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Committee

Paediatric Persistent Pain Service for children aged up to 16 years

Commissioning Policy: CP290

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Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Review Date	January 2028

Contents

Abbreviations	4
Policy Statement	5
Welsh Language	5
Decarbonisation	5
Disclaimer	5
1. Introduction	7
1.1 Plain Language Summary	7
1.2 Aims and Objectives	7
1.3 Epidemiology	9
1.4 Current Treatment.....	9
1.5 What NHS Wales has decided.....	9
1.6 Relationship with other documents	9
2. Criteria for Commissioning	12
2.1 Inclusion Criteria	12
2.2 Continuation of Treatment	13
2.3 Acceptance Criteria	13
2.4 Transition of Care	13
2.5 Patient Pathway (Annex i)	14
2.6 Service Providers/Designated Centres	15
2.7 Exceptions	15
2.8 Clinical Outcome and Quality Measures	15
2.9 Responsibilities	16
3. Evidence	17
3.1 Date of Review	17
4. Equality Impact and Assessment.....	18
5. Putting Things Right:	19
5.1 Raising a Concern.....	19
5.2 Individual Patient Funding Request (IPFR)	19
Annex i Patient Pathway & Integrated Care.....	20
Annex ii Glossary	21
Contact Us.....	22

Abbreviations

AfC	Agenda for Change
CHfW	Children's Hospital for Wales
CYP	Children and Young People
ENT	Ear, Nose and Throat
EQIA	Equality Impact Assessment
GP	General Practitioner
IPFR	Individual Patient Funding Request
MDT	Multi-Disciplinary Team
NHS	National Health Service
NICE	The National Institute for Health and Care Excellence
NRI	National Reportable Incident
NWJCC	NHS Wales Joint Commissioning Committee
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
WTE	Whole Time Equivalent

Policy Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission a Specialised Paediatric Persistent Pain Service for children aged up to 16 years in accordance with the criteria outlined in this document.

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

Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the [Welsh Language 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, NWJCC 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

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 judgment, knowledge and expertise when deciding whether it is appropriate to apply this policy.

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

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

1. Introduction

This policy has been developed for the planning and delivery of a Specialised Paediatric Persistent Pain Service for children aged up to 16 years resident in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to residents of all seven Health Boards in Wales.

1.1 Plain Language Summary

Children and young people (CYP) who suffer persistent pain and pain associated disability (disease and non-disease related) that is refractory to primary, secondary and non-specialised tertiary healthcare input.

Persistent pain in CYP is recurrent pain which persists beyond the usual course of an acute disease or which is associated with an underlying chronic condition. Persistent pain in CYP is usually considered as pain present after a period of three months. However, there are definite persistent pain conditions, such as complex regional pain syndrome and some cancer pains, which manifest before this period has elapsed.

1.2 Aims and Objectives

This policy aims to define the commissioning position of NWJCC on the use of the Specialised Paediatric Persistent Pain Service for children aged up to 16 years' resident in Wales.¹

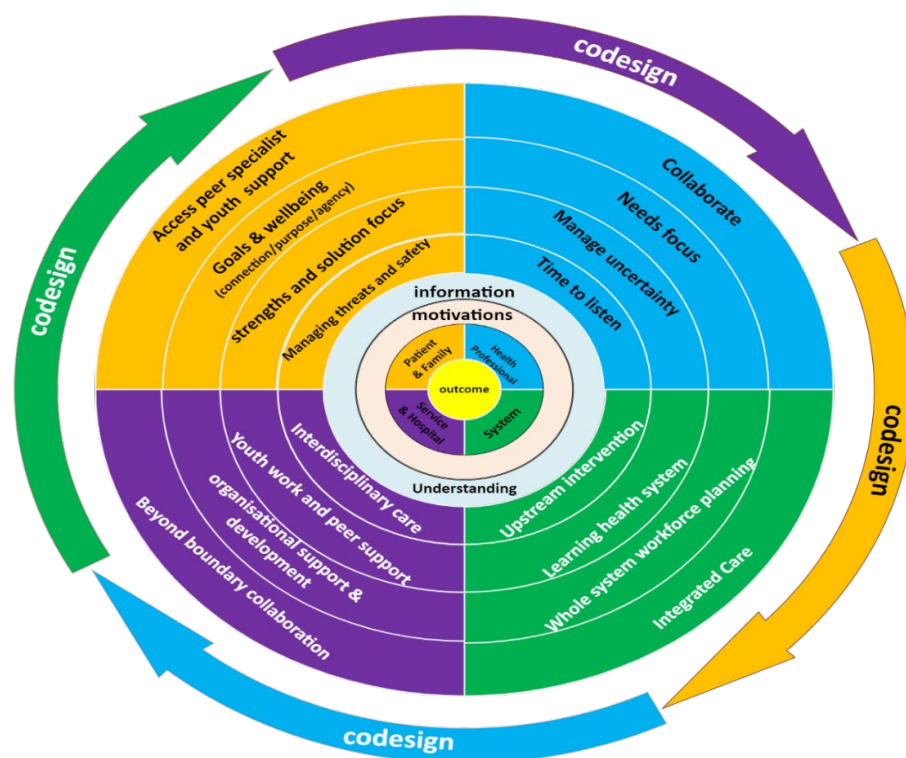
The aim is to provide a timely, specialist multi-disciplinary approach to the diagnosis and management of persistent pain in children aged up to 16 years and their families, putting in place a patient specific management plan, which aids improvement in quality of life and functional abilities and reduces the socioeconomic burden of pain for the family. The mental health needs of the child will be considered and addressed throughout the pathway utilising all MDT members.

