



GIG
CYMRU
NHS
WALES

Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Specialised Services Policy Position Statement PP245

Selective Dorsal Rhizotomy (SDR) for the treatment of spasticity in cerebral palsy in children aged 3-9 years

*March 2024
Version 1.0*



Document information

Document purpose	Policy Position Statement
Document name	Selective Dorsal Rhizotomy (SDR) for the treatment of spasticity in cerebral palsy in children aged 3-9 years
Author	Welsh Health Specialised Services Committee
Publication date	March 2024
Commissioning Team	Women & Children
Target audience	Chief Executives, Medical Directors, Directors of Finance, Consultant Neurosurgeons, Consultant Neurologists, Consultant Orthopaedic Surgeons, General Paediatricians, Physiotherapists, Occupational Therapists
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document No	PP245
Review Date	2027

Contents

Policy Statement	4
1. Introduction	6
1.1 Plain language summary	6
1.2 Aims and Objectives	7
1.3 Epidemiology	8
1.4 Current Treatment.....	8
1.5 Proposed Treatment	8
1.6 What NHS Wales has decided.....	9
2. Criteria for Commissioning	10
2.1 Inclusion Criteria	10
2.2 Exclusion Criteria	10
2.3 Acceptance Criteria.....	10
2.4 Patient Pathway (Annex i)	11
2.5 Exceptions.....	11
2.6 Clinical Outcome and Quality Measures	12
2.7 Responsibilities	12
3. Documents which have informed this policy	13
4. Date of Review	14
5. Putting Things Right.....	15
5.1 Raising a Concern.....	15
5.2 Individual Patient Funding Request (IPFR)	15
6. Equality Impact and Assessment.....	16
Annex i Patient Pathway	17
Annex ii Assessment for SDR Selection.....	18
Annex iii Codes	22
Annex iv Prior Approval Form.....	23
Annex v Abbreviations and Glossary	25

Policy Statement

Welsh Health Specialised Services Committee (WHSSC) will commission Selective Dorsal Rhizotomy (SDR) for the treatment of spasticity in cerebral palsy in children aged 3-9 years in accordance with the criteria outlined in this document.

In creating this document WHSSC has reviewed the relevant guidance issued by the National Institute of Health and Care Excellence (NICE)¹ and the Evidence Review² commissioned by NHS England and has concluded that SDR should be made available.

Welsh Language

WHSSC 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 Act \(1993\)](#), 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, WHSSC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered and people have access to either a translator or 'Language-line' if requested. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

WHSSC 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 WHSSC commitment.

Disclaimer

WHSSC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this policy position statement.

¹ [Overview | Selective dorsal rhizotomy for spasticity in cerebral palsy | Guidance | NICE](#)

² [Selective-dorsal-rhizotomy-for-the-treatment-of-spasticity-in-cerebral-palsy-children-aged-3-9-years.pdf \(england.nhs.uk\)](#)

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.

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

1. Introduction

This Policy Position Statement has been developed for the planning and delivery of Selective Dorsal Rhizotomy (SDR) for children aged 3-9 years and resident in Wales. 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

Cerebral palsy is a descriptive term for a problem of motor control caused by an irreversible structural difference or damage to the brain that happens before birth, around the time of birth or in the first two years of life. It is associated with abnormalities of movement, balance and posture. Although the brain injury does not get any worse as the child gets older, the difficulties it causes can change in the growing child. The problems of movement can often be accompanied by other clinical, functional and developmental challenges.

The pattern of movement problems are dependent on which part of the brain has been damaged. Sometimes the main problems can be stiffness (spasticity), weakness and a problem with controlling patterns of movement (dystonia).

How large the area of brain damage is usually determines the severity of movement problems. The severity of the child's motor problems is described on a scale of one to five (one the least and five the most) using the Gross Motor Functional Classification System (GMFCS). As with any child movement changes with growth, and stiffness in the muscles can lead to pain and tightness over time and can impair the child's ability to walk.

For children with cerebral palsy who have spasticity mainly affecting their legs and with not much weakness and no 'dystonia' and who can walk but have problems with their pattern, SDR can be considered. This group of movement disorder used to be known as spastic diplegia, but it is now referred to as bilateral spastic cerebral palsy GMFCS levels II and III.

