GIG CYMRU NHS WALES
Cyd-bwyllgor Comisiynu
Joint Commissioning Committee

Paediatric Persistent Pain Service for children aged up to 16 years

Service Specification: SS290

Document Information	
Document Name	Paediatric Persistent Pain Service for children aged up to 16 years
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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

AfC	Agenda for Change
AWMSG	All Wales Medicines Strategy Group
CHfW	Children's Hospital for Wales
CYP	Children & Young People
DHCW	Digital Health and Care Wales
ENT	Ear, Nose and Throat
EQIA	Equality Impact Assessment
GP	General Practitioner
HEIW	Health Education and Improvement Wales
IPFR	Individual Patient Funding Request
MDT	Multi-Disciplinary Team
NHS	National Health Service
NEST	Nurturing, Empowering, Safe, Trusted framework for mental health and wellbeing
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
SMC	Scottish Medicines Consortium
WTE	Whole Time Equivalent

Statement

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

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

Welsh Language

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

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

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

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of 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 Background

Children aged up to 16 years' 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 children aged up to 16 years' 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 children aged up to 16 years' 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.

Pain is described as an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human experiences pain.

1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering a specialised paediatric persistent pain service for children aged up to 16 years' resident in Wales.[1]

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

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.

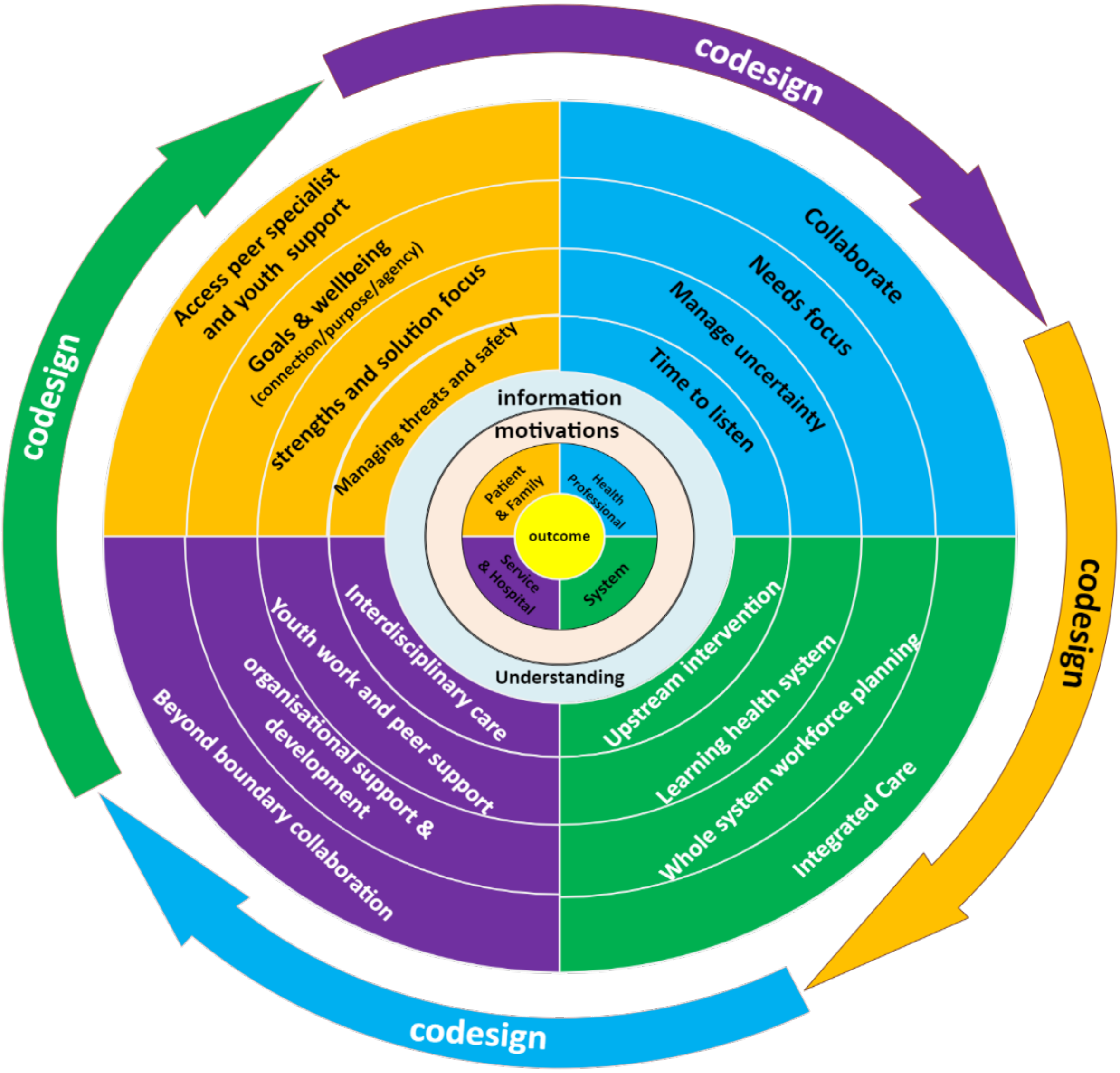
The specialised service will work within a wider model of care that can support high numbers of children, some of which will have high levels of complexity. The wider model is based on the local provision of care, with skilled MDTs in every health board with links to schools, providing timely access to expertise, with a joined up consistent MDT approach. Only a very small number of children will need access to tertiary level support. The team within the specialised service, will support the development of a 'Community of practice', engaging across healthcare providers and working in partnership with the newly established Child Health Strategic Network and the Persistent Pain Clinical Implementation Network.

