comprehensive care which is linked to local services, other tertiary centres, nationally designated specialist services and demonstrate compliance with the

🟥	Requirements for networks for children's cancer.
A9	The National Children's Epilepsy Surgery Service (CESS) centres will develop a training plan for their networks, which will Build on best practice including awareness of symptoms requiring investigation, escalation and the mechanisms for this. This will inform the training plan for the Partnership Board of the Children's Neuroscience Networks
A10	There should be evidence of good communication covering the different levels of interactions between clinicians, and Between clinicians and parents / carers and between clinicians and children / young people. Protocols for communication will be developed and agreed with local referring paediatricians, paediatric neurologists, specialist nurses, clinical psychologists and patient groups.
A11	Children transferring between services will be accompanied by high quality information, including a health records summary (With the responsible clinician's name) and an on-going management plan agreed and shared with carers.
A12	All referring hospitals (specialist DGHs, other Children's Neurosurgical Centres, Children's Neurological Centres, Principal Treatment Centres and Adult Neurosurgical Centres) within the CESS epilepsy network must have imaging facilities and links, which allow for immediate transfer of images to the CESS centre.

B. MAKING CHOICES

B1	Information must be made available to children and their families in different formats. It must include information about the condition and the range of treatments appropriate to their needs at various points of the pathway. It should be clear, understandable, and culturally sensitive and evidence based.
B2	Parents/carers must be kept fully informed about their child's care (including care plan and progress) and be partners in decision making about their child's care. The family must be helped to understand the child's condition, the effect it may have on their child's health and future life and the treatment that they will receive. They must be encouraged to actively participate at every stage in their child's care.
B3	Patients, parents and carers whose first language is not English must be provided with appropriate interpreting and translation services.
B4	Where surgery is planned, the child and their parents or carers must have the opportunity to visit the centre and to meet the clinicians who will be responsible for their care, including an opportunity to discuss the planned operation with the consultant paediatric neurosurgeon with specialist interest and experience in epilepsy surgery. Agreement to proceed to planned procedures must be sought by the consultant in advance of the week of admission and

	The status of consent re-checked before the operation, reflecting that the process of consent is continuous.
B5	Parents, carers and all health professionals involved in the child's care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration, before or after surgical intervention and what steps they should take. They must have immediate 24- hour access to a member of the on call-team for advice, information and support if required. A clear view of the sharing of responsibility between the local team and the CESS centre needs to be given to the family.
B6	Parents and carers must be fully supported in obtaining further opinions when requested (both within the centre and from neurosurgeons and neurologists) outside the centre).

C. THE PATIENT AND FAMILY EXPERIENCE

C1	There must be dedicated clinical facilities that are designed around the needs of children (diagnostic, ward, theatre, staffing, support).
C2	Each child must have a named individual (specialist nurse/key worker) responsible for coordinating their care, and who acts as a liaison between the clinical team and the child throughout their care.
C3	Parents and carers must be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.
C4	Children, their parents and carers should be encouraged to provide feedback on the quality of care and their experience of the service, and they should be encouraged to participate in national Patient Reported Outcome/Experience Measures (PROMS) and patient experience measures and surveys. Centres must make this feedback openly available, and they must demonstrate how they take this feedback into account when planning and delivering their services.
C5	CESS centres must support patient and family support groups and networks. The key worker/specialist nurse should provide children and their families/carers with information about how to get in touch with patient groups. Additional information should be available for families on support groups and other parents who are willing to share their experiences

C6	CESS centres must provide facilities that are easy and convenient for parents and carers to use. Facilities and support include: sufficient accommodation for a member of the family to stay at the hospital and for parents to stay with their child in the ward 24 hours per day when appropriate, access to refreshments, and to be able to play and interact with their child (and their other children). There must be a quiet room available on the ward or centre completely separate from general family facilities. Access to care should not be inhibited by problems of parking facilities or cost.
C7	There should be access to culturally appropriate support services including faith support, social workers, interpreters, clinical psychologists benefits advice and bereavement counsellors. These should be made available at the specialist centre and links to facilitate this at a local level should also be developed.
C9	Children should have access to general resources including toys, books, magazines, computers and other age-appropriate activity coordinated by play therapy teams.
C10	Staff in the multidisciplinary team should receive training in communication with children, young people and parents, which shall include training in conveying difficult information in a sympathetic way.
C11	Parents, carers and support groups will be regularly updated with appropriate information on issues of clinical governance and the results of local and national audits