The GMFCS is a standardised classification system that describes the gross motor function of children and young people with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility. Distinctions between levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, the actual quality of movement. The GMFCS is categorised into the following 5 levels:

Level I - Walks without restrictions: Children walk at home, school, outdoors and in the community. They can climb stairs without the

use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

Level II - Walks without assistive devices: Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

Level III - Walks with assistive devices: Children walk using a handheld mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

Level IV – Has limited self-mobility / may use powered mobility: Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

Level V – Has severely limited self-mobility even with assistive devices: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Selective dorsal rhizotomy (SDR) is an operation used to reduce spasticity (muscle stiffness) in cerebral palsy. The surgery involves cutting nerves in the lower spine that are responsible for muscle stiffness in order to ease muscle spasticity and improve mobility.

1.2 Aims and Objectives

This Policy Position Statement aims to define the commissioning position of WHSSC on the use of SDR to treat spasticity for children aged 3-9 years with cerebral palsy.

The objectives of this policy are to:

- ensure commissioning for the use of SDR is evidence based
- ensure equitable access to SDR
- define criteria for children aged 3-9 years old with cerebral palsy to access treatment
- improve outcomes for children aged 3-9 years old with cerebral palsy

1.3 Epidemiology

The prevalence of cerebral palsy in developed countries is stable at around 2 in 1000 live births. Approximately 40% of cerebral palsy cases are children who have been born prematurely. With a birth rate of around 700,000 per year, 1 in 400 children will have a form of cerebral palsy.

Considering the breakdown of cerebral palsy subtypes, around 75 percent of children will have a predominantly spastic muscle tone of which one third will have a diplegic pattern (lower limb predominant). This constitutes around 1 in 1000 live births.

The population for Wales is estimated at 3.2 million with around 560,000 aged 0-15 years³. The birth rate in Wales is around 29,000 per year⁴.

Using the figures above, the estimated prevalence of children born with diplegia in Wales is therefore around 29 per year. The GMFCS breakdown further suggests that around 20-30% will be at GMFCS levels of II and III. Taking all these estimates together, the total number of children who are likely to require SDR surgery in Wales is estimated at 9 per year.

1.4 Current Treatment

There are a number of other available treatments to help reduce the effects of spasticity to improve function and movement that may be used together with or instead of SDR. These include medication, long-term physiotherapy, occupational therapy and splints (orthotics), targeted botulinum toxin injections into the muscles as well as a variety of orthopaedic procedures.

1.5 Proposed Treatment

SDR is a complex specialised neurosurgical procedure for the treatment of spasticity (muscle stiffness) associated with cerebral palsy. SDR involves the irreversible division of some of the sensory nerves in the dorsal lumbar spinal cord, performed under general anaesthesia. It aims to reduce spasticity by decreasing sensory stimulation whilst preserving voluntary

³ [Stats Wales 2020 mid-year estimates](#)

⁴ [Office for National Statistics: Live births in England and Wales](#)

movement. Before considering children for this operation, brain scans are taken as well as x-rays of a child's hips to confirm that they are stable.

Following surgery, regular physiotherapy is necessary to obtain the best results after SDR and children and their families need to be motivated and show that they are able to cooperate with the therapy. The level of physiotherapy is linked to the severity of the child's motor problems and physiotherapy teams will review children at 6 months, 12 months and 24 months. Subsequent physiotherapy frequency may be adjusted, linked to review outcomes.

1.6 What NHS Wales has decided

WHSSC has carefully reviewed the relevant guidance issued by the National Institute of Health and Care Excellence (NICE)⁵ and the Evidence Review⁶ commissioned by NHS England and has concluded that SDR should be made available within the criteria set out in section 2.1.

⁵ [Overview | Selective dorsal rhizotomy for spasticity in cerebral palsy | Guidance | NICE](#)

⁶ [Selective-dorsal-rhizotomy-for-the-treatment-of-spasticity-in-cerebral-palsy-children-aged-3-9-years.pdf \(england.nhs.uk\)](#)

2. Criteria for Commissioning

The Welsh Health Specialised Services Committee will approve funding of SDR for the treatment of spasticity in cerebral palsy in children aged 3-9 years in line with the criteria identified in the policy.