The objectives of this service specification are to:

- provide leadership for a biopsychosocial model of care, based on an integrated and triaged approach that matches healthcare resource to the level of need and level of complexity
- provide a consultation/ second opinion multi professional patient specific assessment for the most complex patients and discuss and agree an individual management plan with the referring clinician, child and young person and their family
- promote the highest possible quality of life for children aged up to 16 years with pain and pain associated disability and their families
- provide care and support that is delivered at or as close to the child's home as possible
- offer pharmacological (only when 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 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
- in rare cases provide in-patient support particularly around the management of pain problems of high medical and psychological complexity,
- ensure that effective communication takes place between all related professionals and service providers

- 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 leadership to ensure pathways are designed for effective pain management
- develop tools based on best available evidence for access by other stakeholders and to support remote access to care
- provide training and support for an effective integrated approach to care including access to 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 Population Covered

This service is for children with persistent pain conditions requiring specialised intervention and management with an integrated psychosocial care approach that matches resource to need at the closest point to home as outlined within this specification. 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. Both sites will provide this tertiary service and provide support for the surrounding childhood population in partnership with their local secondary care services.

1.4 Current Service Model

This service does not currently exist in Wales.

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

1.5 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)
    - Health & Care Standards Framework April 2015
    - A Healthier Wales: Our Workforce strategy for health and social care 2020
    - NHS Wales Performance Framework 2022-2023

- **Welsh Government**
    - All Wales Attendance Framework (gov.wales) 2012
    - 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
    - Health and Social Care (Quality and Engagement) (Wales) Act 2020
    - Quality and Safety Framework: Learning and Improving Welsh Government 2021
    - National Clinical Framework: A Learning Health and Care System Welsh Government 2021
    - The Transition and Handover Guidance, Welsh Government February 2022

  - NEST Framework: full repport, Welsh Government, last update 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
  - Specialised Paediatric Rheumatology Service Specification (CP172) November 2021
  - Specialised Paediatric Gastroenterology, Hepatology and Nutrition (PGHAN) (CP211) May 2023
  - In-Patient Child and Adolescent Mental Health Services (CAMHS):General Adolescent Unit (GAU) and Extra Care Area (ECA) (CP150) November 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**
  - 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
  - Management of Chronic Pain, SIGN 136, Health care improvement Scotland, August 2019

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission a Paediatric Persistent Pain Service for children and young people aged up to 16 years, in line with the criteria identified in this specification.