D. ACCESS TO SERVICES

D1	All children must have access to consultant paediatric neurosurgical advice and care on a 24 hour, 7 days per week basis, with a formal designated rota which is widely shared and understood within the network of referring hospitals. A management plan for *the* acutely ill child must be agreed within an hour. All new admissions for epilepsy surgery must be assessed by a consultant paediatric neurosurgeon with experience in epilepsy surgery or consultant neurologist within 24 hours of admission and all children requiring neurosurgical input (including ward, HDU and PICU) must be reviewed daily by a paediatric neurosurgeon. All patients must have a clearly designated Lead Consultant for their care in hospital and this includes patients undergoing invasive recording.
D2	Relevant middle grade paediatric cover must be available on-site 24/7. Middle grade neurosurgical cover must be available within 30 minutes 24 hours a day.

	A paediatric resuscitation team must be available on site 24/7.
D3	Each CESS centre will be co-located with a paediatric intensive care unit and there must be access to a defined neurosurgical high dependency care area. (This is red/mandatory relationship within the DH framework of critical inter-dependencies 2008[3])
D4	Each CESS centre will have paediatric anaesthesia co-located with paediatric neurosurgery. (This is red/mandatory relationship within the DH framework of critical inter-dependencies 2008) Paediatric anaesthetists must demonstrate that they have continuing experience in paediatric neuroanaesthesia and with special reference to epilepsy surgery.
D5	Each CESS centre will be co-located with 24/7 paediatric neurology services (This is a red/mandatory relationship within the DH framework of critical inter-dependencies 2008) and must include appropriate early rehabilitation services.
D6	The CESS centre must be able to provide specialist services in accordance with the Framework of Critical Inter-Dependencies[4].
D7	The CESS centre must have access to a full range of diagnostic equipment: • Computed Tomography (CT) Scanner, including CT angiography – this must be available at all times (24/7 access) and with quick access to the CT scanner from the neurosurgery theatre/s and from the paediatric intensive care unit (PICU) such that a scan must be completed and reported within 60 minutes of a request, where clinically indicated. • Magnetic Resonance Imaging (MRI) scanner – available at all times (24/7 access) • Functional Magnetic Resonance Imaging - available from Monday to Friday within normal working hours (5 day access) It would be highly desirable for the centre to have access to a High gradient 3T neuro-optimised scanner with functional Magnetic Resonance Imaging – with capacity to undertake spectroscopy. All out-patient neuro-imaging (including GA MRI scans) must be completed according to National neuro-radiological standards, or within current NHS wait-time targets.
D8	The CESS centre must have access to a full range of diagnostic procedures:

---

[3] Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008

[4] Department of Health, *Commissioning Safe and Sustainable Specialised Paediatric Services: A framework of Critical Inter-Dependencies*, August 2008

	• Biplane angiography & interventional neuroradiology – available 5 days a week from 9 am to 5 pm (7 day access desirable) • EEG Electroencephalography – available 7 days a week • EEG Videotelemetry – should be available as a minimum 5 days a week • for invasive recording with intracranial monitoring, EEG video-telemetry must be 24 hours and 7 days per week throughout the period of recording. A Clinical Neurophysiologist must also be available within this period. • Interictal sleep EEG recording • MRI with specified protocols including serial scans • Neuropathology reporting service - available from Monday to Friday from 9 am to 5 pm (5 day access) and available for frozen section and smears Neuropathology reporting service - available (as a minimum) from Monday to Friday from 9 am to 5 pm (5 day access) and available for frozen section and smears. This should be reported by neuropathologists who can show evidence of current participation and satisfactory performance in the national neuropathology ECQ scheme. There must be consultant radiology support available 24/7 for neuroradiological imaging and an ability to provide paediatric anaesthesia for GA scans to a standard specified by the Royal College of Anaesthetists.
D9	The CESS centre must have access to a full range of intraoperative techniques: • EEG/cortical monitoring - 5 day access • Evoked potentials - 5 day access • Intraoperative image guidance system 24/7 access • Neuro-endoscopy - 24/7 access • Imaging ultrasound - 24/7 access • Ultrasonic aspirator - 24/7 access • Operating microscope – 24/7 access • High speed surgical drill – 24/7 access
D10	The CESS centre must have access to: • Single Photon Emission Computed Tomography (SPECT) and Positron Emission Tomography (PET), 3T MRI, MEG, tractography • Intraoperative MRI, CT and advanced intraoperative ultrasound (5 day access)

