GIG CYMRU NHS WALES
Cyd-bwyllgor Comisiynu
Joint Commissioning Committee

Functional Neurosurgical Service for patients with movement disorders (for people aged 16 and over)

Service Specification: SS332

Document Name	Functional Neurosurgical Service for patients with movement disorders (for people aged 16 and over)
Document No	SS332
Document Purpose	Service Specification
Publication Date	August 2026
Version No	1.0
Commissioning Team Author	Neurosciences and Long-Term Conditions
Target Audience	Chief Executives, Medical Directors, Directors of Finance, Directors of Nursing, Consultant Neurologists, Care of the Elderly Consultants, Clinical Nurse Specialists, Directorate Manager and Lead Nurse – Neurosciences. Consultant Neurosurgeons, Parkinson's UK Wales, Dystonia Society, Care of the Elderly Parkinson's Disease Leads, Llais
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy

Contents

Abbreviations

AWMSG	All Wales Medicines Strategy Group
BMT	Best Medical Therapy
CT	Computerised tomography (CT) scanner
DBS	Deep Brain Stimulation
EIA	Equality Impact Assessment
FNS	Functional Neurosurgical Service
IPFR	Individual Patient Funding Request
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NWJCC	NHS Wales Joint Commissioning Committee
PD	Parkinson's Disease
PET	Positron Emission Tomography
SMC	Scottish Medicines Consortium
TcMRgFUS	Transcranial Magnetic Resonance Guided Focused Ultrasound
UCHL	University College Hospital London

Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission a Functional Neurosurgical Service for people aged 16 years and older with movement disorders including Parkinson's disease, tremor and dystonia for the management of movement disorders in patients whose symptoms are resistant to medical therapy in accordance with the criteria outlined in this specification.

In creating this document NWJCC has reviewed the requirements and standards of care that are expected to deliver this service.

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 document.

This document 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 document has been developed as the Service Specification for the planning and delivery of a Functional Neurosurgical Service (FNS) for people aged 16 and over registered with a general practice in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies all seven Health Boards in Wales and external providers within NHS England.

1.1 Background

Functional neurosurgery for movement disorders such as Parkinson's disease, tremor, and dystonia involves the placement of focal lesions or the application of Deep Brain Stimulation (DBS) within circuits that modulate motor function in people whose symptoms are resistant to medical therapy, aiming to restore neurological function and improve quality of life. These conditions are usually treated with drugs, but surgery may be considered for people who have responded poorly to drugs and/or who have severe side effects from medication.

Stereotactic neurosurgery uses imaging studies like MRI and/or CT, to identify discrete target locations and help guide the approach to the target area of the brain to treat movement disorders. Specific stereotactic treatment interventions include:

- Deep Brain Stimulation
- Radiofrequency Ablation Thalamotomy
- Focused Ultrasound
- Transcranial Magnetic Resonance Guided Focused Ultrasound (TcMRgFUS) Thalamotomy

DBS is a procedure in which stimulating electrodes are placed into a target area of the brain. The electrodes are connected to a battery powered implantable pulse generator, which is inserted under the skin of the chest wall[1].

Ablative stereotactic procedures (thalamotomy, pallidotomy, capsulotomy, cingulotomy) are performed in patients where DBS is not indicated or desirable.

Transcranial MR guided Focused Ultrasound thalamotomy is a new procedure for the treatment of Essential Tremor. This procedure uses focused ultrasound waves generated externally to the body that are directed to, and alter the function of, the VIM nucleus to improve tremor. This is done under magnetic resonance imaging (MRI) guidance. This is a non-invasive procedure that does not require the introduction or maintenance of

[1] https://www.england.nhs.uk/wp-content/uploads/2013/04/d03-p-b.pdf

hardware into the brain, avoiding the maintenance of the inserted hardware (i.e. battery replacement) and minimising the risk of bleeding within the skull, stroke and infection. This can be done as a day-case procedure.

1.2 Epidemiology

Parkinson's Disease

The prevalence of Parkinson's Disease increases with age and is higher for men than women. For men aged 50-89 years, prevalence is 1.5 times higher than for women in the same age-group. The results from the Clinical Practice Research Datalink Summary report[2] estimated that the prevalence of Parkinson's Disease for people over the age of 20 years in 2018, for the population of Wales would be in the region of 7,692. With an ageing population growth, the level of prevalence is likely to increase by 18% between 2018 and 2025.

