Cyd-bwyllgor
Comisiynu
Joint Commissioning
Committee

Children's Epilepsy Surgery Services

Commissioning Policy: CP174

Document Information	
Document Name	Children's Epilepsy Surgery Services (CESS)
Document No	CP174
Document Purpose	Commissioning Policy
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Commissioning Team Author	Women & Children
Target Audience	Chief Executives, Medical Directors, Directors of Finance, Paediatric Neurologists, Paediatricians, Neurosurgeons
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document Update Information	Hyperlinks and references updated. Content updated following stakeholder comments.

Contents

Abbreviations

AEDs	Anti-epileptic drugs
CESS	Children’s Epilepsy Surgery Services
EEG	Electroencephalography
IPFR	Individual Patient Funding Request
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NICE	National Institute for Health and Care Excellence
NWJCC	NHS Wales Joint Commissioning Committee
PET	Positron Emission Tomography
SUDeP	Sudden Unexpected Death in Epilepsy
VNS	Vagus nerve stimulation

Policy Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission Children’s Epilepsy Surgery Services (CESS) in accordance with the criteria outlined in this document.

In creating this document NWJCC has reviewed this clinical condition and the options for its treatment. It has considered the place of this treatment in current clinical practice, whether scientific research has shown the treatment to be of benefit to patients, (including how any benefit is balanced against possible risks) and whether its use represents the best use of NHS resources.

Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the Welsh Language (Wales) Measure 2011 and the Welsh Language Standards (No.7) Regulations 2018.

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient’s needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgement, knowledge and expertise when deciding whether it is appropriate to apply this policy.

This policy may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

NWJCC disclaims any responsibility for damages arising out of the use or non-use of this policy.

1. Introduction

This policy has been developed for the planning and delivery of Children's Epilepsy Surgery Services (CESS) aged up to 16 years for people resident in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to residents of all seven Health Boards in Wales.

1.1 Plain Language Summary

Epilepsy is a common neurological disorder characterised by recurring seizures. A seizure happens when there is a sudden burst of intense electrical activity in the brain. There are many different types of seizure depending on which part of the brain is affected, and how far the seizure activity spreads.

Different types of epilepsy have different causes. Possible causes of epilepsy include:

- Brain damage, for example damage caused by a stroke, head injury or infection
- Brain tumours
- Problems with the way the brain developed in the womb
- Genetic factors

However, in over half of all people with epilepsy, there is no known cause[1].

The main way for epilepsy to be controlled is with anti-epileptic drugs (AEDs). Two-thirds of people with active epilepsy have their epilepsy controlled satisfactorily with AEDs. For people whose epilepsy is not satisfactorily controlled with AEDs, other approaches may include surgery.

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)[2].

According to research, for drug-resistant epilepsy, surgery is more effective than continued medical treatment in achieving seizure freedom, a better quality of life, and potentially coming off anti-seizure medications[3].

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[1] Epilepsy Action

[2] NHS England Service Specification Children's Epilepsy Surgery Service January 2018

[3] Surgery for pediatric drug resistant epilepsy: a narrative review of its history, surgical implications, and treatment strategies George W Koutsouras, Walter A Hall, Translational Pediatrics 2023 Feb 13;12(2):245–259

1.2 Aims and Objectives

This policy aims to define the commissioning position of NWJCC in accessing Children's Epilepsy Surgery Services (CESS).

The objectives of this policy are to:

- ensure commissioning for the use of Children's Epilepsy Surgery Services is evidence based
- ensure equitable access to Children's Epilepsy Surgery Services.
- define criteria for people with Children's Epilepsy Surgery Services to access treatment
- improve outcomes for people with Children's Epilepsy Surgery Services.

1.3 Epidemiology

Epilepsy affects around one in every 100 people in the UK. One in every 220 children under 18 will have a diagnosis of epilepsy. That is an average of two children with epilepsy in every primary school and nine in every secondary school[4].The prevalence of epilepsy, which is proportional to the degree of socio-economic deprivation, is higher in South Wales than much of the UK[5].