D11	All children requiring neurosurgical investigation, treatment and care must receive that care from *staff trained in looking after children* and *trained specifically in neurosciences* according to the requirements for their profession/discipline. Children must be admitted to a dedicated neurosurgical ward or a neuroscience ward, which is staffed by nurses trained in the care of children with acute neurological problems including children with complex epilepsy investigations, monitoring, and surgery. This is in accordance with the RCN (2011) Health care service standards in caring for neonates, children and young people, London: RCN and RCN (2003) Defining safe staffing levels for children and young people's services, London: RCN .
D12	CESS centres must ensure that they plan sufficient capacity (resources and bed capacity) to accommodate expected and unpredictable peaks in demand. Neurosurgical and neuroscience epilepsy patients must not be "lodged" on wards staffed by nurses who are not trained in the care of these children ; support and advice from staff with the relevant expertise must be available at all times.
D13	Children requiring high dependency level care (HDC) must be looked after within a high dependency unit or within a paediatric intensive care unit (PICU) – providing that the HDU capacity is protected and not disadvantaged by surges in PICU requirements. All hospitals admitting children for neurosurgical care must be able to deliver HDC. Children requiring HDC must be looked after by nurses who have received formal training in HDC, and with a nurse to patient ratio of 1:2 (or 1:1 if the patient is looked after in a single occupancy cubicle) in line with "Health care service standards in caring for neonates, children and young people" (Royal College of Nursing 2011) and "Defining staffing levels for children and young people's services" (Royal College of Nursing 2003). Children requiring HDC must be reviewed by both paediatric neurosurgical and medical (general paediatrics, paediatric neurology, and PICU or paediatric anaesthesia) teams, with consultant-led ward rounds at least twice a day. There must be access to on-site middle grade paediatric cover, and if required an anaesthetic / PICU registrar, at all times. Episodes of HDC must be documented on a daily basis using the Paediatric Critical Care Minimum Dataset (PCCMDS). Data must be submitted by Trusts to the Secondary User Service (SUS).
D14	All paediatric epilepsy neurosurgery (for a planned operation or for an emergency procedure) must be carried out in a dedicated theatre specifically equipped and staffed for paediatric neurological surgery. This will occur in a paediatric theatre suite. CESS centres must ensure that they have sufficient theatre capacity for children requiring both planned and unplanned operations
D15	CESS centres must provide sufficient theatre capacity and related resources to ensure a low cancellation rate for planned operations. The cancellation rate must be no more than 0.5% over a 6month period and there must be immediate access to a theatre for life-threatening cases.

D16	Theatres will be equipped with the specialist equipment required for paediatric epilepsy neurosurgery. This includes a specialist table and headrest, an image-guidance system, ultrasonic aspirator, imaging ultrasound, EEG, spinal cord monitoring, and at least one theatre must be equipped with C-arm X-ray imaging.
D17	Paediatric anaesthetic cover must be provided according to standards set out in Appendix B of the children's neuroscience networks specification standards
D18	Paediatric Intensive Care Units must comply with the PICS (Paediatric Intensive Care Society) Standards and the RCN (2011) Health care service standards in caring for neonates, children and young people)
D19	Paediatric Intensive Care Units must have sufficient capacity (beds, staff, equipment, transport) to meet the needs of their catchment population and to accept all emergency paediatric neurosurgical referrals in their catchment area.,
D22	CESS centres must have access to consultant paediatric neuro-oncology opinion 7 days a week. A paediatric neuro-oncologist is defined as a paediatric oncologist who is on the GMC specialist Register for Paediatrics (Paediatric Oncology). The preferred model would be for Principal Treatment centres for children's cancer dealing with brain tumours, to be co-located with CESS centres. Oncology (inc haemato-oncology) has an Amber 3* relationship according to "A Framework of Critical Inter-Dependencies" which is essential to provide a full specialised service. There must be discussion between the oncologist and surgeon of the management plan for all tumour cases on presentation.
D23	CESS centres providing specialist care will have a nurse specialist/s covering each of the relevant areas : o Epilepsy and epilepsy surgery
D25	CESS centres will ensure that, as a minimum, the on-site multi-disciplinary team includes the following specialist staff members with specialised training in managing patients with complex epilepsy including: • Paediatric epileptologist. (This is a paediatric neurologist who had done an epilepsy fellowship, or spent a period of training in an epilepsy surgery centre). • Paediatric Neurosurgeon with expertise in paediatric epilepsy, • Neurophysiologist and clinical neurophysiologists with an expertise in paediatric neurophysiology, • Neuroradiologist with expertise in paediatric neuroradiology, • Paediatric neuropsychology, • Paediatric neuropsychiatrist, • Paediatric neuroanaesthetist, neuropathologist and paediatric ophthalmologist