2.1 Proposed Service

Specialised services for children with persistent pain in addition to the standards required within the contract, specific quality standards and measures will be expected. The provider must also meet the standards as set out below.

- Assessment of referral letter.
- Clinician to undertake wait list assessment with patient and family virtually e.g. via Teams.
- Outpatient assessment with patient and family, or in-patient consultation where the patient is already an in-patient, to confirm or make a diagnosis of persistent pain, including a review of benefits and adverse effects of current and new medication.
- Multidisciplinary team (MDT) discussion with relevant professionals – to agree patient specific management plan.
- Follow-up appointments with therapists to provide pain management strategies.
- Follow-up out-patient appointments to monitor patient.
- Inpatient attendance (only where deemed appropriate).
- Resource to support teaching and training, audit and research.

There are rare instances when an intensive residential pain management programme might be deemed appropriate, in these instances a child may require referral to an English provider.

The service will be developed through a phased approach with phase 1 enabling the specialised paediatric persistent pain service to have scope to support the development of local services in conjunction with the newly established Child Health Strategic Network and the Persistent Pain Clinical Implementation Network, and achieve objectives set out in this service specification. A review will be undertaken in 2026/2027, once local services are established to assess what the ongoing requirements of the tertiary service are.

The objectives for phase 1 are the provision and support for the following:

- a consultation/second opinion service for children aged up to 16 years with persistent pain, along with the delivery of care to a small number of referrals with high complexity
- the provision of overarching professional leadership, collaborating with every Health Board and with all relevant paediatric specialised services
- developing links with Health Education and Improvement Wales (HEIW) and Digital Health and Care Wales (DHCW)
- co-designing web resources / Apps and workshops for users and professionals
- co-designing pathways to support primary and community care, and establish the remit for secondary and tertiary care
- working with local teams to support the development of locally based services
- working with relevant groups on data analytics to identify populations of need.

Staffing

The provider will be required to develop a multidisciplinary team that has the expertise to ensure effective delivery of pathways of care to a small number of referrals with high complexity. The provider will be required to provide the necessary infrastructure to support the delivery of the objectives outlined above, including the requirement to setup and support a community of practice model (Annex i).

Essential Staff for Phase 1:

- Medical Consultant (with further training specific to persistent pain)
- Physiotherapy
- Practitioner Psychologist
- Occupational Therapy
- Clinical Fellow (with flexibility to appoint from any profession represented within the team)
- Project Manager
- Administrative Support
- Access to a Gynaecologist with an interest in pelvic pain.

2.2 Interdependencies with other services or providers

The aim is to support the development of a fully integrated service to ensure pain management and paediatric rehabilitation are the responsibility of all involved in paediatric healthcare. The service will need to link with:

Specialists in Paediatric:

- Rheumatology
- Gastroenterology

- Anaesthesia
- Neurology
- Orthopaedic Surgery
- General Surgery
- Gynaecology
- Urology
- Dentistry
- Neurosurgery
- Plastic Surgery
- ENT Surgery
- Oncology
- Mental Health Services
- Community Teams, including all Allied Health Professionals
- Palliative Care.
- Social services
- Primary care (GP’s and community nursing)
- Educational services
- Adult persistent pain services to ensure robust transitional arrangements are in place

2.3 Acceptance Criteria

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

2.4 Transitional 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.

All transition arrangements should be in line with Transition from children's to adults' services for young people using health or social services (NG43) and Welsh Government guidance the transition and handover from children’s to adult services (February 2022)

Transition involves a process of preparation for young people and their families for their transition to adulthood and their transition to adult services. This preparation should start from early adolescence 12-13 year olds. The exact timing of this will ideally be dependent on the wishes of the young person but will need to comply with local resources and arrangements.