The objectives of this service policy are to:

- Provide a multi professional patient specific assessment of the patient's needs and put in place an individual management plan
- Promote the highest possible quality of life for CYP with pain and pain associated disability and their families
- Provide accurate diagnosis where appropriate and possible
- Appraise and communicate the therapeutic options to the child and family to ensure agency and joint decision making

¹ [International Association for the Study of Pain \(IASP\) definition of pain 2020](#)

- Offer pharmacological (where appropriate), physical, psychological and behavioural interventions that support patients, the whole family unit, including siblings, in managing their pain, enabling them to engage in meaningful roles and routines within their everyday lives with reduced disability
- Provide leadership for an integrated approach to managing pain at all sites engaging necessary partners and facilitating upstream intervention
- Develop tools based on best available evidence for access by other stakeholders and to support remote access to care
- Provide interventional pain procedures when appropriate
- Promote independence and wellbeing for patients through the provision of structured self-management support, with concomitant benefits of fewer inappropriate medical appointments and readmissions
- Ensure that effective communication takes place between all related professionals and service providers
- Provide in-patient support particularly around the management of pain problems of high medical and psychological complexity (required in exceptional circumstances)
- Provide leadership to ensure pathways are designed for effective pain management
- To ensure that transition to adult persistent pain management services is managed effectively to minimise disruption to management and unnecessary suffering to the patient (see section 2.4)
- Provide training and support for an effective integrated approach to care including access to a community of practice
- The following diagram provides an illustration of Stakeholder Commitments and how the community of practice will support the development of a whole system approach.



1.3 Epidemiology

Persistent pain affects 8-40% of children and young people (CYP) and is severe in 5%, affecting quality of life and participation in social, family and physical activities including school attendance. Across a number of studies^{2,3,4} it is reported that between 3-6% of pupils have long term school absences of >10% where pain is cited as a major contributing factor to missing school. This means in Wales at least 18,000 pupils do not have their needs met when managing persistent pain.

Furthermore, some of these patients overlap with the 2,600 children having difficulties with chronic fatigue or other disabling symptoms.

1.4 Current Treatment

This service does not currently exist in Wales.

Patients are referred to specialist services in Bath, Birmingham, Liverpool and Great Ormond Street for persistent pain management.

1.5 What NHS Wales has decided

NWJCC has carefully reviewed the evidence for a Specialised Paediatric Persistent Pain Service for children aged up to 16 years. We have concluded that there is enough evidence to fund the use of specialised persistent pain services within the criteria set out in section 2.1.

1.6 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)
 - [All Wales attendance Framework \(gov.wales\) 2012](#)
 - [Health & Care Standards Framework April 2015](#)
 - [Prudent Healthcare Securing health & well-being for future generations \(2016\)](#)
 - [Well-being statement 2017 - Prosperity for all: the national strategy](#)
 - [A Healthier Wales: our Plan for Health and Social Care 2018](#)
 - [Living with Persistent Pain in Wales \(gov.wales\) 2019](#)
 - [A Healthier Wales: Our Workforce strategy for health and social care 2020](#)

² [The epidemiology of chronic pain in children and adolescents revisited: a systematic review - PubMed \(nih.gov\)](#)