2.1 Inclusion Criteria

SDR will be routinely commissioned for the treatment of spasticity in cerebral palsy, mainly affecting the legs, in children functioning at GMFCS levels II and III who meet the following criteria:

- the child is aged 3 years to 9 years inclusive with a diagnosis of cerebral palsy with spasticity mainly affecting the legs **and**
- the child has dynamic spasticity in lower limbs affecting function and mobility and no dystonia **and**
- the MRI brain scan shows typical cerebral palsy changes and no damage to key areas of brain controlling posture and coordination⁷ **and**
- the child functions at GMFCS level II or III **and**
- there is no evidence of genetic or neurological progressive illness **and**
- the child has mild to moderate lower limb weakness with ability to maintain antigravity postures **and**
- the child has no significant scoliosis or hip dislocation (Reimer's index should be <40%)

2.2 Exclusion Criteria

SDR will not be routinely commissioned where:

- the MRI brain scan shows damage to key areas of brain controlling posture and coordination (lesions in basal ganglia or cerebellum)
- the child functions at GMFCS level I, IV or V
- there is evidence of genetic or neurological progressive illness
- the child has significant scoliosis or hip dislocation (Reimer's index $\geq 40\%$)

2.3 Acceptance Criteria

The service outlined in this policy is for children aged 3 to 9 years ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes children who whilst resident in Wales, are registered

⁷ The typical MRI changes are those of white-matter damage of prematurity or periventricular leucomalacia (PVL). Lesions in basal ganglia or cerebellum are contra-indications to SDR, since they are associated with other cerebral palsy types (dystonia / ataxia).

with a GP practice in England, but includes children resident in England who are registered with a GP Practice in Wales.

2.4 Patient Pathway (Annex i)

Children can be identified as potentially suitable candidates for SDR surgery by any member of the child's local team, but must be endorsed in writing by the child's orthopaedic surgeon, paediatric neurologist or a paediatrician with expertise in Neurodisability. Referrals should be made to an NHS commissioned SDR centre for discussion by the SDR multi-disciplinary team (MDT). If the criteria for assessment for SDR surgery are met, the child and their family will be invited to attend outpatient assessment appointments. These will include physiotherapy and consultant assessments and further MDT discussion. If the child is suitable for SDR surgery, they will be listed for SDR surgery and inpatient physiotherapy.

This will be followed by community-based physiotherapy after discharge from the SDR centre, the provision of which will be delivered by the resident Health Board of the child. In addition to the home exercise program that will be developed for each child to perform daily, the following frequency of sessions with a Physiotherapist are recommended⁸:

GMFCS Level II

- hospital discharge to 4 months post-op: 2 times per week
- 4 to 6 months post-op: once per fortnight
- 6 to 12 months post-op: once every 3-4 weeks
- 12-24 months post-op: monthly or as required

GMFCS Level III

- hospital discharge to 4 months post-op: 3 times per week
- 4 to 6 months post-op: once per week
- 6 to 12 months post-op: once per fortnight
- 12-24 months post-op: once per 2-4 weeks or as required

Follow-up reviews at the SDR centre should take place at 6 months, 1 year and 2 years.

2.5 Exceptions

If the child 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.

⁸ [Bristol Royal Hospital for Children - What we do | University Hospitals Bristol NHS Foundation Trust \(uhbristol.nhs.uk\)](#)

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](#)

2.6 Clinical Outcome and Quality Measures

The Provider should work to written quality standards and provide monitoring information to WHSSC.

The centre will enable the child's, carer's and advocate's informed participation and should be able to demonstrate this. Provision should be made for children with communication difficulties.

Centres providing SDR are required to collect and record the following data preoperatively and post-operatively at 6 months, 1 year, and 2 years post-procedure:

- patient demographics including sex, age, height, weight
- GMFCS level
- muscle tone – Modified Ashworth Scale
- strength score – Modified Oxford
- selectivity scale – Boyd and Graham
- joint Range of movement – Goniometry
- GMFM-66
- 3-Dimensional gait analysis (pre-op and at 2-years post-operatively)
- CPQoL
- hip x-ray – pre-operatively and at 2 years post -operatively in line with cerebral palsy integrated pathway (CPIP) protocol
- spine x-ray – pre-operatively and at 2-years post-operatively.

2.7 Responsibilities

Referrers should:

- inform the child 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 the alternative treatment with the child and/or parent or guardian
- advise the child and/or parent or guardian of any side effects and risks of the potential treatment
- inform the child and/or parent or guardian 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.

Each provider organisation treating children under this policy will be required to assure itself through its own internal governance arrangements that the referral criteria have been fulfilled and that appropriate assessments are completed before SDR is performed. WHSSC can ask for documented evidence that these processes are in place.

This will involve the SDR centres collecting and recording the standardised preoperative and post-operative assessments (as with CtE). Data should be recorded in a common format. The national network of SDR centres will meet on an annual basis to share outcome data and review clinical practice. This annual meeting would also be attended by NHS Specialised Commissioners.