Individuals living with chronic epilepsy face significant barriers that affects their quality of life, including physical and psychological health risks, socioeconomic status, academic achievement, fewer employment opportunities and income. Research has indicated that epilepsy prevalence is higher in the most socially deprived areas compared to the least socially deprived areas[6] and approximately one fifth of the population who have an epilepsy diagnosis will have co-existing learning or intellectual disabilities. This evidence emphasises the importance of identifying suitable patients and providing them with the appropriate interventions at the earliest opportunity, to reduce the negative implication of seizures on their health, social factors, educational achievement and wellbeing.

Sudden Unexpected Death in Epilepsy (SUDEP) is rare, affecting around 1 in 1,000 adults with epilepsy each year[7]. In the past, studies seemed to show that the risk of SUDEP was less common in children than in adults. But some newer research now suggests that the risk might be about the same as for adults. Some children will be more at risk than others, but we don't know as much about SUDEP risk in children as we do for adults.[8] Although

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[4] Epilepsy Action

[5] The incidence and prevalence of epilepsy in the United Kingdom 2013–2018: A retrospective cohort study of UK primary care data, Wigglesworth et al, European Journal of Epilepsy, 2023-02-01, Vol 105, P 37-42

[6] Epilepsy and deprivation, a data linkage study, William O. Pickrell et al, Epilepsia, March 2015

[7] A systemic review of sudden unexpected death in epilepsy (SUDEP) in childhood, Omar Abdel-Mannan et al, Epilepsy & Behaviour, 2019-01-01, Vol 90, P99-106

[8] Epilepsy Action SUDEP and epilepsy related deaths

inroads have been made with respect to our understanding of SUDEP pathophysiology, it remains largely unknown. Paediatric-specific SUDEP studies are also limited, as is our knowledge of childhood-specific risk factors. Furthermore, we are still unable and limited in our ability to predict the individualized risk of SUDEP accurately. Adequate control of convulsive seizures using medical and surgical therapies, lifestyle changes, and possibly nocturnal supervision are the main preventive strategies at this time[9].

1.4 Current Treatment

The NICE Guideline for epilepsies in children, young people and adults (NG217)[10] makes recommendations on the diagnosis, treatment and management of epilepsy and seizures in children, young people and adults in primary and secondary care. The main way for epilepsy to be controlled is with anti-epileptic drugs (AEDs). NICE states that the AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and comorbidity, the child, young person or adult's lifestyle, and the preferences of the person, their family and/or carers as appropriate.

Psychological interventions

Psychological interventions (relaxation, cognitive behaviour therapy) may be used in children and young people with drug-resistant focal epilepsy. Psychological interventions may be used as adjunctive therapy. They have not been proven to affect seizure frequency and are not an alternative to pharmacological treatment.

A ketogenic diet

A ketogenic diet is a specialist diet which is high in fat but lower in carbohydrates and protein than a typical diet. It can be considered by a specialist for children and young people with epilepsy whose seizures have not responded to appropriate AEDs.

Vagus nerve stimulation (VNS)

Vagus nerve stimulation (VNS) therapy involves a small electrical device, like a pacemaker being implanted under the skin of the chest. The device sends electrical impulses to the brain through the vagus nerve in the neck. VNS is indicated for use as an adjunctive therapy in reducing the frequency of seizures in children and young people who are refractory to antiepileptic medication but who are not suitable for respective surgery. This includes children and young people whose epileptic disorder is dominated by focal seizures (with or without secondary generalisation) or generalised seizures.

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[9] Sudden unexpected death in epilepsy in children, Robyn Whitney, Suvasini Sharma, Rajesh Ramachandrannair, Developmental Medicine & Child Neurology, P1134-1135, 17th February 2023

[10] Epilepsies in children, young people and adults, NG217, updated 30th January 2025

Cannabis based medicinal products and Fenfluramine

Cannabis based medicinal products can provide therapeutic and medicinal benefits for people aged 2 years and older with particular types of epilepsy. The use of cannabidiol with clobazam is commissioned by the NWJCC for treating seizures associated with Dravet syndrome or Lennox–Gastaut syndrome[11]. Although it is not a cannabis based medicine, fenfluramine is commissioned for treating seizures associated with Dravet syndrome or Lennox–Gastaut syndrome. Cannabidiol is also commissioned for treating seizures caused by tuberous sclerosis complex in people aged 2 years and above[12].