³ [Oxford Textbook of Pediatric Pain | Oxford Academic \(oup.com\)](#)

⁴ [School Absence Associated With Childhood Pain in the United States - PubMed \(nih.gov\)](#)

- [Health and Social Care \(Quality and Engagement\) \(Wales\) Act \(2020\)](#)
- [Quality and Safety Framework \(2021\)](#)
- [National Clinical Framework for Wales \(2021\)](#)
- [NHS Wales Performance Framework 2022-2023](#)
- [NEST Framework: full report, Welsh Government, updated August 2023](#)
- [Living with Persistent Pain, Welsh Government, September 2023](#)

- **NHS Wales Joint Commissioning Committee policies and service specifications**
 - [Specialised Services Service Specification: Services for Children with Cancer \(CP86\)](#)
 - [Specialised Paediatric Neurological Rehabilitation \(CP160\) April 2018](#)
 - [In-Patient Child and Adolescent Mental Health Services \(CAMHS\):General Adolescent Unit \(GAU\) and Extra Care Area \(ECA\) \(CP150\) November 2023](#)
 - [Specialised Paediatric Rheumatology Service Specification \(CP172\) November 2021](#)
 - [Specialised Paediatric Gastroenterology, Hepatology and Nutrition \(PGHAN\) \(CP211\) May 2023](#)

- **National Institute of Health and Care Excellence (NICE) guidance**
 - [Transition from children's to adults' services for young people using health or social services \(NG43\)](#)
 - [Chronic pain \(primary & secondary\) in over 16s: assessment of all chronic pain & management of chronic primary pain \(NG193\)](#)

- **Relevant NHS England policies**
 - [Paediatric Surgery - Chronic Pain](#)
 - [Adult highly specialist pain management services](#)

- **Other published documents**
 - [Management of Chronic Pain, SIGN 136, Health care improvement Scotland, August 2019](#)
 - [Guidelines on the management of chronic pain in children WHO 2020](#)
 - [Guidelines on the management of chronic pain in children: executive summary WHO 2021](#)
 - [Core Standards for Pain Management Services in the UK 2nd Ed. Faculty of Pain Medicine 2021](#)
 - [Cochrane Review CHAMPION study published October 2023](#)

• **Published Articles**

- [The epidemiology of chronic pain in children and adolescents revisited: a systematic review - PubMed \(nih.gov\)](#) King S, Chambers CT, Huguet A, MacNevin RC, McGrath PJ, Parker L, MacDonald AJ
- [School Absence Associated With Childhood Pain in the United States - PubMed \(nih.gov\)](#) Groenewald CB, Giles M, Palermo TM
- [The prevalence of sickness absence among primary school pupils - reason to be worried? - PubMed \(nih.gov\)](#) Pijl EK, Vanneste YTM, de Rijk AE, Feron FJM, Mathijssen J
- [Addressing medical absenteeism in pre-vocational secondary students: Effectiveness of a public health intervention, using a quasi-experimental design — Tilburg University Research Portal](#) Vanneste YT, Mathijssen JJP, Goor LAM, van de R-d VMC, Feron FJM
- [Oxford Textbook of Pediatric Pain | Oxford Academic \(oup.com\)](#) Bonnie J. Stevens (ed.), Gareth Hathway (ed.), William T. Zempsky (ed.)

2. Criteria for Commissioning

The NHS Wales Joint Commissioning Committee will approve funding for specialised paediatric persistent pain services for children aged up to 16 years' resident in Wales who suffer persistent pain associated disability (disease and non-disease related) that is refractory to primary, secondary and non-specialised tertiary healthcare input.

Persistent pain in CYP is recurrent or persistent pain which persists beyond the usual course of an acute disease or which is associated with an underlying chronic condition. Persistent pain in CYP is considered as pain present after a period of three months. However, there are definite persistent pain conditions, such as complex regional pain syndrome and some cancer pains, which manifest before this period has elapsed in line with the criteria identified in this policy.

2.1 Inclusion Criteria

Patients up to age 16 who have previously been seen by a paediatric secondary or tertiary specialist for management of their persistent pain would be eligible for referral to the service.

It is difficult to be rigid about referral criteria, but generally it would normally include: significant absence from school (pupils who have missed more than 10% of school sessions⁵) because of pain; frequent, repeated attendance at the Emergency Department; high frequency of urgent paediatric or pain outpatient appointments; prolonged inpatient episodes due to uncontrolled pain and pain associated symptoms.

