GIG CYMRU NHS WALES

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Welsh Health Specialised Services Committee (WHSSC)

Specialised Services Commissioning Policy: CP160

Specialised Paediatric Neurological Rehabilitation

April 2018

Version 5.0

Document information	
Document purpose	Policy
Document name	Specialised Paediatric Neurological Rehabilitation
Author	Welsh Health Specialised Services Committee
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Commissioning Team	Neurological and Complex Conditions
Target audience	Chief Executives, Medical Directors, Directors of Finance, Consultant Neurosurgeons and Rehabilitation Consultants, Director of Therapy Services, Commissioning Managers.
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document No	CP160
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Contents

Policy Statement

Background	Where Specialised Paediatric Rehabilitation for neurological conditions is needed, the seven Welsh Health Boards commission this jointly via The Welsh Health Specialised Services Committee (WHSSC). This policy sets out: • when patients can use these jointly commissioned specialised services • where these services are located • how patients can be referred • when patients cease to be eligible for funding under this policy. To describe the rehabilitation need that is eligible for this level of service and the features of the services, the policy uses the definitions and standards in the guideline "Specialised Neurorehabilitation Service Standards 7. 30/04/2015", from the British Society of Rehabilitation Medicine[1]. Royal College of Paediatrics and Child Health Stroke in Childhood: Clinical guideline for diagnosis, management and rehabilitation (2017)[2].
Summary of Access Criteria	Patients must: • be aged 1 year to 16 years old. Young adolescent patients aged 16-18 who satisfy the acceptance criteria should be discussed with the Neurorehabilitation MDT and Nursing Manager of Noah Ark's Children's Hospital for Wales (NACHfW) (South Wales) and Alder Hey Children's NHS Foundation Trust (North Wales). • have significant functional deficit as a result of acute brain or spinal injury or another diagnosed neurological condition

[1] https://www.bsrm.org.uk/downloads/specialised-neurorehabilitation-service-standards--7-30-4-2015-forweb.pdf

[2] https://www.rcpch.ac.uk/system/files/protected/page/20170601%20Stroke%20in%20Childhood%20-%20Full%20Clinical%20Guideline%20v3.4%20FINAL.pdf

	• require inter-disciplinary treatment (by 2 or more professionals) • be medically stable • no longer requiring regular and active input from acute medical or surgical teams • have clear functional goals identified • be likely to benefit from rehabilitation programme • have parent's patient consent for referral into the rehabilitation programme.
Responsibilities	Referrers should: • refer via the agreed pathway using the set criteria • inform the patient that this treatment is not routinely funded outside the criteria in this policy, and Clinician considering treatment should: • discuss all the alternative treatment with the patient • advise the patient of any side effects and risks of the potential treatment • 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. Where the clinician considers rehabilitation is appropriate but it falls outside the eligibility criteria or contractual agreement, they should request specific funding by submitting an Individual Patient Funding Request (IPFR).[3] The treatment centre should: • inform WHSSC when a patient needs a further period of rehabilitation funded by WHSSC at the centre • inform WHSSC when a patient is ready for discharge but is remaining at the centre for external reasons

[3] Welsh Health Specialised Services Committee (WHSSC) | Corporate Policies

	• inform WHSSC when patients are discharged • complete and retain the admission checklists.

1. Aim

1.1 Introduction

After a disease or injury patients may benefit from a period of rehabilitation that aims to improve as far as possible their ability to function and participate in society and their quality of life. Normally rehabilitation is organised and funded by each Welsh Health Board for the patients from their area. However, sometimes the needs for rehabilitation require a level of expertise that can best be provided by specialised paediatric centres. In this case, the seven Health Boards commission services jointly through the offices of the Welsh Health Specialised Services Committee (WHSSC).

This document is the commissioning policy which describes:

- when patients can use these jointly commissioned specialised services
- where these services are located
- how patients can be referred
- when patients cease to be eligible for funding under this policy.

This commissioning policy applies equally to residents of all Health Boards in Wales.

It only covers rehabilitation which needs specialised care for neurological conditions.

1.1.1 Period of Rehabilitation

Rehabilitation is a time-limited process which will end when either:

- the specific aims agreed in the rehabilitation programme have been met

or

- when the multi-disciplinary team consider that the patient can no longer benefit from the specialised rehabilitation they provide

or

- that the rehabilitation can be appropriately provided by a less specialised service.

