GIG CYMRU NHS WALES

Cyd-bwyllgor Comisiynu
Joint Commissioning Committee

Specialised Paediatric Rheumatology Service

Service Specification: SS172

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Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document Update Information	Content changed post stakeholder comments, Hyperlinks updated

Contents

Abbreviations

ABUHB	Aneurin Bevan University Health Board
AHP	Allied Health Professional
ARMA	Arthritis and Musculoskeletal Alliance
AWMSG	All Wales Medicines Strategy Group
BCUHB	Betsi Cadwaladr University Health Board
BSPAR	British Society for Rheumatology
CVUHB	Cardiff and Vale University Health Board
CHfW	Childrens Hospital for Wales
CNS	Clinical Nurse Specialist
CPD	Continuous Professional Development
CYP	Children & Young People
CTMUHB	Cwm Taf Morgannwg University Health Board
DMARD	Disease Modifying Anti Rheumatic Drugs
HDUHB	Hywel Dda University Health Board
HLH	Haemophagocitic Lymph histiocytosis
IPFR	Individual Patient Funding Request
JIA	Juvenile Idiopathic Arthritis
JSLE	Juvenile Systemic Lupus Erythematosus
JDM	Juvenile Dermatomyositis
MDT	Multi-Disciplinary Team
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute of Clinical Excellence
NWJCC	NHS Wales Joint Commissioning Committee
OPD	Outpatient Department
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcome Measures
PTHB	Powys Teaching Health Board
SMC	Scottish Medicines Consortium
SBUHB	Swansea Bay University Health Board
SLE	Systemic Lupus Erythematous

Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission the service of specialist paediatric rheumatology 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 (Wales) Measure 2011 and the Welsh Language Standards (No.7) Regulations 2018.

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient’s needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgement, knowledge and expertise when deciding whether it is appropriate to apply this document.

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

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

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of specialist rheumatology services for children aged up to 16 years resident in Wales or otherwise the commissioning responsibility of the NHS 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

The Paediatric Rheumatology Service is to meet the needs and optimise the future of children and young people with acute and long-term rheumatic and musculoskeletal conditions. This should include support for early intervention and prevention of adverse musculoskeletal health, as well as pathways of care from primary care, through community and secondary care and on to specialist services. Patients referred to paediatric rheumatology services require clinical assessment to establish the correct diagnosis. Many conditions are diagnosed primarily using clinical findings rather than by specific diagnostic tests such as laboratory or radiological imaging.

Once a diagnosis is made, an appropriate treatment plan is required to:

- rapidly control the condition
- restore, support and maintain physical, social, educational, vocational and emotional growth and development
- minimise chronic disability and deformity
- achieve and maintain remission of disease
- provide appropriate ongoing clinical and holistic care to support physical and mental health and well-being
- provide patient and family education to support the family and allow the child to better manage the condition and limit its impact on day to day activities.

The core work of paediatric rheumatology teams is the long-term care of complex and chronic MSK conditions throughout childhood and adolescence, aiming to improve quality of life, prevent pain and disability, and minimise the impact of chronic conditions on education and psychosocial development. Paediatric rheumatology teams provide care to two discrete cohorts of young people. CYP with inflammatory rheumatological conditions are cared for throughout the paediatric disease course, from diagnosis to discharge or transfer of care to adult rheumatology. CYP with non-inflammatory, often painful, MSK conditions may be seen around the time of diagnosis, often with a view to excluding inflammatory rheumatic disease, and usually with the aim of discharge from specialist care with repatriation to local therapeutic services if needed.

Network leads should work with commissioners, acute healthcare providers, community MSK services, primary care, family hubs and relevant patient organisations to ensure care is co-ordinated and delivered by the right person, in the right place, at the right time[1].

By establishing the needs and / or diagnosis intervention can be provided in terms of medication if appropriate but equally important is supported self-management and improvements in quality of life including school attendance.

Conditions managed by a specialist paediatric rheumatology team are often considered as either inflammatory or non-inflammatory conditions.

Inflammatory Rheumatic conditions are characterised by inflammation that affects the connecting or supporting structures of the body, most commonly the joints, but also sometimes the tendons, ligaments, bones, and muscles. It can affect the whole body and organs such as the lungs, heart and eyes. This is caused by the immune system attacking organs and is referred to as an “auto-immune” and “auto-inflammatory” condition. The nature of auto-immune and auto-inflammatory conditions are unpredictable with fluctuating symptoms.