It is estimated that 1-10% of those diagnosed with Parkinson's Disease would benefit from this procedure.

Tremor

The prevalence of essential tremor increases with age and is considered one of the most common neurological movement disorders. It is 20 times more prevalent than Parkinson' Disease. It is a slowly progressive chronic condition. It is characterised by involuntary, rhythmic tremor of a body part, most typically the hands and arms[3]. It affects around four in 100 adults over 40 years of age. Some people only have a mild tremor at first, which may get more severe over time.

Dystonia

Dystonia is a hyperkinetic movement disorder which causes involuntary spasms and contractions[4], impacting both physical and social functioning.

A retrospective population-based cohort study using anonymised electronic health care data in Wales was conducted to identify individuals with dystonia between 1 January 1994 and 31 December 2017. The trial developed a case ascertainment algorithm to determine dystonia incidence and prevalence in the Wales. Of the 54,966 cases identified 41,660 had adult onset idiopathic dystonia (>20 years). The median age at diagnosis was 41 years with males significantly older at the time of diagnosis compared to females. The prevalence rates ranged from 0.02% in 1994 to 1.2% in 2017. The average incidence

[2] https://www.parkinsons.org.uk/sites/default/files/201801/CS2960%20Incidence%20and%20prevalence%20report%20branding%20summary%20report.pdf
[3] How to spot a tremor
[4] NHS Direct Wales - Encyclopaedia : Dystonia

was 87.7/100,000 per year, increasing from 49.9/ 49.9/100,000/year (1994) to 96.21/100,000/year (2017)[5].

1.3 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering a functional neurosurgical service including DBS for the treatment of movement disorders which includes Parkinson's Disease, Tremor and Dystonia whose symptoms are resistant to medical therapy.

The objectives of this service specification are to:

- detail the specifications required to deliver a Functional neurosurgical service
- ensure that service delivery is informed by up-to-date high-quality training, guidelines and evidence
- ensure that service delivers safe and effective interventions and outcomes using recognised techniques such as continuous improvement cycles
- ensure that services have clear governance processes
- ensure that services are accessible, responsive and personalised to meet the needs of a diverse population and aim to equip service users to self-manage their long-term health conditions
- develop blended service models combining both in-person and virtual contacts, to enhance flexibility and capacity whilst maintaining quality of care
- ensure equitable access to a Functional neurosurgical service including Deep Brain Stimulation (DBS) for Welsh patients irrespective of geographical location
- ensure equitable waiting times for all patients.

1.4 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 (NWJCC) Service Specification: CP178 Neurosurgery (Adults)
  - NHS Wales Joint Commissioning Committee (NWJCC) Policy: PP258 Transcranial Magnetic Resonance Guided Focused-Ultrasound-(TcMRgFUS) Thalamotomy for treatment of medication refractory essential tremor for people aged 18 and over policy

[5] Adult-onset idiopathic dystonia: A national data-linkage study to determine epidemiological, social deprivation, and mortality characteristics - PubMed (nih.gov)

- **National Institute of Health and Care Excellence (NICE) guidance**
  - Deep Brain Stimulation for Parkinson's Disease. NICE Interventional procedures guidance [IPG19], November 2003.
  - Deep brain stimulation for tremor and dystonia (excluding Parkinson's disease) NICE Interventional procedures guidance [IPG188], August 2006.

- **Relevant NHS England policies**
  - Clinical Commissioning Policy: Deep Brain Stimulation (DBS) in Movement Disorders (Parkinson's Disease, Tremor and Dystonia), April 2013, Reference:NHSCB/D03/P/b.

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission access to a Functional Neurosurgical Service (FNS) including Deep Brain Stimulation (DBS) for people aged 16 and over in line with the criteria identified in this specification.

2.1 Access Criteria/Referrals

Referrals of patients for consideration of DBS surgery should be made by consultant neurologists or consultant physicians with a special interest in Parkinson's Disease, dystonia or tremor.