Acceptance criteria would remain at the discretion of paediatric specialists who feel that the child's symptoms are disabling and not well managed by their expertise. The persistent pain service will guide and support the delivery of care through existing service and supplement with the right resource.

Examples of appropriate referrals would be: children with specific disease related pain that has become unmanageable – e.g. childhood arthritis leading to intractable limb pain, inflammatory bowel disease leading to persistent abdominal pain and children with specific pain conditions such as complex regional pain syndrome, neuropathic pains, juvenile fibromyalgia, intractable headaches and cancer patients whose pain is not controlled by the policies and procedures of the oncology unit (this is particularly relevant for children with tumours involving major nerves).

Referrals will need to be based on the following:

⁵ [Why is school attendance important and what support is available? The Education Hub. Gov.UK. September 2023](#)

- that the referral is considered appropriate by the specialist centre
- that the referring specialist is not able to manage the child's pain symptoms
- all investigations relevant for that individual have been completed, results obtained and feedback given to the patient/family
- all appropriate simple analgesics have been considered and utilised using the WHO analgesic ladder⁶
- an explanation to the patient and family of the multi-disciplinary pain management service has been given and the patient/family is in agreement with the referral
- where the referral has not originated from a Consultant, the referral must have been agreed by the responsible Consultant.

2.2 Continuation of Treatment

Healthcare professionals are expected to review a patient's health at regular intervals to ensure they are demonstrating an improvement to their health due to the treatment being given.

If no improvement to a patient's health has been recorded, then clinical judgement on the continuation of treatment must be made by the treating healthcare professional.

2.3 Acceptance Criteria

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

2.4 Transition of Care

All children and young people with a specialist persistent pain condition need a coordinated transitional care programme leading to transfer of care to an adult persistent pain team and persistent pain MDT services at an appropriate age.

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 NG43⁷ and the Welsh Government Transition and Handover Guidance⁸.

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

⁶ [WHO Analgesic Ladder](#)

⁷ [Transition from children's to adults' services for young people using health or social care services NG43 February 2016](#)

⁸ [The Transition and Handover Guidance. Welsh Government. February 2022](#)

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.

2.5 Patient Pathway (Annex i)

Local Health Boards will have their own referral forms for referral to the specialised Persistent Pain service, and the Community of Practice will consider the development of a standardised All Wales referral form.

Clear documented pathways of care will be in place between local providers and specialist centres.

Referrals will only be accepted from secondary, tertiary and quaternary care. Primary care persistent pain referrals are triaged by secondary care general paediatric colleagues.

Referrals will be accepted from all health boards within Wales.

2.6 Service Providers/Designated Centres

The service at the Noah's Ark Children's Hospital for Wales will provide a tertiary service for the residents of South Wales and South Powys and support the development of the Community of Practice for all of Wales. The tertiary service for the residents of North Wales and North Powys will be provided by Alder Hey Children's Hospital.

Noah's Ark Children's Hospital for Wales
Cardiff and Vale University Health Board
Heath Park Way
Cardiff
CF14 4XW

Alder Hey Children's hospital
Eaton Road
Liverpool
L12 2AP

2.7 Exceptions

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

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

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

2.8 Clinical Outcome and Quality Measures

The Provider must work to written quality standards and provide monitoring information to the lead commissioner which includes:

- all National Reportable Incidents (NRI'S)
- complaints
- themes and trends from NRI's and complaints
- workforce challenges
- admission refusals
- Quality Improvement initiatives
- PREMS/PROMS

- staff well-being and support

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

- The provider should have a recognised system to demonstrate service quality and standards.
- The provider should have an approved database to ensure the quality of data collection.
- The service should 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 should be subject to regular clinical and management audit.

The provider is required to undertake regular patient surveys, develop and implement an action plan based on findings.

2.9 Responsibilities

Referrers should:

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

Clinicians considering treatment should:

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

In all other circumstances an IPFR must be submitted.

3. Evidence

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

3.1 Date of Review

This document is scheduled for review before January 2028 where we will check if any new evidence is available. If no new evidence or intervention is available, the review date will be progressed.

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

4. Equality Impact and Assessment

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

This policy has been subjected to an Equality Impact Assessment.