1.5 Proposed Treatment

The NICE guideline NG217 states that all children and young people with epilepsy should have access via their specialist to a tertiary service when circumstances require. If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, children and young people should be referred to tertiary services for further assessment.

For complex or refractory epilepsy in children and young people, the Children's Epilepsy Surgery Service (CESS) is commissioned by the NWJCC for children from Wales to provide specialist epilepsy pre-surgical evaluation and surgery. Surgery can only be carried out in a designated CESS.

Epilepsy surgery

There are many different types of surgical epilepsy treatment. These include:

- Focal resection - where a small damaged part of the brain is removed. If the part of the brain causing the seizures is in the temporal lobe, the surgery is called a 'temporal' resection. If the part of the brain causing the seizures is in one of the other lobes, it is called an 'extra-temporal' resection.
- Corpus callosotomy - where the 2 hemispheres of the brain are separated during surgery. It is mainly used for generalised seizures, particularly frequent drop attacks (tonic and atonic seizures), and myoclonic seizures that affect the whole body. It is also used for severe focal seizures that start in one hemisphere and spread to the other.
- Hemispherectomy/Hemispherectomy - major surgical procedures to remove or separate (disconnect) one half of the outer layer of the brain from the other. It is for children who have seizures because one half of their brain is badly damaged or not working properly. Removing one hemisphere is called an anatomical hemispherectomy. Sometimes the hemisphere is not removed, but completely disconnected from the rest of the brain. This is called a functional hemispherectomy.

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[11] PPS203 Drug treatments for seizures associated with Dravet syndrome or Lennox-Gastaut syndrome in people aged 2 years and older April 2025

[12] PPS272 Cannabidiol for treating seizures caused by tuberous sclerosis complex in people aged 2 years and above December 2023

1.6 What NHS Wales has decided

NWJCC has carefully reviewed the evidence of specialist paediatric epilepsy surgery services. We have concluded that there is enough evidence to fund the use of treatment, within the criteria set out in section 2.1.

1.7 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**

All Wales Policy: Making Decisions in Individual Patient Funding requests (IPFR).

- **NHS Wales Joint Commissioning Committee policies and service specifications**
  - PP272 Cannabidiol for treating seizures caused by tuberous sclerosis complex in people aged 2 years and above December 2023
  - PPS203 Drug treatments for seizures associated with Dravet syndrome or Lennox-Gastaut syndrome in people aged 2 years and older April 2025
  - CP23 Vagus Nerve Stimulation for adults, young persons and children, May 2024
  - SS50 Positron Emission Tomography - Computed Tomography (PET-CT)(Fixed and Mobile Site), March 2025

- **National Institute of Health and Care Excellence (NICE) guidance**
  - NG217 Epilepsies in children, young people and adults updated 30th January 2025
  - TA614 Cannabidiol with clobazam for treating seizures associated with Dravet syndrome published 18th December 2019
  - TA615 Cannabidiol with clobazam for treating seizures associated with Lennox–Gastaut syndrome published 18th December 2019
  - NG43 Transition from children's to adults services for young people using health or social care services published 24th February 2016

- **Relevant NHS England policies**
  - NHS England Service Specification Children's Epilepsy Surgery Service January 2018

2. Criteria for Commissioning

The NHS Wales Joint Commissioning Committee approve funding of Children's Epilepsy Surgery Services (CESS) for people resident in Wales up to their 16th birthday in a designated CESS in line with the criteria identified in the policy.

2.1 Inclusion Criteria

The paediatric neurology service will refer children and young people up to their 16th birthday for assessment for epilepsy surgery at a CESS[13] if they meet the following criteria:

- A recognised unilateral lesion.
- All children <24months, with evidence of focality or lateralisation.
- All children with epilepsy associated with congenital hemiplegia who has failed two 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, Rasmussen Syndrome; Hypothalamic Hamartoma.