There will be agreed written referral guidelines and patient information documentation shared by the FNS with referring centres covering communication between clinicians and between clinicians and parents and carers. The documentation will be agreed with local referring neuroscience centres and patient groups. The referring clinician must ensure that the necessary information is shared with patients and support provided to allow patients to make an informed decision regarding referral for treatment.

The FNS should hold regular regional virtual MDTs to discuss suitability of individual patient for specialised intervention (e.g. DBS) prior to referral. This will ensure that patients who could benefit are identified and referred in a timely manner and serve to improve the knowledge of referring clinicians in identifying suitable patients.

If the referring clinician believes that the patient meets the access criteria stipulated in section 2.2, they should contact the provider for their area. The referral should be accompanied with copies of relevant clinic letters and clinical history to support the referral. The service will be expected to implement an electronic referral system such as refer as a patient.

Patients referred onto the pathway should be discussed by the Functional Neurosurgical MDT (which should include neurologists with specialist expertise in movement disorders, neuroradiologist, functional neurosurgeon and appropriate specialist nursing and neuropsychological input). For patients who are not considered suitable for DBS, the Functional Neurosurgical MDT will advise on alternative options including the option of going onto the MRgFUS pathway. Patients should have a full neuropsychology assessment in advance of the MDT and surgery.

The referring clinician will continue to have responsibility for the patient for their entire patient pathway and will ensure that relevant Quality Standards and national specifications are met whilst ensuring care will be provided in a timely manner in order

to improve quality of life and participation for the patient, and to reduce the stress and burden on families and carers.

2.2 Eligibility Criteria

JCC will fund the referral to a Functional Neurosurgical Service including DBS and Transcranial magnetic resonance guided focused ultrasound (TcMRgFUS) for people aged 16 and over with a diagnosis of:

- Parkinson's Disease
- Generalised Dystonia
- Focal and Segmental Dystonia
- Status Dystonicus
- Essential or Dystonic Tremor
- Mid Brain Tremor

Replacement generators:

- JCC will fund the replacement of pulse generators on the grounds that the device is no longer functioning and that withdrawal of treatment would be to the detriment of the patient.

DBS is only routinely commissioned for people aged 16 years and over that meet all of the general criteria in section 2.2.1, **and** the revised criteria for either Parkinson's Disease (see section 2.2.2) **or** Dystonia (see section 2.2.3 -2.2.5) **or** Tremor (see section 2.2.6 – 2.2.8) or Mid Brain Tremor (see 2.2.9)

2.2.1 General Criteria

People aged 16 years and older, **and:**

- are in good general health and are considered to have a life expectancy of 5 or more years as assessed by a detailed medical history and post liaison with other professionals
- symptoms are severe enough to significantly compromise quality of life and the activities of daily living, **and**
- have no evidence of dementia or current serious non-drug related psychopathology, **and**
- are fit to undergo DBS surgery under general anaesthesia with no contra-indications for surgery (e.g. sepsis/coagulopathy).

2.2.2 Parkinson's Disease

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and**:

- have an established diagnosis of Parkinson's Disease as assessed by the UK Parkinson's Disease Society Brain Bank Criteria, **and**
- have symptoms of motor complications severe enough to compromise function and quality of life - on/off fluctuations; L-dopa induced dyskinesias or medication resistant functionally impairing tremor, **and**
- all appropriate medical and surgical interventions have been considered, exhausted or are not felt to be applicable, **and**
- are free from clinically significant cognitive impairment.

2.2.3 Generalised Dystonia

People aged 16 years and older with generalised dystonia which is either primary or secondary and who meet all the general criteria in section 2.2.1, and have one or more of the following:

- have not had an adequate response to botulinum toxin treatment
- have failed to tolerate botulinum toxin treatment
- require such large or frequent treatments with botulinum toxin as to make such treatment impractical
- are unsuitable for botulinum toxin treatment.

and meet the following criteria:

- have an established clinical diagnosis of generalised Dystonia as determined by a consultant neurologist, **and**
- exhibit focal or generalised dystonia of sufficient severity to compromise quality of life, **and**
- the dystonia is the primary cause of the disability, **and**
- there are no significant postural defects or significant fixed joint deformities, **and**
- all appropriate medical and surgical interventions have been considered and exhausted where appropriate. In the case of medical interventions dystonia will have been shown to be refractory to the use of tolerated or applicable best medical therapy (BMT) post assessment by a movement disorder consultant neurologist, **and**
- a diagnosis of functional dystonia should have been considered and excluded as far as clinically possible.

