

Specialised Services Commissioning Policy: CP174

Children's Epilepsy Surgery Services

August 2022 Version 1.0







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Policy Statement

Welsh Health Specialised Services Committee (WHSSC) commission Children's Epilepsy Surgery Services (CESS) in accordance with the criteria outlined in this document.

In creating this policy WHSSC 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.

Disclaimer

WHSSC assumes that healthcare professionals will use their clinical judgment, 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 quardian.

WHSSC 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 for children resident in Wales up to their 16th birthday. This service will only be commissioned by the Welsh Health Specialised Services Committee (WHSSC) 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 cause¹.

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, epilepsy surgery is four times more likely to offer freedom from seizures than continued medical treatment alone³ and presents additional benefits such as improved quality of life and a greater likelihood of reduced or eradicated need for AEDs⁴.

¹ Epilepsy Action

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

³ (Schmidt & Stavem, 2009), <u>Surgical versus medical treatment for refractory epilepsy:</u> Outcomes beyond seizure control - Perry - 2013 - Epilepsia - Wiley Online Library

⁴ (Wiebe et al., 2001) <u>Surgical versus medical treatment for refractory epilepsy:</u> Outcomes beyond seizure control - Perry - 2013 - Epilepsia - Wiley Online Library

1.2 Aims and Objectives

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

The objectives of this policy are to:

- ensure equitable access to specialist paediatric epilepsy surgery services
- define the criteria for children with epilepsy to access surgical treatment
- ensure commissioning for the use of specialist paediatric epilepsy services, including CESS is evidence based
- improve outcomes for children with epilepsy.

1.3 Epidemiology

Epilepsy affects around one in every 100 people in the UK⁵. In children and young people (aged 0-17 years) the incidence of epilepsy is approximately 1 in 200. The prevalence of epilepsy, which is proportional to the degree of socio-economic deprivation, is higher in South Wales than the majority of the UK⁶.

Individuals living with chronic epilepsy face a number of 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 25% higher in the most socially deprived areas compared to the least socially deprived areas⁷ 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 year⁸. SUDEP is less common in children than in adults. It is estimated that each year, for every 4,500 children aged 17 and under with epilepsy, one will die from SUDEP⁹. This figure is for children with epilepsy in general, and some children will be more at risk

⁵ Epilepsy Action Cymru [Wales] | Epilepsy Action

⁶ Epilepsy Statistics, UK Parliament, Oct 2010,

https://researchbriefings.files.parliament.uk/documents/SN05691/SN05691.pdf

⁷ Gaitatzis A, Majeed A, Purcell B et al. (2002) Epilepsy prevalence and prescribing patterns in England and Wales. Health Statistics Quarterly 15: 23–31

⁸ <u>A systematic review of sudden unexpected death in epilepsy (SUDEP) in childhood - ScienceDirect</u>

⁹ https://www.epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy

than others. Not as much is known about the risk of SUDEP in children as in adults. However, a recent review of studies into SUDEP in children concluded that there is currently insufficient evidence to determine the aetiology of paediatric SUDEP and that current best practice to prevent paediatric SUDEP is to optimise the management of epilepsy¹⁰.

1.4 Current Treatment

The NICE Guideline for epilepsies in children, young people and adults (NG217)¹¹ 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 resective surgery. This includes children and young people whose epileptic disorder is dominated by focal seizures (with or without secondary generalisation) or generalised seizures.

¹⁰ A systematic review of sudden unexpected death in epilepsy (SUDEP) in childhood, Epilepsy and Behaviour January 2019

¹¹ NICE NG217 Epilepsies in children, young people and adults April 2022

Cannabis based medicinal products

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 WHSSC for treating seizures associated with Dravet syndrome or Lennox–Gastaut syndrome¹².

1.5 Proposed Treatment

The NICE guideline NG217¹³ 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 WHSSC for children from Wales to provide specialist epilepsy pre-surgical evaluation and surgery. Surgery can only be carried out in a 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 'extratemporal' 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/hemispherotomy 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 hemispherectomy. Sometimes the hemisphere is not removed, but completely disconnected from the rest of the brain. This is called hemispherotomy.

¹² See WHSSC <u>Policy Position Statement PP203 Cannabidiol with clobazam for treating seizures associated with Dravet syndrome or Lennox-Gastaut syndrome in people aged 2 years and older.</u>

¹³ <u>NICE NG217</u> Epilepsies in children, young people and adults

1.6 What NHS Wales has decided

WHSSC 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).

WHSSC policies and service specifications

- PP203 Cannabidiol with clobazam for treating seizures associated with Dravet syndrome or Lennox-Gastaut syndrome in people aged 2 years and older. Policy Position Statement, February 2021.
- o CP23 Vagal Nerve Stimulation. Commissioning Policy, August 2014.
- <u>CP50a Positon Emission Tomography (PET) Commissioning Policy</u>
 June 2022

National Institute of Health and Care Excellence (NICE) guidance

- NICE clinical guideline, <u>Epilepsies in children</u>, <u>young people and adults</u> (NG217), April 2022
- NICE technology appraisal <u>Cannabidiol with clobazam for treating</u> <u>seizures associated with Dravet syndrome</u> (TA614), December 2019
- NICE technology appraisal <u>Cannabidiol with clobazam for treating</u> <u>seizures associated with Lennox-Gastaut syndrome</u> (TA615), December 2019

• NHS England policies and service specifications

o Children's Epilepsy Surgery Service (CESS) (E09), January 2018

Other documents

The Transition and Handover Guidance. February 2019

2. Criteria for Commissioning

The Welsh Health Specialised Services 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 CESS¹⁴ if they meet the following 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 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.