3. Documents which have informed this policy

The following documents have been used to inform this policy:

- **National Institute of Health and Care Excellence (NICE) guidance**
 - [Spasticity in under 19s: management \(CG145\) 2012 \(updated 2016\)](#)
 - [Selective Dorsal Rhizotomy for spasticity in cerebral palsy \(IPG373\) 2010](#)
- **NHS England policies**
 - [Clinical Commissioning Policy: Selective Dorsal Rhizotomy \(SDR\) for the treatment of spasticity in Cerebral Palsy \(children aged 3-9 years\)](#)

- **Other published documents**

- [King's Technology Evaluation Centre Commissioning Through Evaluation: Selective Dorsal Rhizotomy Final Report September 2018](#)

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

- **NHS Wales**

- All Wales Policy: [Making Decisions in Individual Patient Funding requests](#) (IPFR).

4. Date of Review

This document will be reviewed in 2026, or when information is received which indicates that the policy requires revision before this time.

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 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, 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](#)

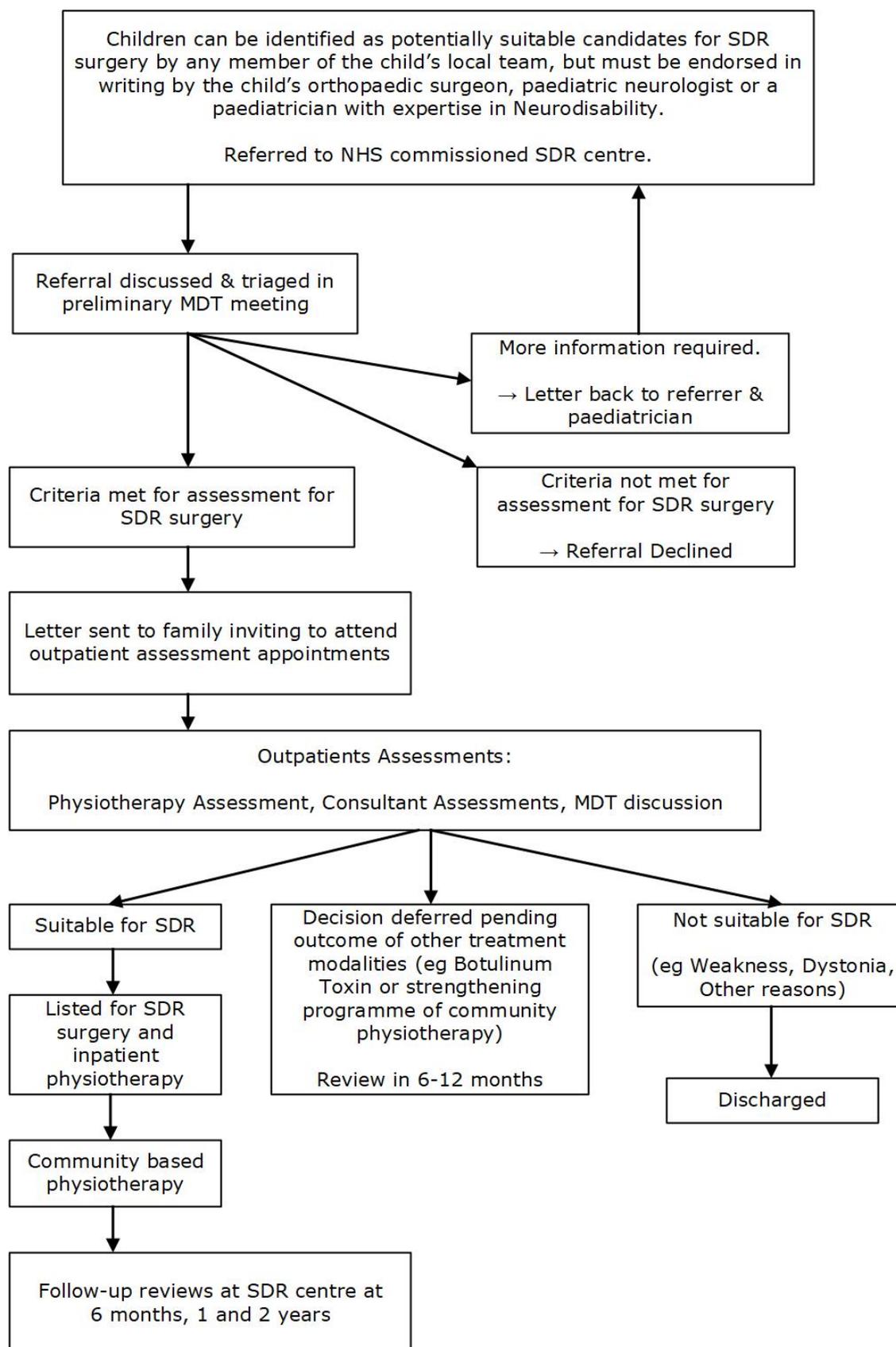
6. Equality Impact and Assessment

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 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.