2.2 Referrals to Children's Epilepsy Surgery

For patients requiring further investigation and consideration of surgery by a CESS team, approval from a NWJCC designated clinical gatekeeper is required.
Referrals to the CESS should 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.

Preliminary Clinical Review

A preliminary clinical review provides the initial clinical assessment of the patient in line with one or more of the parameters outlined in the inclusion criteria in section 2.1. Following the preliminary clinical review, a management plan is agreed between the CESS and the tertiary paediatric neurology service. 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.

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[13] These inclusion criteria mirror the access criteria listed in the NHS England Children's Epilepsy Surgery Service (CESS) service specification

Pre-surgical Evaluation

For children and young people where specialist treatment is indicated, a comprehensive specialist in-patient assessment and pre–surgical evaluation will be required following preliminary review.

The data resulting from the above evaluation will be discussed by the Epilepsy MDT[14] and a clinical decision made for the appropriate surgical treatment. Local services, the tertiary paediatric neurology service and the CESS should determine where each of the pre-surgical tests can be undertaken in accordance with the principle for care of children: as much care provided locally as possible and specialised when needed.

Pre-surgical Assessment

The pre-surgical assessment will incorporate:

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

Further information about the pre-surgical tests can be found in NICE NG217 and from Epilepsy Action.

Epilepsy Surgery

Cases that should have epilepsy surgery in a CESS[15] are:

- Hemispheric procedures, Invasive EEG monitoring, Surgery for Rasmussen syndrome, 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).

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[14] See NHS England Service Specification Children's Epilepsy Surgery Service January 2018 for further information

[15] 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.

- Callosotomy.

Reviewing and Monitoring

Ongoing reviews and monitoring will be agreed as part of the management plan shared with other services. Consideration of transition arrangements should be part of this where appropriate (see section 2.5).

2.3 Exclusion Criteria

Vagal Nerve Stimulation (VNS) is excluded from this policy. However, VNS should not normally be considered unless the case has been discussed at a CESS centre to ensure it is part of an appropriate management plan for the child.

Long-term follow-up care is not included in this document 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.

2.4 Acceptance Criteria

The service outlined in this policy is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP Practice in England, but includes patient's resident in England who are registered with a GP Practice in Wales.

2.5 Transition Arrangements

Transition arrangements should be in line with Transition from children's to adults' services for young people using health or social care services NICE guidance NG43 and The Transition and Handover Guidance from Welsh Government February 2022

Transition involves a process of preparation for young people and their families for their transition to adulthood and their transition to adult services. This preparation should start from early adolescence 12-13 year olds. The exact timing of this will ideally be dependent on the wishes of the young person but will need to comply with local resources and arrangements.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service.

The manner in which this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice taken into account together with individual health board and environmental circumstances factored in.

For the specialised paediatric services that it commissions, the JCC will routinely commission treatment up until a patient is 16 years old. The JCC does not commission specialised paediatric services for patients aged 18 years and older. For patients aged 16 or 17 years of age, the JCC will continue to commission ongoing specialised treatment initiated before the patient's 16th birthday and under the ongoing care of a specialised paediatric team.

2.6 Patient Pathway (Annex i)

Referrals to a CESS can be only be made by a tertiary paediatric neurology service where the patient has undergone a thorough evaluation of their epilepsy (see section 2.2) and meets the inclusion criteria in section 2.1.

2.7 Designated Centre

Patients meeting the criteria in section 2.1 can be referred and treated at any one of the four recognised Children's Epilepsy Surgery Service (CESS) centres in England. Where possible, referral to a treatment centre should be as close to the patient's home as possible.