	• Children’s epilepsy specialist nurse, • Opthalmologist • Occupational therapist • Speech and language therapist • Physiotherapists • Play therapist • Dietician • Social worker • Data collection manager • Paediatric pharmacist – access to advice at all times • Hospital school teacher – access to service.
D26	Children and families should have the opportunity to have their child’s mental health needs assessed as part of the pre-surgical evaluation, and be offered brief, focused treatment as appropriate, in conjunction with local services.
D27	Each CESS centre will have access to dedicated neuro-rehabilitation facilities either on site or as part of the care pathway; they will be responsible for managing the early rehabilitation plan. The CESS centre will provide early involvement of rehabilitation and neuropsychology teams in assessing a child’s and family’s needs in a care package and in conjunction with the local CNC will agree the ongoing rehabilitation and aftercare required by the child and their family. Transition arrangements will be in place for age appropriate continued follow up.
D31	Electrodes for invasive recording can only be inserted in children as part of the assessment and management plan agreed by the CESS centre MDT. They must be inserted by paediatric neurosurgeons with the relevant skills and experience (in line with standard D1 and G1). The relevant MDT skills need to be available to ensure that there is the ability to stimulate the electrodes for functional mapping and to examine the cortex and interpret the results. For clinical governance purposes a clear decision of the lead clinician for this admission needs to be made. All children with intracranial electrodes should be nursed on an individual basis within a single room with video telemetry equipment and continuous EEG and event monitoring. Where a single room is not available they should be nursed in an appropriate bay which maintains the privacy and dignity of the child and their family. They should be nursed by appropriately skilled paediatric neurosurgical nurses on a 1:1 basis for the whole of their monitoring period.

🟥	The child should be reviewed at least daily by the multidisciplinary team comprising the paediatric neurosurgeon, paediatric neurologist, and neurophysiologist and clinical physiologist who have the skills and experience in monitoring and reviewing the child’s condition with specific reference to complications. A clear plan for the invasive monitoring needs to be made prior to the recording and be reviewed regularly, on a daily basis, throughout the process. Prior to the completion of Invasive Monitoring and removal of the electrodes the information should be presented to appropriate members of the MDT and recommendations made to the child and their family about the results of the recording and stimulation, the team decisions based on these findings and clear information about risks and benefits of any resective or disconnected surgery recommended.

E. AGE APPROPRIATE CARE

E1	Planning the transition from children’s to adult services should start at 16 years of age. There should not be a fixed age for transition from children’s to adult services which will vary according to the needs of the child and their family. CESS centres will be responsible for developing a transition plan that will include the close involvement of the adult neurosurgeon and neurologist; full discussion with the child/adolescent and their parents/carers about the clinical issues their views, opinions and feelings. During the period of transition continuity of care with the paediatric neurosurgical team will be maintained if this is required, This should also be in accordance with RCN (2004) Adolescent transition care. Guidance for nursing staff, London: RCN and RCN (2011) Health care service standards in caring for neonates, children and young people, London: RCN
E4	The patient’s management plan must be reviewed at each consultation to make sure that it continues to be relevant to their particular stage of development.
E5	Young people should have the opportunity to be seen by the consultant for part of the consultation without a parent being present.