If patients remain in this specialised service after these conditions have been met, they will be no longer meet the eligibility criteria in

this Commissioning Policy, and the provider will reclaim the placement costs from the patient's Health Board.

WHSSC funding for patients under this commissioning policy will cease when they are discharged from the service.

WHSSC will initially fund referrals for a maximum of 12 weeks. Funding will be extended beyond this where there is demonstrable benefit from further specialised rehabilitation.

Reference should be made to Annexe (iii) – Delayed Transfer of Care, which details the implementation of placement costs, when patients no longer meet the eligibility criteria in this Commissioningpolicy.

1.2 Plain language summary

This specification covers Specialised Paediatric Rehabilitation for children, who are aged 1 year to 16 years old with injuries or conditions which affect their nervous system. Young adolescent patients aged 16-18 who satisfy the acceptance criteria should be discussed with the Neurorehabilitation MDT and Nursing Manager of NACHfW[4,5] (South Wales) and Alder Hey Children's NHS Foundation Trust (North Wales). The specification concerns the tertiary and specialised rehabilitation for patients, as opposed to secondary or local community rehabilitation.

1.3 Relationship with other Policies and Service Specifications

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

- Specialised Services policy for Neuro-psychiatry: CP128
- Specialised Services policy for Specialised rehabilitation – Neurology : CP 140
- Specialised Services policy for spinal cord injury rehabilitation: CP 141
- Specialised Services policy for assistive technologies: CP25
- Service Specification for all Wales posture and mobility service: CP59
- All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR)[3].
- Specialised Neurorehabilitation Service Standards 7. 30/04/2015, from the British Society of Rehabilitation Medicine

[4] NICE Evidence Search | transition paediatric to adult
[5] Childrens - National Service Framework

- Royal College of Paediatrics and Child Health
- Stroke in Childhood: Clinical guideline for diagnosis, management and rehabilitation (2017)[2]
- Royal College of Paediatrics and Child Health Paediatric Service Specification
- Services for Children and Young People following Acquired Brain Injury
- Public Health Agency – Discharge Pathway for Children with Complex Health Needs
- Welsh Health Circular WHC (2017)008 – NHS Wales Policy for the Repatriation of Patients
- National Standards for Children with Cancer Aged 0 to 15 NHS Wales
- Royal College of Nursing – Adolescent Transition Care – RCN Guidance for Nursing Staff
- Welsh Government – Children's National Services Framework.

2. Scope

2.1 Definition

The Paediatric Neuro-Rehabilitation Service will be delivered by a Specialist Interdisciplinary Consultant led team which consists of:

- Consultant
- Inpatient nurses
- Team Lead/Coordinator
- Occupational Therapist
- Physiotherapist
- Speech and Language Therapist
- Neuro-Psychologist
- Clinical Assistant in Neuropsychology
- Dietician
- Rehabilitation assistants
- Clinical Therapy Assistant

2.2 Aims and objectives

The aim is to develop a 24-hour approach to rehabilitation through integrated working of all professionals in conjunction with the family of the child. The professional team is made up of:

- The Paediatric Neurological Rehabilitation Consultant
- Junior Medical Staff
- Nursing Staff
- Physiotherapist
- Clinical Neurological Psychologist
- Clinical Assistant in Neuropsychology
- Speech and Language Therapist
- Occupational Therapist
- Dietician
- Clinical Therapy Assistant
- Play Therapist
- Hospital Education Service
- Dietician
- Neurological Rehabilitation Team lead/Coordinator.

The lead neuro-rehabilitation consultant is responsible for convening the correct mix of individuals to provide appropriate interdisciplinary input into the patient's management.

The service will provide early interdisciplinary team assessment and joint goal setting with the family to ensure patient and family centred care. An appropriate level of interdisciplinary Neuro-rehabilitation therapy will be tailored to the individuals need, and intensity will be

phased to support the seamless transitions from tertiary to local services, accessed either from home or in the local hospital. This will also empower the child and family in managing their ongoing needs.

Patients who have sustained an acute acquired brain (ABI) or neurological injury will be referred to the Paediatric Neuro-Rehabilitation Service following a period of medical stabilisation.

The objectives are to:

- Improve health outcomes to ensure full participation of children following ABI and their families in their communities.