CESS is currently provided at the following specialist centres:

Birmingham Children's Hospital
Steelhouse Lane
Birmingham
B4 6NH

Bristol Royal Hospital for Children
Department of Paediatric Neurology
Level 6 Research & Education Centre
Upper Maudlin Street
Bristol
BS2 8AE

Great Ormond Street Hospital for Children NHS Foundation Trust and King's College Hospital NHS Foundation Trust[16]

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[16] Surgery for children aged 5 years and under will be undertaken at Great Ormond Street Hospital for Children NHS Foundation Trust

Great Ormond Street Hospital
Great Ormond Street
London
WC1N 3JH

King's College Hospital
Denmark Hill
London
SE5 9RS

Alder Hey Children's NHS Foundation Trust (Liverpool) and Royal Manchester Children's Hospital (Central Manchester University Hospitals NHS Foundation Trust)[17]

Alder Hey Children's Hospital
Eaton Road
West Derby
Liverpool
L12 2AP

Royal Manchester Children's Hospital
Hathersage Road
Manchester
M13 0JH

2.8 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: Individual Patient Funding Requests

2.9 Clinical Outcome and Quality Measures

The Provider must work to written quality standards and provide monitoring information to the lead commissioner.

The centre must enable the patient's, carer's and advocate's informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

2.10 Responsibilities

Referrers should:

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[17] Surgery for children aged 5 years and under will be undertaken at Central Manchester University Hospitals NHS Foundation Trust

- inform the patient and/or their parent or guardian that this treatment is not routinely funded outside the criteria in this policy, and
- refer via the agreed pathway.

Clinicians considering treatment should:

- discuss all alternative treatments with the patient and/or their parent or guardian;
- advise the patient and/or their parent or guardian of any side effects and risks of the potential treatment
- inform the patient and/or their parent or guardian that treatment is not routinely funded outside of the criteria in the policy, and
- confirm that there is contractual agreement with NWJCC for the treatment.

In all other circumstances an IPFR must be submitted.

3. Evidence

NWJCC is committed to regularly reviewing and updating all of its commissioning policies based upon the best available evidence of both clinical and cost effectiveness.

3.1 References

Uldall, P., Alving, J., Hansen, L. K., Kibaek, M. & Buchholt, J. (2006). The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events; Archives of disease in childhood;91(3):219-21.

Engel J; McDermott P; Wiebe S; et al (2012); JAMA; Early Surgical Therapy for Drug Resistant Temporal Lobe Epilepsy - A Randomized Trial; vol 307, Article 9, P. 922-930

Manali Chitre (2013), Pitfalls in the diagnosis and misdiagnosis of epilepsy; Paediatrics and Child Health; Vol 23, Is 6, P237-242

(Liu JT, Liu B & Zhang H 2017) Surgical versus medical treatment of drug resistant epilepsy: A systematic review and meta-analysis, Epilepsy & Behaviour, 2018-05-01. Vol 82, P 179-188

Rizvi S; Ladino LD; Hernandez-Ronquillo L; Tellez-Zentano JF (2017), Epidemiology of early stages of epilepsy: Risk of seizure recurrence after a first seizure; Seizure: European Journal of Epilepsy, Vol 49, P46-53

Conte F.; Legros B; Van Paesschen W; Avbersek A; Muglia P; Depondt C (2018); Seizure:European Journal of Epilepsy; Long-term seizure outcomes in patients with drug resistant epilepsy; Vol 62; P74-78.

Epilepsy Action. Epilepsy facts, figures and terminology.

NHS England Service Specification Children's Epilepsy Surgery Service January 2018

Sudden unexpected death in epilepsy in children, Robyn Whitney, Suvasini Sharma, Rajesh Ramachandrannair, Developmental Medicine & Child Neurology, P1134-1135, 17th February 2023

World Health Organization, Epilepsy, 7th February 2024

Biset g, Abebae N, Gebeyehu NA, Estifanos N, Birrie E & Tegegne KB (2024); Prevalence, incidence, and trends of epilepsy among children and adolescents in Africa: a systematic review and meta-analysis, BMC Public Health 24, Article 771.

QS211 Epilepsies in children, young people and adults, published 20th December 2023

Young Epilepsy (2024); What I Need in School (WINS): The views of children with epilepsy, their caregivers and teachers.

3.2 Date of Review

This document is scheduled for review every three years, unless information is received which indicates that the policy requires revision.

If an update is carried out the policy will remain extant until the revised policy is published.