2.5 Patient Pathway (Annex ii)

Primary care will be the initial point of contact for individuals seeking pain management services. Patients will be supported to learn about their condition and have a full range of health assessments for physical, emotional, and social well-being and treatment plans developed to manage their needs. If unable to meet the needs of the patient, a referral to secondary care services will follow for appropriate specialists to investigate.

Secondary care providers will facilitate patients to see a specialist doctor in pain management with knowledge and expertise for diagnosing and treating patients who have been referred from primary care. They will collaborate with other health care professionals e.g. physiotherapists, occupational therapists to ensure the best possible outcomes for the patient.

To ensure continuity of care, only secondary care providers will refer patients to the tertiary persistent pain service. Once referred the patient will receive highly specialised care for severe, complex persistent pain management with a multidisciplinary approach.

The specialised paediatric persistent pain service will establish a community of practice working in partnership across subspecialties and health boards, supported by the newly established Child Health Strategic Network and the Persistent Pain Clinical Implementation Network to highlight service need and support the development of staff to meet patient need. The service will work with the community of practice to facilitate the development of common resources including coproduction of workshops and patient information that accommodates different learning styles. The service will also work with relevant groups to establish data analytics across Wales to identify populations of need. The service will collaborate with other bodies including in the fields of education, mental health, pain research both nationally and internationally.

The NWJCC is responsible for commissioning the specialised tertiary service element of the pathway on behalf of local health boards in Wales as outlined in this document. Referrals will be accepted from all health boards within Wales.

Local Health Boards will have their own referral forms for referral to the specialised Persistent Pain service, while an All Wales referral form is developed by the Community of Practice. Referrals will only be accepted from secondary, tertiary and quaternary care. Primary care persistent pain referrals will be triaged by secondary care general paediatric colleagues.

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

2.6 Service provider/Designated Centre

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

3. Quality and Patient Safety

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

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children up to 16 years.

3.1 Quality Indicators (Standards)

Provider outcomes

The provider should report to the NWJCC:

- All National Reportable Incidents (NRI'S)
- Complaints
- Themes and trends from NRI's and complaints
- Workforce challenges
- Refusals
- Quality Improvement initiatives
- PREMS/PROMS
- Staff well-being and support

3.2 National Standards

- NICE Quality Standards
- National Service Framework for Children, Young People and maternity Services, Department of Health

3.3 Other quality requirements

- 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

4. Performance Monitoring and Information Requirement

4.1 Performance Monitoring

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

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

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

NWJCC will conduct performance and quality reviews on an annual basis

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

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

The agreed phase 1 outcome measures are:

- Delivery of tertiary level care
- Establishment of a coalition across subspecialties and health boards to highlight and develop staffing to meet patient needs supported by the newly established Child Health Strategic Network and the Persistent Pain Clinical Implementation Network
- Development of common resources including coproduction of workshops and patient information that accommodates different learning styles
- Data analytics across Wales to identify populations of need
- Collaboration with other bodies including in education, mental health, and pain research services both nationally and internationally

4.3 Date of Review

This document is scheduled for review before January 2028, where we will check if any new evidence is available.

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

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 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.

6. Putting Things Right

6.1 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.