2.2.4 Focal and Segmental Dystonia

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and**:

- have an established clinical diagnosis of focal or segmental dystonia e.g. focal and segment forms of dystonia as determined by a consultant neurologist, **and**
- exhibit focal or segmental dystonia of sufficient severity to compromise quality of life, **and**
- the dystonia is the primary cause of the disability, **and**
- there are no significant postural defects or significant fixed joint deformities.

2.2.5 Status Dystonicus

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and**:

- have been seen by a consultant neurologist (adult and/or paediatric) and neurosurgeon to arrive at final decision, **and**
- have severe and frequent episodes of generalised dystonia which require urgent hospital admission with or without systemic complications (e.g. respiratory or renal compromise, rhabdomyolysis), **and**
- there is a presence of an established diagnosis for the underlying disease resulting in status for example primary / secondary dystonia and a cause for secondary if possible, **and**
- any underlying trigger for the status dystonicus has been identified and treated if this is possible, **and**
- the condition is refractory to medical management which includes sedation, muscle relaxation and supportive treatment, **and**
- are fit to undergo deep brain stimulation surgery under general anaesthesia without contra-indication to DBS surgery (significant brain atrophy or pathology in anatomical area targeted for dystonia).

2.2.6 Essential Tremor or Dystonic Tremor

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and**:

- have an established diagnosis of essential tremor or dystonic tremor as determined by a consultant neurologist, **and**
- the tremor impairs activities of daily living to an extent that impairs quality of life, **and**

- are fit to undergo DBS surgery under general anaesthesia (assessed by an anaesthetic opinion) with no contra-indications for surgery (e.g. sepsis/ coagulopathy), **and**
- all appropriate medical and surgical interventions have been considered and exhausted where appropriate, or are not felt to be applicable post -assessment by a movement disorder consultant neurologist in a functional neurosurgery for movement disorders team, **and**
- the treatment of the tremor is likely to produce a functionally useful improvement in disability.

2.2.7 For Essential Tremor

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and:**

- Beta blockers have been tried and failed or not tolerated or not applicable, **and / or**
- Primidone has been tried and failed or not tolerated or not applicable, **and /or**
- Gabapentin has been tried and failed or not tolerated or not applicable.

2.2.8 For Dystonic Tremor

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and**:

- anticholinergics have been tried and failed or not tolerated or not applicable.

2.2.9 Mid Brain Tremor

People aged 16 years and older that meet all of the general criteria in section 2.2.1, **and:**

- have an established diagnosis of mid brain tremor as determined by a consultant neurologist, **and**
- the mid brain tremor should have an established aetiology and be severe enough to significantly compromise quality of life and performance of activities of daily living, **and**
- are fit to under DBS surgery under general anaesthesia (by anaesthetic opinion) with no contra-indications for surgery (e.g. sepsis/coagulopathy), **and**
- all appropriate medical and surgical interventions have been considered and exhausted or are not felt to be applicable post assessment by a movement disorder consultant neurologist, **and**
- medication should have been tried and failed, or not tolerated or applicable, **and**
- an MRI has been performed which does not demonstrate pathological involvement/destruction of the target site for DBS.

and one of the following:

- The underlying diagnosis is multiple sclerosis (MS) and the predominant functional impairment is felt to be due to tremor rather than ataxia plus there is not sufficient spasticity, weakness, numbness or proprioceptive loss to prevent a return of function if tremor is removed.

or

- The underlying diagnosis is infarction and there is not sufficient spasticity, weakness, numbness or proprioceptive loss to prevent a return of function if tremor is removed.