- Provide care that is safe, effective and evidence based (or based on consensus on best practice where evidence base is limited).

- Ensure health care services after the acute phase of care for children and young people following ABI are coordinated with the full array of mental health, educational, social, and other community-based services needed by and provided to children and young people and their families.

- Ensure that children and young people following ABI, and after the acute phase of care, receive their care as close to home as possible.

- Reduce inequalities in outcome due to regional differences in the provision of services to children and young people following ABI.

- Enhance development and functional outcomes for children and young people following ABI, and improve family life, through appropriate and ongoing access to rehabilitative services, monitoring for known complications following ABI and the delivery of effective, outcome-based, high-quality medical care.

- Ensure effective and seamless transition of care from children's to adult health services where required, and to maximise the young person's understanding of their condition and optimise their autonomy and ability to manage their health care.'

- Support parents and families in meeting their responsibilities to nurture and to enhance their child's development.

2.3 Designated centres

The seven Health Boards via WHSSC have commissioned the following centres to provide these services:-

Neurorehabilitation - South Wales

- Noah's Ark Children's Hospital for Wales (NACHfW)
  University Hospital of Wales
  Heath Park
  Cardiff
  CF14 4XW

Neurorehabilitation - North Wales

- Alder Hey Children's NHS Foundation Trust
  East Prescot Road
  Liverpool
  L14 5AB

2.4 Codes

WHSSC commissioning policies can define eligibility for services by listing the relevant diseases, using the code numbers from the International Classification of Diseases (ICD 10). A list of codes like this often does not relate to a person's need for rehabilitation and potential to benefit from it and so has not been included in this policy.

3. Access Criteria

Patients will be managed collaboratively with the other teams that are actively involved with their care. This will include but is not exclusive:

- PCCU
- Neurosurgery
- Acute neurology
- Oncology
- General Paediatricians (Acute and Local)

3.1 Clinical Indications – general principles

A comprehensive specialist Paediatric Neuro-rehabilitation service comprises of four aspects:

- Acute rehabilitation carried out alongside acute neurological, neurosurgical and oncological treatment.
- Tertiary specialist Neuro-rehabilitation carried out after the acute illness phase has ended.
- Long term rehabilitation carried out by the local community multidisciplinary team/ services on discharge from the tertiary centre.
- Outpatient follow up will be provided by the Neuro-rehabilitation Consultant for up to one year.

3.1.1 The Tertiary Specialist Neuro-rehabilitation service

On receiving an appropriate referral the patient will be assessed by the MDT to establish their baseline function and cognition to identify their rehabilitation needs. These needs will then be discussed within the MDT meeting, where a rehabilitation plan and appropriate goals for the patient will be established. The rehabilitation plan and goals should also be discussed and agreed with the patient and their family. Rehabilitation will be carried out by the team and progress will be reviewed and discussed at weekly MDT meetings and treatment plans and goals will be updated.

Local teams will be invited to participate in the arranged MDT meetings early on in the patient's journey.

Rehabilitation intensity and frequency will be phased as the patients' needs change, to empower the family and carers to confidently manage their child's condition in anticipation for discharge and home.

Discharge will be phased and will include full care by family on the ward prior to overnight or weekend leave.

Local community services will be informed of patients that are identified as being likely to require ongoing rehabilitation on discharge.

3.1.2 Outpatient Care

- Approximately one week after discharge from hospital a follow up telephone call will be made to the patient's family or carers to ensure effective discharge and transition from the acute service.
- Parents or carers are able to seek advice from the Neuro-rehabilitation team via telephone until discharge from the Neuro-rehabilitation Consultant.
- Patients will receive outpatient follow by the Neuro-rehabilitation Consultant on discharge. Patient's needs will be identified and referrals made to the local services as indicated.
- The Neuro-rehabilitation team will support local services in an advisory role following discharge from inpatient care.
- There are various pathways for long term care:
    - condition resolves – patient discharged from all services
    - condition stable – shared management with secondary care or management entirely by secondary care
    - complex or long term – management by secondary care and tertiary specialist services (as appropriate).
- Patients discharged to secondary or primary care who later develop problems related to their neurological condition can be re-referred to the tertiary Neuro-rehabilitation service. Patients will be accepted based on access criteria.
- Patients still requiring Specialist Neuro-rehabilitation services between the ages of 16-19 years will be transitioned to the appropriate adult services.