G. EXCELLENT CARE

G1	Children must be treated by a paediatric-trained neurosurgeon. A paediatric neurosurgeon is defined as a consultant neurosurgeon who has undertaken a one-year recognised Fellowship in a recognised paediatric neurosurgical centre as recommended in Safe Paediatric Neurosurgery (2001). Where this fellowship is undertaken overseas this should be

	Approved by BPNG/SBNS. This standard will be applied to all new appointments, and it is acknowledged that some existing consultants with substantial paediatric practice may not have undertaken formal fellowships. Paediatric neurosurgery consultants undertaking epilepsy must have undertaken a period of attachment to a recognised epilepsy surgery centre either in the United Kingdom or abroad. A substantial proportion of the consultant’s job plan must be allocated to paediatric neurosurgery. It is recommended that this should translate into being involved in at least 50 operative cases per year, although it is accepted that this individual operative workload may vary with some PNS doing significantly more than this within a CNC team with particular paediatric or adult sub-specialist interests. There must be evidence of regular, validated (officially recognised), funded Continuing Professional Development (CPD) in children’s neurosurgery. The consultant should have routine and emergency access to dedicated paediatric beds, regular dedicated paediatric neurosurgical operating lists and dedicated paediatric outpatient clinics; working within a department with other paediatric neurosurgeons who participate in structured national audit programmes and data collection for children’s neurosurgery. It should be noted that all qualified neurosurgeons are competent to undertake lifesaving care for children in an emergency situation.
G2	There will be dedicated time allocated within consultant paediatric neurosurgeon’s job plan for training of junior staff, update education of adult neurosurgeons within the network and mentoring of new consultant paediatric neurosurgeons.
G5	CESS centres will develop and maintain a training Programme and training register for all members of the multi-disciplinary team. This training would include the care of children with complex epilepsy. All members of the multi-disciplinary team will take part in continuing education and continuing professional development.
G8	Children should be anaesthetised by an anaesthetist or anaesthetists with the appropriate paediatric and neuroanaesthesia competencies (in line with appendix B) of the Children’s Neuroscience Network (for the neurosurgical child) Specification Standards October 2012.
G9	Within each CESS centre, there must be a lead radiologist with a special interest in paediatric neuro-radiology who is responsible for arranging cover of the relevant MDTs, prioritising imaging protocols (in accordance with national guidelines and studies). Such a post must allow provision for appropriate CPD. CESS centres must ensure there is access to GA imaging in a timely fashion and relevant training for staff.

G10	All clinical teams will operate within a robust and documented clinical governance framework that includes morbidity and mortality reviews, clinical incident reporting and review, clinical audit and improvement measures.
G11	All CESS centres must undertake an annual audit of clinical outcomes, using appropriate benchmark comparators, and must produce a report for the clinical network and the host commissioner. The annual audit of clinical outcomes must include all cases operated on. The proposed performance and outcome measures for each subspecialty are set out below. Results will be monitored and compared against national outcome statistics in particular 30 day mortality figures, and 30 day readmission rates for all Paediatric Neurosurgical cases. Action plans will be developed and improvements made.
G16	CESS centres will monitor performance and outcomes using the following measures: • Mortality (peri-surgical and late) with cause • Peri-operative surgical morbidity (within 30 days) • Late surgical morbidity • Seizure outcome 1 and 5 years (related to procedure and pathology) • Neurological outcome (Better/no change/worse /expected/unexpected) • Neurodevelopment/cognitive/neurobehavioral outcome at 2 and 5 years (better/no change/deterioration) • Re-operation rate • Quality of life • Patient satisfaction.
G18	CESS centres must contribute to existing/new national databases, registries and audits, with defined minimum data sets, including: • Registration of patients to the Children's Cancer and Leukaemia Group • Shunt registry • Paediatric Intensive Care Audit Network data • British Paediatric Neurosurgical Group (BPNG) basic numbers audit and morbidity / mortality audit.
G19	Systems will be in place to allow the managed introduction of new treatments and techniques into the centre. Centres will follow mandatory NICE guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance[5].

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[5] A summary of how NICE develops interventional procedures guidance is available at www.nice.org.uk/guidance

G20	CESS centres will collaborate nationally at a clinical, audit, research and administrative level, and will take part in formal inter-unit and network peer review. For research activity there must be a focus on contributing to a few high-quality multi-centre epilepsy research projects, rather than single centre case series. All CESS centres nationally with academic links will be expected to initiate and coordinate studies and collaborate together on research-proposals.