2.2.10 TcMRgFUS Thalamotomy Criteria

TcMRgFUS thalamotomy is only routinely commissioned for people aged 16 years and over that meet all of the criteria. Patients meeting all the following (relevant) criteria should be considered for TcMRgFUS thalamotomy for treatment of medication refractory ET:

- Patients with medication-refractory tremor
- Patients who are not eligible for DBS
- Patients with either a postural tremor or an intention tremor of grade 3 or 4 in the target upper limb (scored using the CRST part A, see Appendix)
- A score of 2 or above in any one of its items in the CRST Part C (items 16-23). Tremor sufficient to significantly impair activities of daily living to an extent that it impairs quality of life supported by a clinical tremor rating score.
- All other medical and surgical interventions have been considered and exhausted or are not felt to be applicable post assessment by a movement disorder consultant neurologist in a functional neurosurgery for movement disorders team.

2.3 Service description

The overarching aim of a FNS for movement disorders such as Parkinson's Disease, tremor, and dystonia is to restore neurological function and improve quality of life, in people whose symptoms are resistant to medical therapy.

The FNS service should:

- provide comprehensive care which is linked to the patient’s local neurology centre and enable as much of the care to take place as close to the patient’s home as possible
- ensure that adequate and documented systems of communication are in place between the centre and referring neurology clinics, as well as between clinicians, patients and carers

- ensure that the management of each patient is discussed and planned at a joint neurosurgical / neurology Multi-Disciplinary Team (MDT). In the MDT, each patient is presented by the clinician responsible for their care. Each referral is discussed by the multidisciplinary team to ensure optimised clinical outcomes and a holistic patient-centred approach. Within 24 hours of the MDT meeting an outcome proforma is completed including the individual treatment plan for the patient
- provide the necessary information and support to allow patients to make an informed decision regarding treatment
- provide the facilities and support to allow patients to have the best possible experience with the hospital in which treatment is being provided, including access to virtual appointments where possible
- ensure that services are planned around the needs of the patient and that services are delivered in a timely and efficient manner, and are subject to continuous quality improvement
- have a link with the 'local neurosurgical service', as there will need to be access for patients in an emergency (e.g. removal of infected device)
- ensure that the service has access to the resources, expertise and volume of patients required to maintain a high quality service, and meets the requirements of NHS Wales Joint Commissioning Committee (NWJCC) Service Specification: CP178 Neurosurgery (Adults)
- ensure that patient care is delivered in a coordinated way by a range of skilled professionals and that adequate records and long term outcome monitoring are in place
- have written pathways of care for treatment of each indication
- ensure that the Functional Neurosurgical service's clinical and non-clinical teams have strong channels of communication and well- defined working relationships to ensure optimal patient care across pathways
- ensure that all clinicians, nursing and allied health professional staff will take part in a programme of continuing professional development which can be evidenced
- ensure that the specialist team enhance the knowledge of referring clinical teams by supporting their professional development
- have information management systems and agreed outcomes reporting in place in order to facilitate clinical audit and ongoing evaluation of the service
- have long term follow-up audits in place
- have systems in place that enable the adoption of new Digital technology as it becomes available e.g. remote monitoring
- engage in extensive research aimed at understanding, improving, and extending the use of DBS, stereotactic ablation, and other neurosurgical techniques

2.3.1 Functional Neurosurgical Specialist Teams

The Service Lead should be a Clinician with expertise in Functional Neurosurgery. They will have responsibility for the entire patient pathway and will ensure that relevant Quality Standards and national specifications are met.

DBS surgery should be performed by an appropriately qualified and experienced surgeon with specific expertise in stereotactic and functional neurosurgery working as part of an inter-professional team that includes a movement disorder neurologist, neuropsychologist, psychiatrist, and neurophysiologist. In addition, the support of allied health professionals is important given the symptoms of the diseases and the fact that complications can include speech and gait difficulties. Therefore, patients need to be able to access speech and language therapy and physiotherapy services if required.

Staffing

The FNS service will have onsite access to:

- Neurosurgeons (minimum of two) with expertise in Functional neurosurgery
- Neurology consultants with expertise in movement disorders and DBS
- Neuroradiologist
- Neuropsychologist
- Theatre nursing staff
- Nurse Practitioner or similar specialist nurse
- Physiotherapists
- Senior management support
- Audit and MDT coordinator
- Clerical and administration staff

The tertiary neurosciences centre will have:

- A neurology consultant with expertise in movement disorders and DBS
- A clinical nurse specialist with expertise in movement disorders and DBS
- A Neuropsychologist
- A coordinator

Staff must have access to suitable IT facilities to perform their roles effectively.