6.2 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 Community of Practice

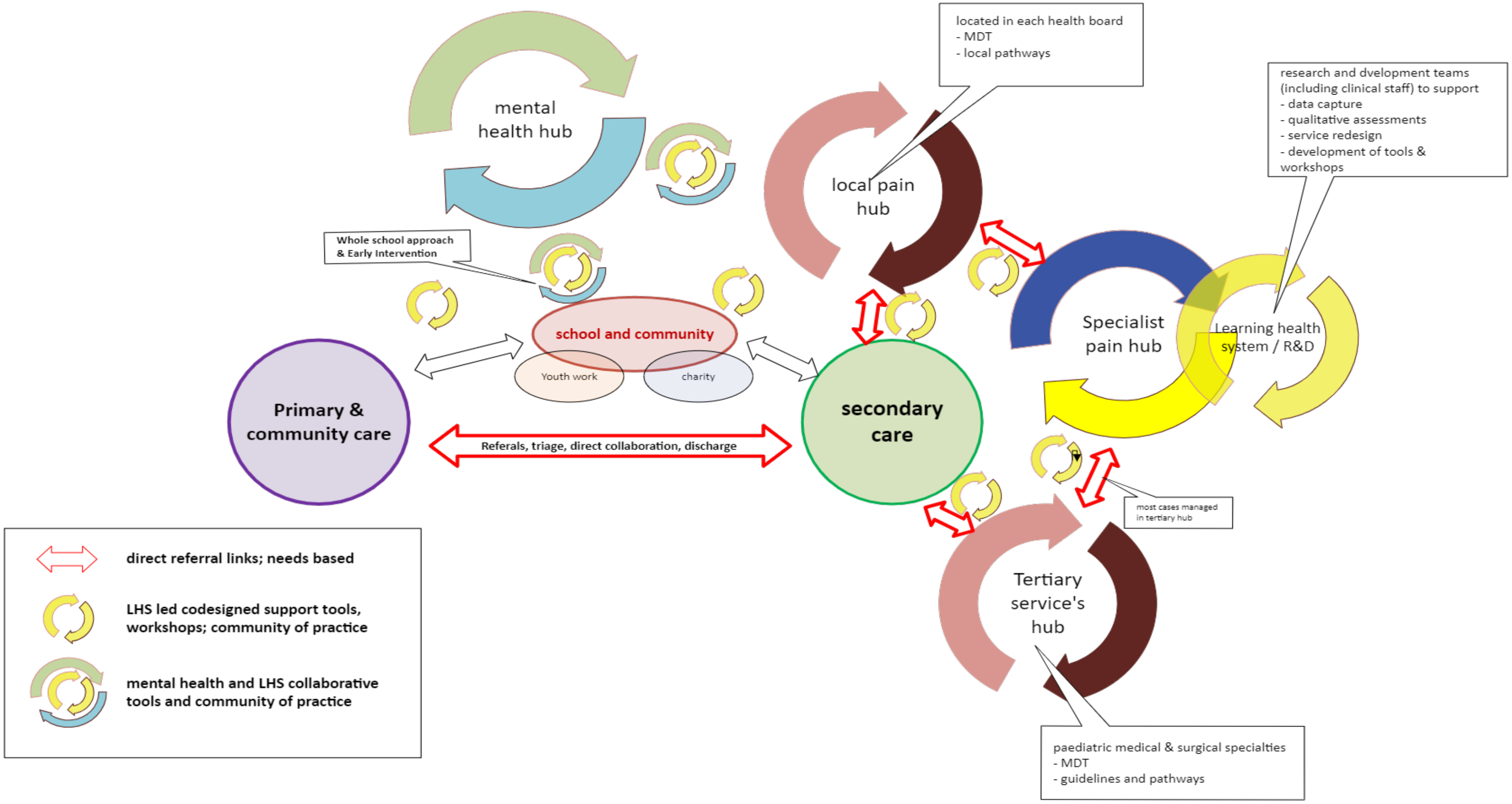
The tertiary service will support the setup of a community of practice across Wales. The service will support the community of practice to:

- establish links with community and hospital care in each health board
- support local teams to develop local services
- establish tiered model
- establish a model that provides support at high incidence settings (based on data analytics)
- set up community of practice workshops / liaison / MDT
- develop Staff and patient education resources
- establish links and resources with schools
- establish links with CAMHS across each health board
- link with safeguarding and social services
- establish links with specialised services including gastroenterology, surgical services and neurology
- link with charities
- set up plans for co-design
- set up data collection, resource use and patient monitoring etc.

Other opportunities:

- Review and benchmark with international best practice
- Young adult pathways.

Annex ii Patient Pathway & Integrated Care



located in each health board
- MDT
- local pathways

research and dvelopment teams (including clinical staff) to support
- data capture
- qualitative assessments
- service redesign
- development of tools & workshops

most cases managed in tertiary hub

paediatric medical & surgical specialties
- MDT
- guidelines and pathways

Annex iii 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