Inflammatory conditions include:

- Juvenile Idiopathic Arthritis (JIA) and associated eye inflammation (uveitis)
- Juvenile Systemic Lupus Erythematosus (JSLE)
- Juvenile Dermatomyositis (JDM)
- Systemic vasculitis
- Scleroderma related conditions
- Genetic auto-inflammatory periodic fever syndromes
- Secondary Haemophagocitic Lymph histiocytosis (HLH)

These diseases are highly significant with potential for organ damage if not adequately treated[2].

Specialist paediatric rheumatologists may be asked to assess patients that have musculoskeletal presentations, such as symptomatic hypermobility or joint pain that has not responded to appropriate therapy intervention, including physiotherapy or podiatry, and where further tertiary advice or assessment is sought by a secondary care clinician. In addition, they may be asked to assess patients with unexplained fever or multisystem

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[1] Paediatric Rheumatology, GIRFT, December 2025

[2] Juvenile Idiopathic Arthritis and other rheumatological diseases in children, Arzu Soybilgic, Rheumatologist, Arthritis-health, May 2015

critical illness in conjunction with other general paediatric or specialist paediatric teams. The full list of conditions is documented in annex i.

Many of the children seen by the specialist paediatric rheumatology services will have challenging multi-system disease and when presenting with both acute and chronic disease, management may be very complex, involving other paediatric specialities. The specialist paediatric rheumatology team will often take the lead role in such circumstances.

Epidemiology

The prevalence of different rheumatological conditions differs depending on factors such as local demographics and ethnic composition. Many of the diseases are very rare. JIA has a prevalence of 1 in 1,000 under the age of 16. Conditions such as Juvenile Dermatomyositis (JDM) are extremely rare.

It is estimated[3] there are:

- 10,000 children <16yrs in the UK
- half of these will go on to have arthritis in adulthood
- Typical onset age is between 2 and 10 years
- JIA is more common in girls – data from JIA registries found 68 to 70% of patients were female

Impact of the diseases

Rheumatological conditions in children and young people can be a cause of disability as well as have an impact on a young person’s life. Without appropriate therapy some conditions such as JSLE, severe systemic onset JIA and many forms of vasculitis although rare can be fatal. Rapid diagnosis and access to specialist treatment delivered by a skilled multi-disciplinary team is crucial.

Population Covered

This service specification is aimed at delivering safe and effective care for children aged between 0 – 16 years with suspected and confirmed inflammatory and non-inflammatory rheumatology conditions, recognising that these needs can continue into early adulthood. This includes the management of a smooth and efficient transition of young people from children’s services to adult services. There should be clear written description of the Multi-Disciplinary Team (MDT) involved in transitional care, locally and in the clinical network.

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[3] The State of Musculoskeletal Health 2025, Arthritis UK

Current Services

Many conditions require specialist multi-disciplinary care, and the specialist teamwork with the local teams to enhance early diagnosis and delivery of optimal care close to the patient's home where possible.

North Wales

Children from North Wales access specialist paediatric rheumatology services from Alder Hey Children's Hospital either by attending Alder Hey Children's Hospital or outreach clinics delivered by the Alder Hey specialist team at:

- Ysbyty Gwynedd –4 clinics a year
- Ysbyty Glan Clwyd – 4 clinics a year
- Wrexham Maelor Hospital– 4 clinics a year.

South Wales

The Paediatric Rheumatology service is based at the Children's Hospital for Wales. Service provision across neighbouring Health Boards is as follows:

Cardiff and Vale University Health Board (CVUHB)
- Paediatric Rheumatology Service, CHfW, Cardiff
- Paediatric Persistent Pain Service, CHfW, Cardiff

Cwm Taf Morgannwg University Health Board (CTMUHB)
- Paediatric Rheumatology Service via a monthly satellite clinic at the Royal Glamorgan Hospital
- Paediatric Rheumatology Service, CHfW, Cardiff

Aneurin Bevan University Health Board (ABUHB)
- Paediatric Rheumatology Service via a monthly satellite clinic at Serennu Children's Centre

Powys Teaching Health Board (PTHB)
- Paediatric Rheumatology Service, CHfW, Cardiff
- Birmingham Children's Hospital, Birmingham Womens and Children's NHS Foundation Trust
- Powys patients can access care through the Hywel Dda network consultant, depending on location in Powys

Swansea Bay University Health Board (SBUHB)
- Paediatric Rheumatology Service, CHfW, Cardiff

- Weekly paediatric clinics held at Neath Port Talbot Hospital and Morriston Hospital led by a local Consultant with an interest in Rheumatology.
- Monthly clinic held at Singleton Hospital by a link paediatrician with an interest.
- Cardiff paediatric rheumatology service provides a network clinic with the link paediatrician 4 times a year.