3.1.3 Physical environment

In addition to beds, an inpatient Neuro–rehabilitation facility requires:

- Therapy space (including facilities for activities of daily living)
- Dedicated Ward Area
- Hospital School
- Play space

- Sensory room
- Access to outdoor space
- Adequate secure equipment storage
- Meeting room
- Quiet room
- Office space for staff
- Parental accommodation
- Access to hydrotherapy.

3.2 Criteria for Treatment

The decision to accept a child or young person for specialist neurological rehabilitation, either as an in-patient or for out-patient consultant review, will be related to their need or otherwise for acute medical management as well as their need for a neurological rehabilitation programme. Patients will be accepted by neurological rehabilitation when their acute illness has stabilised.

In order to be accepted by any of the treatment centres and funded via WHSSC under this commissioning policy patients should:-

- be aged 1 year to 16 years old. Young adolescent patients aged 16-18 who satisfy the acceptance criteria should be discussed with the Neurorehabilitation MDT and Nursing Manager of NACHfW[4,5] (South Wales) and Alder Hey Childrens NHS Foundation Trust (North Wales)
- have significant functional deficit as a result of acute brain or spinal injury or another diagnosed neurological condition
- require inter-disciplinary treatment (by 2 or more professionals)
- be medically stable
- no longer requiring regular/ active input from acute medical or surgical teams
- have clear functional goals identified
- benefit from a specialised rehabilitation programme
- consent from patient/parent for referral into the rehabilitation programme
- would benefit most from Neurorehabilitation up to 3 months from the acquired neurological (Brain or Spinal) injury with a longer period of 6 months for oncology patients, who until they have finished their treatment struggle to fully engage in rehabilitation and therefore would not get the full benefit within the timeframe. Generally, these patients remain inpatients for this time.

If potential patients do not meet the above criteria their acceptance will be discussed by the MDT on a case by case basis.

For admission to the Paediatric Neuro-rehabilitation services patients should in addition to the above criteria have one of the following:

- Acquired Brain Injury (ABI) from a variety of causes e.g. trauma, hypoxia, infection, tumour, ischaemia, haemorrhage, following neuro surgical intervention.
- Severe neurological impairment requiring inpatient assessment and intervention by a specialised MDT.

3.3 Referral Pathway (Annex i & ii)

The referral pathway for each of the services is set out in Annex i and the checklist for referral needs to be completed by the agreed treatment centre (Annex ii).

If the patient wishes to be referred to a provider out of the agreed pathway, an IPFR[3] should be submitted.

If the referrer wishes to refer to a different provider because there are no beds available for admission to the designated centres, an IPFR[3] should be submitted.

3.4 Exclusions

- Patients who are aged 18 years old and above.
- Ongoing medical and/or surgical needs that will impact on ability to participate in rehabilitation.
- Too medically unstable to benefit from neurological rehabilitation therapies.
- Patients with a non-neurological diagnosis.
- Failure of parent or patient to consent to participation in the rehabilitation programme.
- When an appropriate specialist interdisciplinary assessments indicates that the patient is unable to benefit from a neurological rehabilitation programme.

3.5 Exceptions

If the patient does not meet the criteria for treatment, but the referring clinician believes that there are exceptional grounds for treatment, an Individual Patient Funding Request (IPFR)[3] can be made to WHSSC under the All Wales Policy for Making Decisions on Individual Patient Funding Requests (IPFR)[3].

If the patient wishes to be referred to a provider out of the agreed pathway and the referring clinician believes that there are exceptional grounds for treatment at an alternative provider, an Individual Patient Funding Request (IPFR)[3] can be made to WHSSC under the All Wales Policy for Making Decisions on Individual Patient Funding Requests (IPFR)[3].

Guidance on the IPFR process is available at:
www.whssc.wales.nhs.uk

3.6 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

Clinician considering treatment should:

- discuss all the alternative treatment with the patient
- advise the patient of any side effect and risks of the potential treatment
- 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.
- Provide a monthly bed status to WHSSC, primarily to identify those patients fit for discharge.

In all other circumstances, submit an IPFR[3] request.

4. Putting Things Right: Raising a Concern

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

5. 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.