4. Equality Impact and Assessment

The Equality Impact Assessment (EIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable NHS Wales Joint Commissioning Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

5. Putting Things Right:

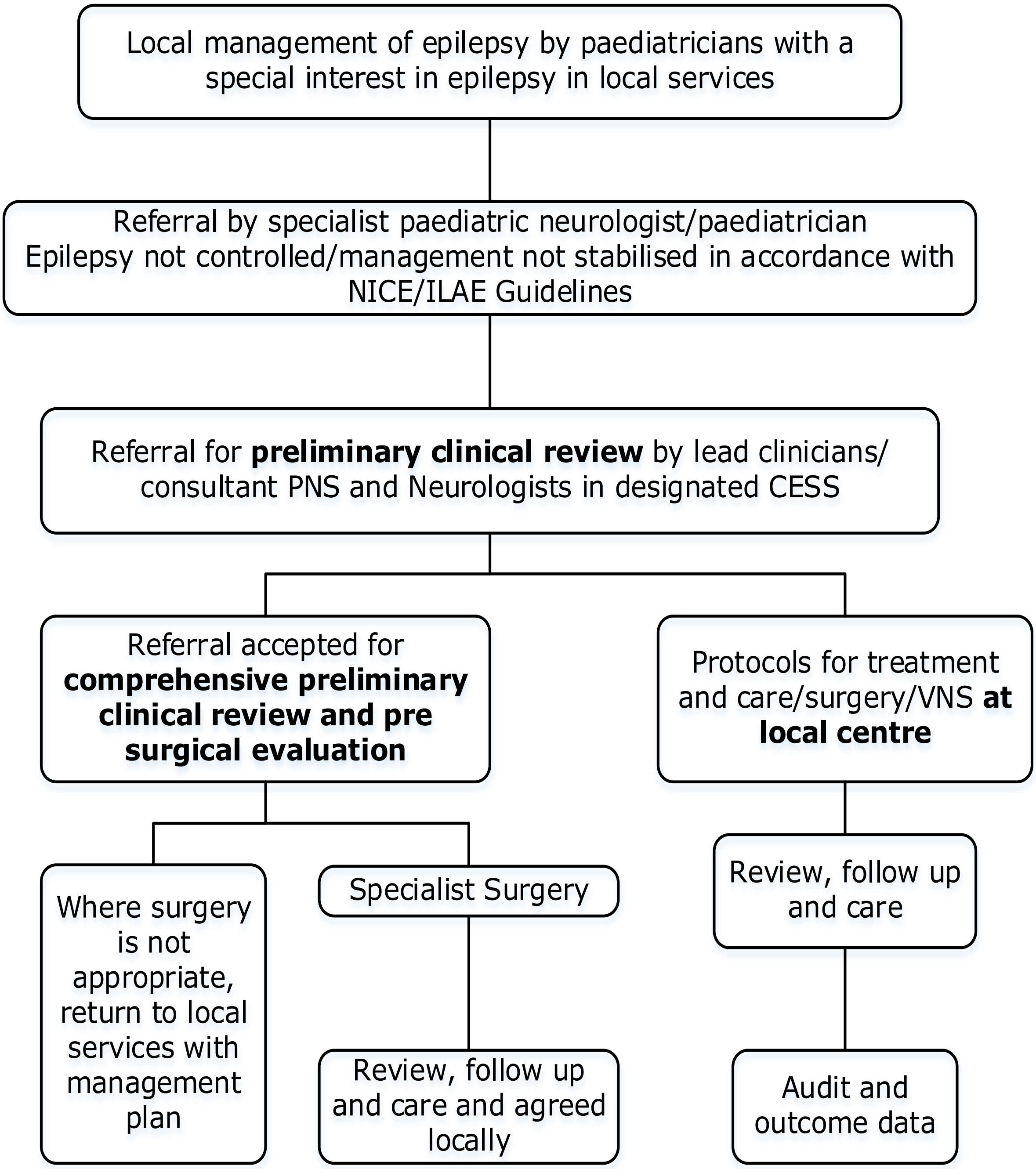
5.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for NHS Putting Things Right. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure, with a copy of the concern being sent to NWJCC.