2.3.2 Facilities and equipment and software for all services

A DBS service should ensure that there is appropriate access to the following facilities and equipment:

- neurosurgical facilities suitable for all acute work, including implant surgery
- theatres suitably equipped for implant work
- interventional surgical MRI suite
- critical care beds
- inpatient surgical beds on an appropriate ward
- appropriate outpatient facilities
- appropriate day-case facilities
- Magnetic Resonance Imaging (MRI) scanner R 46
- Computerised Tomography (CT) scanner
- access to DaTSCAN scanning
- access to Positron Emission Tomography (PET) scanning
- an electronic referral system e.g. refer a patient.

2.4 Interdependencies with other services or providers

Interdependent Services that may be required but not necessarily co-located with the DBS service:

- pain management
- neuropsychology
- neuropsychiatry

2.5 Exclusion Criteria

NWJCC does not fund DBS for any of the following indications:

- Neuropathic pain
- Refractory Epilepsy (all ages)
- cluster headache
- Central Post Stroke Pain
- Refractory Tourette Syndrome (adults)
- psychiatric disorders (e.g. severe depression, psychosis)
- patients with evidence of dementia or current serious non-drug related psychopathology.

Patients who meet any of the following criteria are not suitable for TcMRgFUS thalamotomy for treatment of essential tremor:

- patients who are receiving or are currently eligible to receive DBS
- patients with a diagnosis of Parkinson's Disease
- unable to undergo an MRI scan.

Absolute contra-indications:

- a low Skull Density Ratio (<0.3) preventing enough power being deposited at target site.

Relative contra-indications:

- significant speech impairments
- unsteadiness when walking or turning
- significant cognitive impairments (Mini Mental State Examination less than 25/30) or dementia
- a high level of frailty
- significant other medical co-morbidities (co-existent medical problems), which would increase the risk and diminish the benefits of the procedure (including terminal conditions)
- abnormalities on a cerebral MRI scan that would negatively affect the outcome of
- TcMRgFUS.

2.6 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.

2.7 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 Welsh Government Transition and Handover Guidance

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

2.8 Patient Pathway (Annex i)

Referrals and requests for funding DBS and TcMRgFUS surgery should be made by consultant neurosurgeons, consultant neurologists or consultant physicians with a special interest in movement disorders. There is also a need for clinical neuropsychologists to help inform the decision-making process.

The referral should be accompanied by a completed proforma (see annex iii) with copies of relevant clinic letters and clinical history to support the referral. The role of the gatekeeper is to ensure that the referral meets the agreed criteria.

2.9 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

3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties.

The provider will provider an update on their outcomes and achievements over the preceding 12 months, including how they are embedding learning and developing and a Quality Improvement focus.

3.1 Quality Indicators (Standards)

The provider will comply with national standards and guidelines as described in the following:

- NHS Wales Joint Commissioning Committee (NWJCC) Service Specification: CP178 Neurosurgery (Adults)
- NHS Wales Joint Commissioning Committee (NWJCC) Policy: PP258 Transcranial Magnetic Resonance Guided Focused-Ultrasound-TcMRgFUS Thalamotomy for treatment of medication refractory essential tremor for people aged 18 and over policy
- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site
- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient surveys and develop and implement an action plan based on findings and functional outcomes data
- there must be clearly defined clinical and managerial accountability within the service
- all work processes are to be protocol-led and clearly defined. Any deviation from these protocols will be clearly documented and investigated with regular reviews led by the commissioners with support from each provider and updated where appropriate
- The service participates in national and local audits representing results to network and internal governance meeting at least annually

The service is required to have a database that records Functional outcomes- Formally measured assessments (UPDRS) pre and post procedure:

- Patient reported outcome measures
- Neuropsychology assessments

The following should be reported on annually, with outcomes benchmarked against published literature:

- levels of activity and clinical outcomes
- process indicators- time from referral to review in MDT clinic, time from decision to proceed to surgery being performed, and referral data by Health Board.
- collation of data on diagnosis, surgical procedures, and DBS infection rates, complication rates and revision rates
- PROMS in patients with Parkinson Disease (e.g.: PDQ39 and UPDRS part II).
- PREMS when validated measures are available.