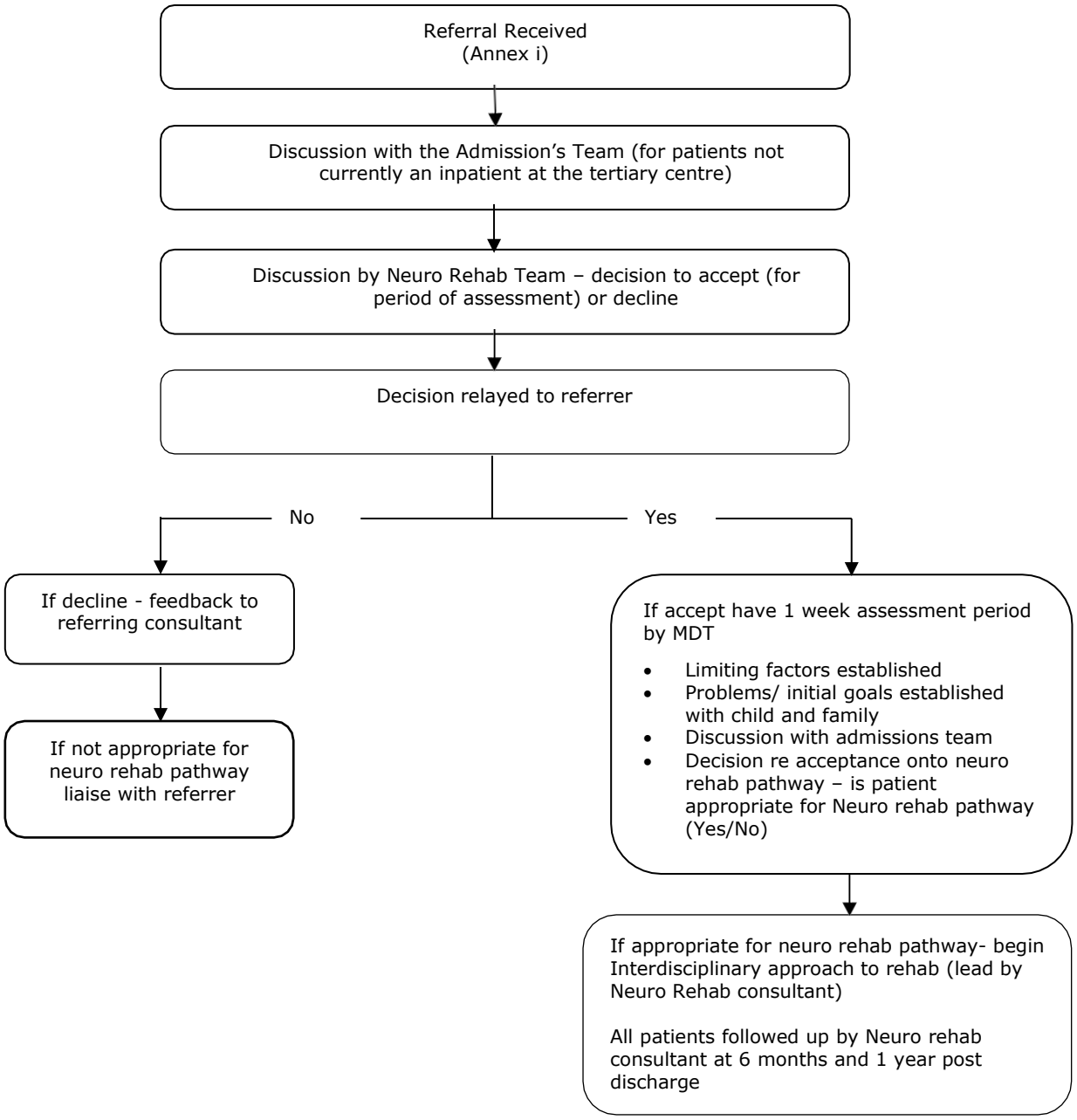
Annex (i) Referral Pathway

Referrals are received from:

Inpatient Referrals for interdisciplinary tertiary care	Outpatient Referrals for Neuro Rehab Consultant Review (Enables access to Neuropsychology Assessment)
Acute Neurology Team	Community Paediatrician
Neuro surgery Team	Neurology Consultant
Oncology Team	Neuro Surgeons
	Oncology Consultants
	Maxillo-facial Consultants