Annex i Patient Pathway



Annex ii Assessment for SDR Selection

Assessment for SDR selection

Please use current CIPIS for accurate information.

NHS Number

Name

Address

Date of Birth

Responsible Health Board

Date of assessment:

Assessor:

Health Professionals:

Physiotherapist

Orthopaedic Surgeon

Community Paediatrician

Occupational Therapist

Orthotist

Clinical Details

GMFCS Level

Has the child had an MRI of the brain? (please state the date)

Are the features consistent with a diagnosis of cerebral palsy? Yes / No / Unsure

Comments:

Is there any evidence of movement disorder other than spasticity? Yes / No / Unsure

Comments:

What is the distribution of neurology?

Monoplegia Diplegia Triplegia Quadriplegia Total Body

Any Spasticity reducing treatments

Oral antispasmodics (Please state)
Botulinum toxin (Date of last injection)
ITB

Any previous surgery

Soft tissue surgery (Details, incl dates)

Bony surgery (Details, incl dates)

Any additional surgical procedures

Clinical Examination.

Spine	Is there a scoliosis?	Yes	/	No
	Sitting	Yes	/	No
	Lumbar lordosis excessive	Yes	/	No
	Thoracic kyphosis excessive	Yes	/	No

Date of last Scolioigram:

Hip

	Right	Left
External rotation (Hip flexion, knee flexion)		
Internal rotation (Hip flexion, knee flexion)		
Fixed flexion deformity		
Abduction (max) in 90o hip neutral, knee flexed		
Pain on passive RoM		
Duncan Ely Test		
Abduction		
Abduction (max) in 90o hip extension and knee flexion		
Abduction (max) in hip extension and knee flexion		
Adduction contracture		
Date of last hip xray		
Migration Index		

Knee

	Right	Left
Popliteal angle (shank to vertical, hip flexed to 90o)		
Fixed flexion (hip extended as far as possible)		
Popliteal Angle R1		
Knee Hyperextension		

Ankle

	Right	Left
Dorsiflexion knee flexed		
Dorsiflexion knee extended		
Dorsiflexion knee flexed R1		
Dorsiflexion knee extended R1		

Foot

Any evidence of a mid foot break?

Management programme

Postural management

- Specialist seating
- Standing equipment
- Sleep system
- Orthoses
- Walking aids

Any barriers to effectiveness of surgery

- Social Factors
- Environmental factors
- Learning difficulties
- Barriers to communication
- Emotional difficulties
- Challenging behaviour
- Other health needs

Annex iii Codes

Code Category	Code	Description
ICD-10-CM	G80	Cerebral palsy
	G80.1	Spastic diplegic cerebral palsy
OPCS-4	A57.2	Rhizotomy of spinal nerve root
	Z07.-	Spinal nerve root

Annex iv Prior Approval Form



PRIOR APPROVAL REQUEST FORM

Please only use this form when **all** treatment options available within locally provided services have been exhausted and it is **clinically appropriate** to consider accessing healthcare services elsewhere.

Details of clinician making the referral:	Details of clinician patient is being referred to:
Name:	Name:
Designation:	Specialty:
Address:	Address:
Postcode:	Postcode:
Telephone number:	Telephone number:
Fax number:	Fax number:
Email:	Email:

Patient Details	
First name:	Last name:
Address:	Date of birth:
	Telephone number:
	NHS number:
Postcode:	Hospital number:

Urgency			
How urgent is the request? (tick as applicable)	Urgent: 24-48 hours	Soon: Within 3 weeks	Non-urgent: 4-6 weeks

Please note: If a decision is required urgently, clinical reasons must be provided. Administrative reasons will not be considered.