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

5. Putting Things Right:

5.1 Raising a Concern

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

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

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

5.2 Individual Patient Funding Request (IPFR)

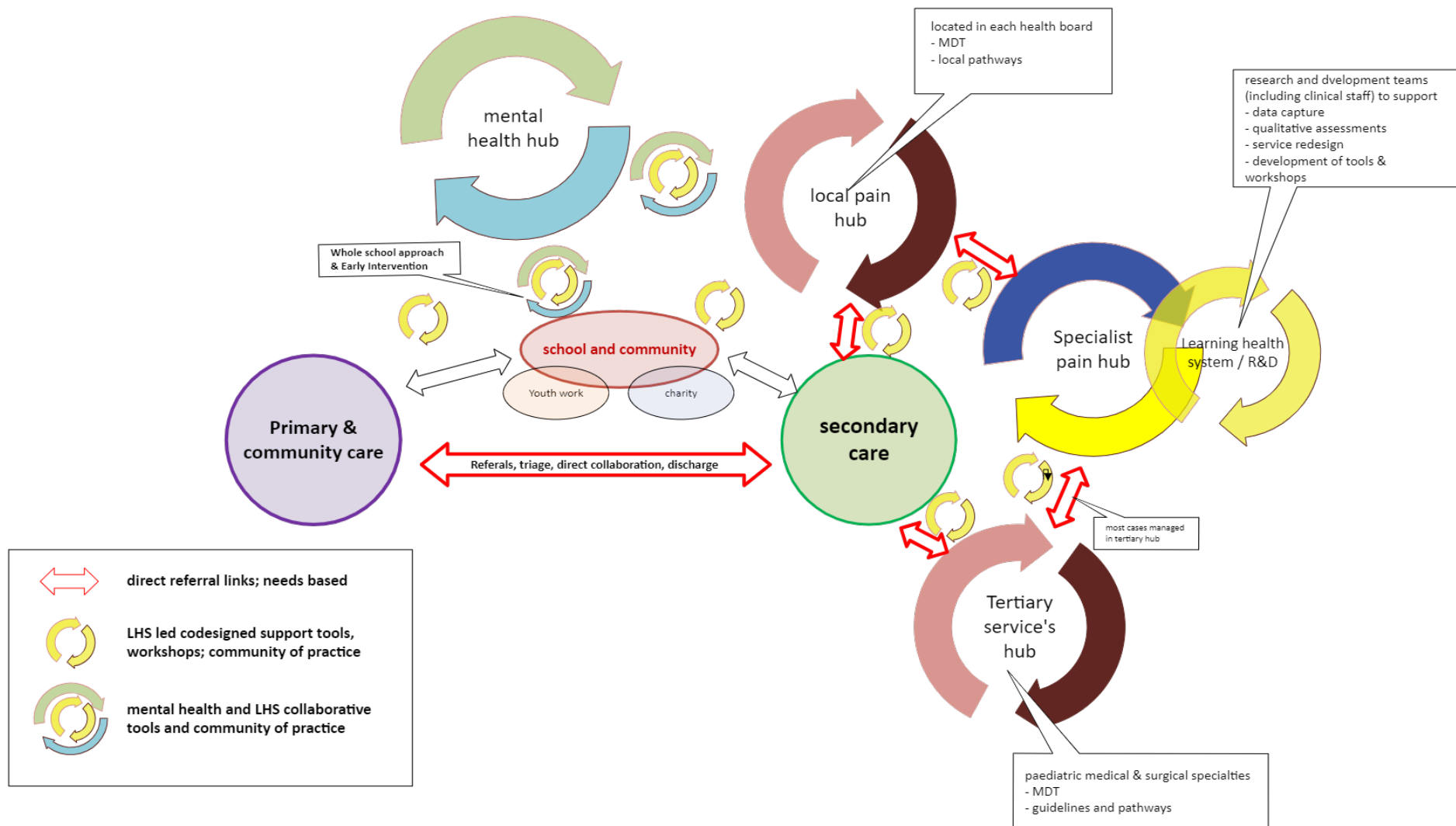
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All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

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

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

Further information on making IPFR requests can be found at: [Individual Patient Funding Requests](#)

Annex i Patient Pathway & Integrated Care



Annex ii Glossary

Glossary

Individual Patient Funding Request (IPFR)

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

NHS Wales Joint Commissioning Committee (NWJCC)

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

Contact Us

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

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

Email:

NWJCC consultation mailbox – nwjccconsultation@wales.nhs.uk

Telephone:

General Enquiries – 01443 433112

Website:

[Contact us - NHS Wales Joint Commissioning Committee](#)

Writing:

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

South Wales Offices

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

North Wales Offices

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