2.2 Referrals to Children's Epilepsy Surgery

For patients requiring further investigation and consideration of surgery by a CESS team, approval from a WHSSC 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

 $^{^{14}}$ These inclusion criteria mirror the access criteria listed in the NHS England Children's Epilepsy Surgery Service (CESS) service specification

pathway/management plan, including the pre- surgical assessment at the CESS and any appropriate procedures to be carried out within defined protocols.

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 MDT¹⁵ 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 NG217¹⁶ and from Epilepsy Action¹⁷.

Epilepsy Surgery

Cases that should have epilepsy surgery in a CESS are 18:

- 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.

¹⁵ See <u>NHS England Service Specification Children's Epilepsy Surgery Services</u> for further information.

¹⁶ NICE NG217 Epilepsies in children, young people and adults April 2022

¹⁷ https://www.epilepsy.org.uk/info/treatment/epilepsy-surgery/children/tests

¹⁸ 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.

- Multilobular resections or disconnections.
- Lobar resections Cortical resections for malformations of cortical development (e.g. focal cortical).
- Dysplasia (polymicrogyria).
- Callosotomy.

Review 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.

Transition Arrangements

Transition arrangements should be in line with <u>Transition from children's to adults' services for young people using health or social care services NICE guidance NG43 and the Welsh Government Transition and Handover Guidance.</u>

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.

If surgery is likely to take place after the patient's 16th birthday, a discussion should take place with the adult epilepsy surgery service.

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 specification 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 patients' resident in England who are registered with a GP Practice in Wales.

2.5 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.

2.6 Designated Centres

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 Trust¹⁹

Great Ormond Street Hospital Great Ormond Street London WC1N 3JH King's College Hospital Denmark Hill London SE5 9RS

¹⁹ 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 (Liverpool) and Royal Manchester Children's Hospital (Central Manchester University Hospitals NHS Foundation Trust)²⁰

Alder Hey Children's Hospital Royal Manchester Children's

Eaton Road Hospital

West Derby Hathersage Road

Liverpool Manchester L12 2AP M13 0JH

2.7 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: Welsh Health Specialised Services Committee (WHSSC) | Individual Patient Funding Requests

2.8 Clinical Outcome and Quality Measures

Providers should work to written quality standards and provide monitoring information to the lead commissioner.

The centre should 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 for children, teenagers and young adults.

2.9 Responsibilities

Referrers should:

- inform the patient 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 the alternative treatment with the patient
- advise the patient of any side effects and risks of the potential treatment

 $^{^{20}}$ Surgery for children aged 5 years and under will be undertaken at Central Manchester University Hospitals NHS Foundation Trust

- inform the patient that treatment is not routinely funded outside of the criteria in the policy, and
- confirm that there is contractual agreement with WHSSC for the treatment.

In all other circumstances an IPFR must be submitted.

3. Evidence

WHSSC 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

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3.2 Date of Review

This document is scheduled for review before 2025 where we will check if any new evidence is available. If no new evidence or intervention is available the review date will be progressed.

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 (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services 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 reassignment, 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: Raising a Concern

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 WHSSC.

5.2 Individual Patient Funding Request (IPFR)

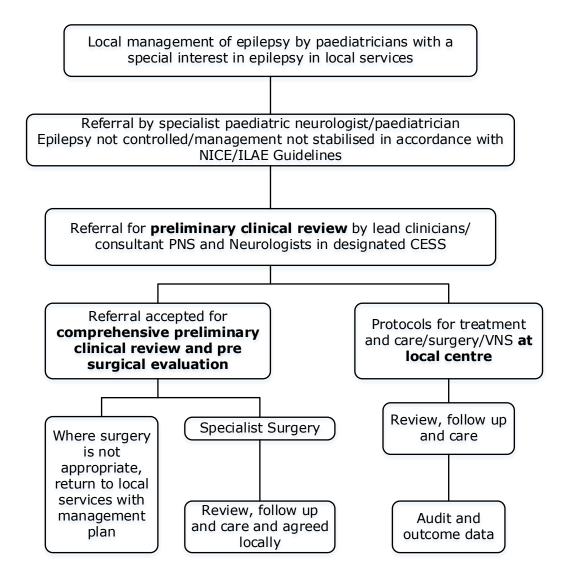
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All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

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

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

Further information on making IPFR requests can be found at: Welsh Health Specialised Services Committee (WHSSC) | Individual Patient Funding Requests

Annex i Patient Pathway



Annex ii Codes

Code Category	Code	Description
OPCS	A011	Hemispherectomy, Functional Hemispherectomy or Hemispherotomy
	A012	Total lobectomy of brain
	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

Code Category	Code	Description
	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

Annex iii Abbreviations and Glossary

Abbreviations

AEDs Anti-epileptic drugs

CESS Children's Epilepsy Surgery Services
IPFR Individual Patient Funding Request

MRI Magnetic Resonance Imaging

NICE National Institute for Health and Care Excellence
SUDeP Sudden Unexpected Death in Epilepsy (SUDeP)

VNS Vagus nerve stimulation

WHSSC Welsh Health Specialised Services Committee

Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

Welsh Health Specialised Services Committee (WHSSC)

WHSSC is a Joint Committee of the seven local health boards in Wales. The purpose of WHSSC is to ensure that the population of Wales has fair and equitable access to the full range of Specialised Services and Tertiary Services. WHSSC ensures that specialised services 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.