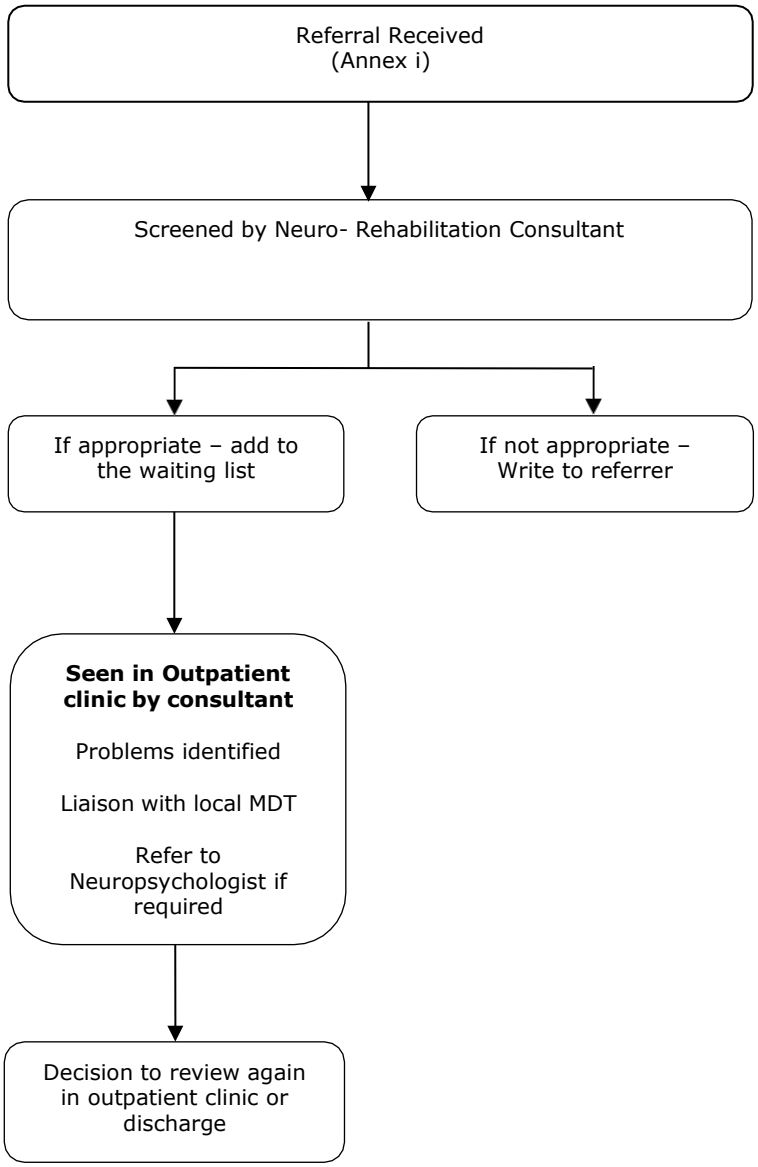
Specialist Paediatric Neuro-rehabilitation

Inpatient Referral Pathway.



Specialist Paediatric Neuro-rehabilitation

Outpatient Referral Pathway.



Annex (ii) Checklist

CP160, Specialised Paediatric Neurological Rehabilitation.

The following checklist should be completed for every patient to whom the policy applies:

i. Where the patient meet the criteria **and** the procedure is included in the contract **and** the referral is received by an agreed centre, the form should be completed and retained by the receiving centre for audit purposes.

ii. The patient meets the criteria **and** is received at an agreed centre, but the procedure is not included in the contract. The checklist must be completed and submitted to WHSSC for prior approval to treatment.

iii. The patient meets the criteria but wishes to be referred to a non contracted provider. An Individual Patient Funding Request (IPFR) Form must be completed and submitted to WHSSC for consideration.

iv. 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.

To be completed by the referring gatekeeper or treating clinician

The following checklist should be completed for ***all*** *patients to whom the policy applies*, before treatment, by the responsible clinician.