3.2 Other quality requirements

- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site
- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient and carer surveys and develop and implement an action plan based on findings

3.3 Additional considerations for patient and family experience

Families, carers and associated professionals should have access to information during the assessment, surgery and after surgery. Including national and local charities and support groups.

Information should be accessible to patients in a language that is appropriate to their preferred method of communication:

- interpreting services for direct patient contact (face to face or remote) including appropriately registered professional British Sign Language, spoken language interpreters and other forms of communication support
- verbal information should be supported by a written summary if required

4. Performance Monitoring and Information Requirement

4.1 Performance Monitoring

NWJCC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

NWJCC will conduct performance and quality reviews on an annual basis.

4.2 Key Performance Indicators

The Functional Neurosurgical Service will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2, the service will be required to align services with the NHS Wales Quality and Safety Framework (Welsh Government 2021)[6].

The service should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

The DBS service will be expected to monitor against the following target outcomes, which are aligned with NHSE Outcomes Framework domains. These domains are identified below:

- 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.

[6] https://www.gov.wales/sites/default/files/publications/2021-09/quality-and-safety-framework-learning-and-improving_0.pdf

4.3 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, this version of the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality and Welsh Language Impact Assessment (EWLIA) 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, socio-economic duty and language (Welsh).

This policy has been subjected to an EWLIA.

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.

6. Listening to People:

6.1 Complaints, Incidents and Redress Process

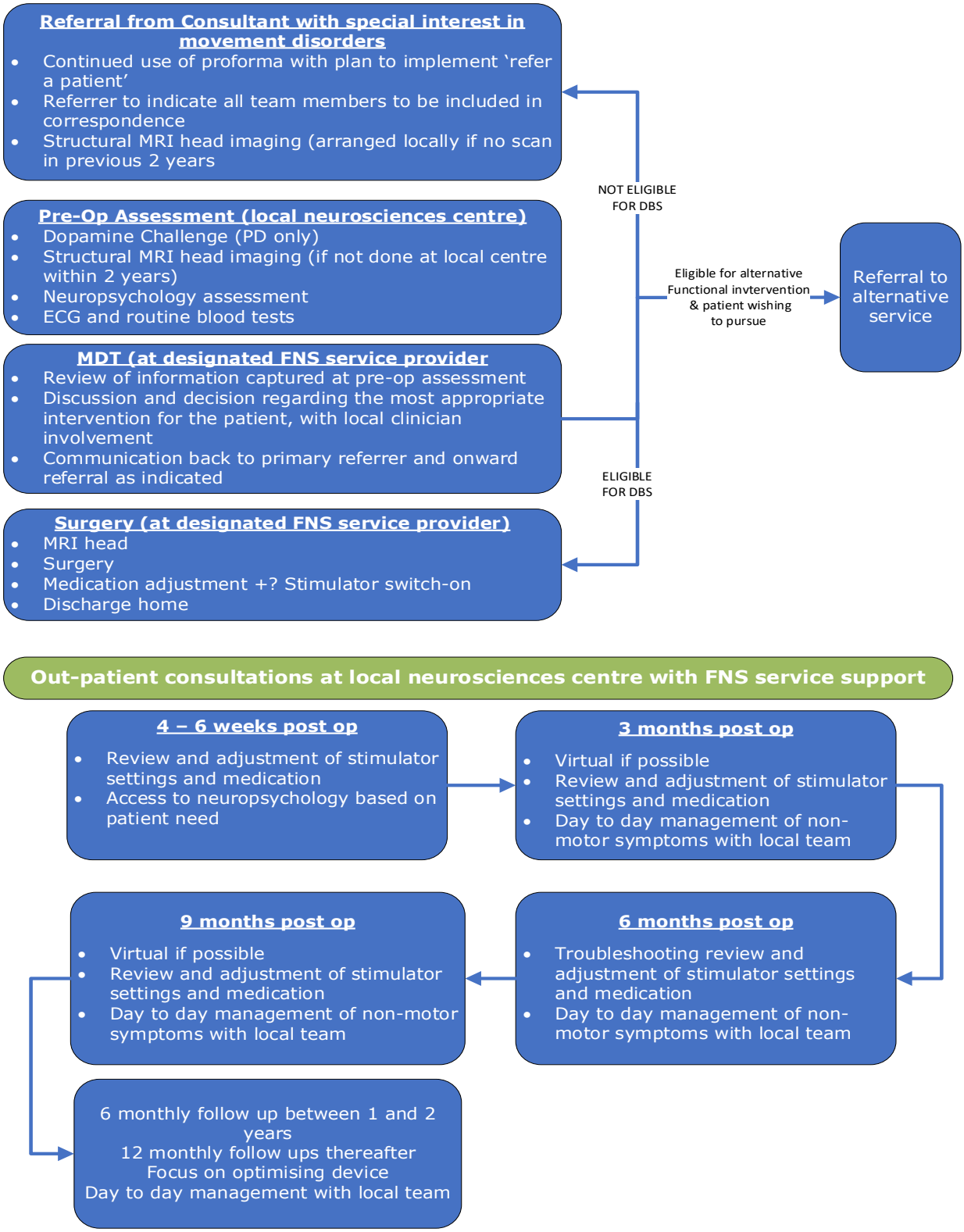
Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