Reason for request
<input type="checkbox"/> Second opinion <input type="checkbox"/> Lack of local/commissioned service provision/expertise <input type="checkbox"/> Clinical continuity of care <input type="checkbox"/> Transfer back to the NHS following self-funding in the private sector <input type="checkbox"/> Re-referral following a previous tertiary referral <input type="checkbox"/> Student <input type="checkbox"/> Veteran <input type="checkbox"/> Other - please specify

Clinical details
Details of treatment requested:
Medical history and current clinical status: (Please provide a copy of the latest clinical report)
What plans are in place to ensure the patient is returned to local services following the treatment/intervention requested?
Has advice been sought from other colleagues or neighbouring Health Boards with whom we hold a contract (please provide details)
Additional information to support the referral: (clinical letters/reports should be attached)
Cost of treatment:

I confirm that as the patients Consultant/GP, I have discussed this application and consent has been provided to obtain further clinical information pertinent to this funding request if required.
Clinician's signature:
Date:

Please return this form with a copy of the referral letter to:
Please return completed form to: Patient Care Team Welsh Health Specialised Services 3a Caerphilly Business Park CF83 3ED Email: whssc.ipc@wales.nhs.uk or whssc.ipc@nhs.net Fax: 029 2086 9534
If you have any questions, please telephone 01443 443443 ext.8123

Annex v Abbreviations and Glossary

Abbreviations

CP	Cerebral Palsy
CPQoL	Cerebral Palsy Quality of Life
GMFCS	Gross Motor Functional Classification System
IPFR	Individual Patient Funding Request
MRI	Magnetic resonance imaging
PVL	Periventricular Leucomalacia
SDR	Selective Dorsal Rhizotomy
WHSSC	Welsh Health Specialised Services Committee

Glossary

Ataxia/ataxic

A term for a group of disorders that affect co-ordination, balance and speech.

Basal ganglia

The central grey matter structures of the brain responsible for the initiation and fluidity of movement (locomotor driving system). They include the Caudate, Putamen and Globus Pallidus that function to control the motor system. Damage in these areas leads to dystonic movement patterns.

Cerebral palsy (CP)

A group of permanent brain disorders originating during foetal development, birth or early childhood. It is associated with abnormalities of movement, balance and posture.

Cerebral Palsy Quality of Life (CPQoL)

An internationally designed and validated tool designed to assess the Quality of Life for children with cerebral palsy across a variety of domains including social wellbeing and acceptance, feelings about functioning, participation and physical health, emotional wellbeing and self-esteem, access to services, pain and impact of disability, and family and parent health.

Dystonia

Involuntary sustained or spasmodic muscle contractions involving co-contraction of the agonist and the antagonist. The movements are usually slow and sustained, and they often occur in a repetitive and patterned manner. They can be unpredictable and fluctuate in severity.

Gross Motor Functional Classification System (GMFCS)

A standardised 5 level classification system that describes the gross motor function of children and young people with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility. Distinctions between levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement.

Gross Motor Function Measure (GMFM)

A clinical tool designed to evaluate change in gross motor function in children with cerebral palsy. There are two versions of the GMFM - the original 88-item measure (GMFM-88) and the more recent 66-item GMFM (GMFM-66).

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.

Magnetic resonance imaging (MRI)

A powerful, accurate, non-invasive radiology scan used for diagnosing a variety of conditions such as cerebral palsy. It allows the doctors to obtain a high-quality scan of the brain to understand the reasons for a patient's condition.

Paralysis

The loss of the ability to move (and sometimes to feel anything) in part or most of the body, including the legs and or arms.

Periventricular Leucomalacia (PVL)

Also known as white matter damage of prematurity, this is the term given for changes in the brain beside the internal fluid spaces of the brain (the ventricles). It indicates that there has been an injury to that part of the brain due to lack of oxygen or poor blood flow either leading up to birth or around the time of birth itself. It is the most common abnormality found on an MRI brain scan of children with cerebral palsy and considered a diagnostic sign of cerebral palsy.

Reimer's Index

The measurement of the percentage migration of the hip joint, measuring whether there is any displacement of the hip bone (head of the femur) out of its socket.

Selective Dorsal Rhizotomy (SDR)

A complex neurosurgery operation involving the irreversible division of some of the sensory nerves in the dorsal lumbar spinal cord, performed under general anaesthesia. It aims to reduce spasticity by decreasing sensory stimulation whilst preserving voluntary movement. Patients usually receive intensive physiotherapy for several months after SDR.

Spasticity

Increased, involuntary, velocity-dependent muscle tone that causes resistance to movement.

Spinal deformity

Involves a change in the normal curvature of the spine. This is a collection of terms that includes an abnormal forward bend of the spine (kyphosis) or abnormal sideways curvature (scoliosis).

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.