Annex i Patient Pathway



Annex ii Codes

The list of ICD codes below is indicative and is not exhaustive. The ICD10 codes have been provided and verified by the Information Standards Team at Digital Health and Care Wales (DCHW). Additional codes may be used for contract monitoring purposes, furthermore some codes may cover indications not included within this policy.

Code Category	Code	Description
OPCS	A01 – A11	Y46 – Open approach to contents of cranium
		Y 47 – Burr hole approach to contents of cranium
		Y68.5 – Approach to organ under navigation guided control)
	A01.1	Hemispherectomy, Functional Hemispherectomy or Hemispherotomy
	A01.2	Total lobectomy of brain
	A01.3	Partial lobectomy of brain
	A01.8	Other specified major excision of tissue of brain
	A01.9	Unspecified major excision of tissue of brain
	A02.1	Excision of lesion of tissue of frontal lobe of brain
	A02.2	Excision of lesion of tissue of temporal lobe of brain
	A02.3	Excision of lesion of tissue of parietal lobe of brain
	A02.8	Other specified excision of lesion of tissue of brain
	A02.9	Unspecified excision of lesion of tissue of brain
	A04.1	Open biopsy of lesion of tissue of frontal lobe of brain
	A04.2	Open biopsy of lesion of tissue of temporal lobe of brain
	A04.3	Open biopsy of lesion of tissue of parietal lobe of brain
	A048.2	Awake brain surgery
	A07.1	Open division of tissue of brain
	A07.5	Multiple subpial transections
	A07.6	Complete callosotomy
	A07.7	Partial callosotomy
	A07.8	Other specified other open operations on tissue of brain
	A07.9	Unspecified other open operations on tissue of brain
	A09.1	Implantation of neurostimulator into brain
	A09.2	Attention to brain neurostimulator generator
	A09.3	Removal of neurostimulator from brain
	A09.4	Operation on neurostimulator in brain NEC

	A09.5	Insertion of neurostimulator electrodes into the brain
	A09.8	Other specified neurostimulation of brain
	A09.9	Unspecified neurostimulation of brain
	A10.8	Other specified other operations on tissue of brain
	A10.9	Unspecified other operations on tissue of brain
	A11.1	Placement of depth electrodes for electroencephalography
	A11.2	Placement of surface electrodes for electroencephalography
	A1.8	Other specified operations on tissue of brain
	A11.9	Unspecified operations on tissue of brain
	A20.1	Drainage of ventricle of brain NEC
	A20.8	Other specified other operations on ventricle of brain
	A20.9	Unspecified other operations on ventricle of brain
	A84.1	Electroencephalography NEC

Annex iii Glossary

Individual Patient Funding Request (IPFR)
An IPFR is a request to NHS Wales Joint Commissioning Committee (NWJCC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

NHS Wales Joint Commissioning Committee (NWJCC)
NWJCC is a joint committee of the seven local health boards in Wales. The purpose of NWJCC is to ensure that the population of Wales has fair and equitable access to the full range of Tertiary Services. NWJCC ensures that services within our portfolio are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.

Contact Us

If you have a question related to this document you can contact us using one of the methods outlined below.

If you would like this document in an alternative format and/or language, please contact us for assistance.

Email:

NWJCC consultation mailbox – NWJCC.consultation@wales.nhs.uk

Telephone:

General Enquiries – 01443 433112

Website:

Contact us - NHS Wales Joint Commissioning Committee

Writing:

If you wish to contact the NHS Wales Joint Commissioning Committee, you can write to us at one of our locations below, we welcome correspondence in Welsh or English:

South Wales Offices
Unit 1, Charnwood Court, Heol Billingsley, Nantgarw, CF15 7QZ
Unit G1 The Willowford, Main Avenue, Treforest Industrial Estate, Pontypridd, CF37 5YL

North Wales Offices
Unit 3, Media Point - Unit 3, Mold Business Park, Mold, CH7 1XY
Preswylfa, Hendy Road, Mold, CH7 1PZ