Please complete the appropriate boxes:

Patient NHS No:		
Patient is Welsh Resident	Post Code:	
Patient is English Resident registered with NHS Wales GP	GP Code:	

Patient meets following criteria for treatment:	**Yes**	**No**
Meets the criteria for category A rehabilitation need. (BSRM Guideline) **and**		
Is deemed medically fit as assessed by specialised MDT **and**		
Is able to be safely supported in an environment of reduced medical support **and**		
Does not have major investigations pending, e.g. for non-traumatic conditions **and**		
Does not require mechanical ventilation **and**		
Is considered by the centre's MDT to have specific goals for assessment and rehabilitation that can be safely met in collaboration between the patient and MDT **and**		
Is able to benefit from an intensive rehabilitation programme **and**		
Does not have significant pre-morbid dementia.		
Patient wishes to be referred to non-contracted provider		
If the patient wishes to be referred to a non-contracted provider an Individual Patient Funding Request (IPFR)[3] must be completed and submitted to WHSSC for approval prior to treatment. *The form can be found at* *http://www.wales.nhs.uk/sites3/docopen.cfm?orgid=898&id=181455*		
Patient does not meet access criteria		
An Individual Patient Funding Request (IPFR)[3] must be completed and submitted to WHSSC for approval prior to treatment. *The form can be found at* *http://www.wales.nhs.uk/sites3/docopen.cfm?orgid=898&id=181455*		

Name_____Designation: _____

Signature: _____Date:_____

	Name (printed):	Signature:	Date:	Yes	No
Authorised by TRM Gatekeeper					
Authorised by WHSSC Patient Care Team					
Authorised by agreed other (please state)					
Patient Care Team/IPFR[3]/TRM Reference number:					

Annex (iii) Delayed Transfers of Care

Management of delayed transfers from specialised rehabilitation services commissioned by the Welsh Local Health Boards via the Welsh Specialised Services Committee (WHSSC).

Background

Rehabilitation is not an open ended treatment but is focussed on achieving specific aims within agreed timescales, subject to review.

The purpose of this policy is to incentivise Local Health Boards to place patients in more appropriate placements at the earliest opportunity once their needs for specialised rehabilitation have been met. The policy does not seek to attach blame or identify reasons for any excess delay but simply recharge Local Health Boards the costs incurred by WHSSC for patients.

The skills and facilities of the specialised rehabilitation services commissioned through WHSSC are valuable resources which need to be focussed on the patients most able to benefit from them.

Similar arrangements have been operated by the Health Boards and WHSSC since 2010 for patients in medium secure mental health placements and have led to significant reduction in inappropriate use of specialist resources.

Implementation

Specialised rehabilitation services will identify target discharge dates during the course of their rehabilitation assessment and programme and will work with the patient's Local Health Board towards achieving this.

When the specialised rehabilitation service multi-disciplinary team agree that:

- the specific aims agreed in the rehabilitation programme have been met

or

- the patient can no longer benefit from the specialised rehabilitation they provide

or

- that the rehabilitation can be appropriately provided by a less specialised service.

They will record this decision and inform the patient's Local Health Board and WHSSC.

The service will continue to work with the LHB towards a planned discharge applying the NHS Wales Policy for the Repatriation of patients.

The service provider and patients LHB will be required to provide evidence, as indicated in the steps outlined below and that they have taken all the necessary measures, to repatriate the patient within the time frames outlined in the NHS Wales Policy for the Repatriation of patients[6].

If the patient remains in the specialised service after these conditions have been met, they will no longer meet the eligibility criteria in this Commissioning Policy. WHSSC will allow an eight week period and then the relevant provider will reclaim the placement costs from the patient's Local Health Board.

The evidence required will be as follows:

Step 1: Date and time patient was identified fit for Discharge from the Specialised service.

Step 2: Date and Time the patients' Health Board was notified the patient was fit for discharge.

Step 3: Has the Patient been repatriated within 24 hours from the time the patient was declared fit for discharge.

Step 4: If no – Date and time escalation procedures commenced.

Step 5: After 48 hours: Date and Time the patients' position was reported to the relevant Operational Manager indicating actions agreed.

Step 6: After 72 hours: Date and Time patients' position reported to Executive Director indicating actions agreed.

Step 7: If the patient remains in the specialised service after all steps have been exhausted they will be considered to be no longer meeting the eligibility criteria in this Commissioning Policy.

Step 8: WHSSC will allow an eight week period and then the relevant provider will reclaim placement costs from the patient's Local Health Board.

[6] http://gov.wales/docs/dhss/publications/170308whc008en.pdf