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 Listening to People, The NHS Wales Complaints, Incidents and Redress Process – People's Guidance 2026. 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

Functional Neurosurgical Service proposed pathway for patients with complex movement disorders



Annex ii Codes

The list of ICD codes is indicative and is not exhaustive. The ICD10 codes below 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.

ICD 10 Codes

Code Category	Code	Description
ICD-10	G20X	Parkinson's Disease
ICD-10	G24	Dystonia
ICD-10	G250	Essential Tremor
ICD-10	G35X	Multiple Sclerosis

OPCS 4 Codes

Code Category	Code	Description
OPCS 4	A091	Implantation of DBS
OPCS 4	A095	Insertion of DBS Electrodes
OPCS 4	A093	Removal of DBS
OPCS 4	A092	Maintenance of DBS

Annex iii Glossary

Deep Brain Stimulation (DBS)
Deep brain stimulation is a procedure in which stimulating electrodes are placed stereotactically into the deep structures of the brain. The electrodes are connected to an implanted pulse generator which is battery powered. Typically, the electrodes are secured to the skull and a cable tunnelled to the pulse generator situated in the front of the chest, although other positions are used.

Electrodes are secured to the skull and a cable tunnelled to the pulse generator situated in the front of the chest, although other positions are used. Battery replacements are required at intervals (measured in years). Rechargeable systems have been developed with a usual lifespan of ten years.

Dystonia
Dystonia is a movement disorder, a syndrome of sustained muscle contraction usually producing twisting and repetitive movements or abnormal postures. A number of different neurological diseases can cause the symptoms of dystonia. The disease can be disabling and is often accompanied by severe pain.

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.

Parkinson's Disease (PD)
Parkinson's Disease [7] is a chronic disease of the brain characterised by gradually worsening tremor, muscle rigidity and difficulties with starting and stopping movements. In advanced stages of the disease there can be severe fluctuations between almost total immobility, with or without tremor, and hypermobility with abnormal involuntary movements (dyskinesia).

[7] https://www.england.nhs.uk/wp-content/uploads/2013/04/d03-p-b.pdf

TcMRgFUS Thalamotomy

TcMRgFUS thalamotomy is a new procedure for the treatment of ET. This procedure uses focused ultrasound waves generated externally to the body that are directed to, and alter the function of, the VIM nucleus to improve tremor. This is done under magnetic resonance imaging (MRI) guidance. This is a non-invasive procedure that does not require the introduction or maintenance of hardware into the brain, avoiding the maintenance of the inserted hardware (i.e. battery replacement) and minimising the risk of bleeding within the skull, stroke and infection. This can be done as a day-case procedure.

Tremor

Tremor is also a symptom arising from a number of neurological diseases. It is an involuntary rhythmic repetitive movement, most frequently affecting the upper limbs. It can occur at rest or be triggered by posture or intentional movement. Severe tremor can be disabling because it affects fine-movement co-ordination.

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 Office
Unit G1 The Willowford, Main Avenue, Treforest Industrial Estate, Pontypridd, CF37 5YL

North Wales Office
Unit 3, Media Point - Unit 3, Mold Business Park, Mold, CH7 1XY