Hywel Dda University Health Board (HDUHB)

- Clinics in Bronglais Hospital, Aberystwyth, Withybush Hospital Haverfordwest and Glangwili Hospital, Carmarthen. These are MDT clinics delivered by a Paediatrician with an interest in Rheumatology.
- Paediatric Rheumatology Service, CHfW, Cardiff
- Cardiff paediatric rheumatology service provides a network clinic with the link paediatrician 4 times a year, in Glangwili Hospital, Carmarthen. There is also a-weekly MDT with HDUHB consultant.

Highly Specialised Services

Children with Rheumatology conditions may also access the following Highly Specialised Services following a referral from the specialised services:

Stem Cell Transplantation

Stem cell transplantation for juvenile idiopathic arthritis and related connective tissue disorders is provided at:

Newcastle Upon Tyne Hospitals NHS Foundation Trust
Great North Children's Hospital
Victoria Wing
Royal Victoria Infirmary
Newcastle upon Tyne
NE1 4LP

Ehlers Danlos National Diagnostic Services
Sheffield Teaching Hospitals NHS Foundation Trust
Ehlers-Danlos Syndrome Service
Department of Clinical Genetics
OPD
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Pain Management Services
Royal National Hospital for Rheumatic Diseases

Upper Borough Walls
Bath
BA1 1RL

Regional Ocular Service
Bristol Royal Hospital for Children
Upper Maudlin Street
Bristol
BS2 8BJ

1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering a specialist paediatric rheumatology service for children up to 16 years with suspected and confirmed inflammatory and non-inflammatory rheumatic conditions.

The objectives of this service specification are to:

- detail the specifications required to deliver specialist paediatric rheumatology services for people who are residents in Wales
- ensure a timely and correct diagnosis is made for children presenting with symptoms that could indicate a paediatric rheumatic condition
- ensure minimum standards of care are set for the use of specialist paediatric rheumatology services
- ensure equitable access to specialist paediatric rheumatology services
- identify centres that can provide specialist and highly specialist paediatric rheumatology services for Welsh patients
- improve outcomes for people accessing specialist paediatric rheumatology services
- ensure Tertiary centres work with local health boards to aid early diagnosis and support best practice.

Key Elements and aims of the Service

- To provide appropriate clinical and holistic care to support physical and mental health and well-being for patients with rheumatic and chronic musculoskeletal symptoms not served elsewhere
- Clinical assessment to establish a diagnosis and level of need
- Rapid control of an acute condition or presentation
- To restore, support and maintain physical, social, educational, vocational and emotional growth and development
- To provide community health pathways
- To provide safe therapeutic surveillance and appropriate ongoing care
- To minimise chronic disability and deformity

- To achieve and maintain remission of the condition where possible
- To facilitate shared decision making at every stage of the child's journey with their condition.
- To provide patient and family education to support the family and allow the child to better manage the condition and limit its impact on day to day activities.

1.3 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).
  - HEIW MSK Capability Framework
  - Living with arthritis & musculoskeletal conditions in Wales: A framework for the future - 2024 to 2029, NHS Wales Executive,

- **Welsh Government**
  - Quality Statement for musculoskeletal health Welsh Government October 2023
  - Living with Arthritis and Musculoskeletal Conditions in Wales: a framework for the future 2024-2029 Welsh Government February 2024

- **NHS Wales Joint Commissioning Committee policies and service specifications**
  - Tofacitinib for treating juvenile idiopathic arthritis in people from 2 years old up to their to 16th Birthday PP229 May 2022
  - Commissioning Medicines for children in specialised services CP299 January 2025

- **National Institute of Health and Care Excellence (NICE) guidance**
  - Abatacept, adalimumab, etanercept and tocilizumab for treating juvenile idiopathic arthritis (TA373) December 2015
  - Transition from children's to adults' services for young people using health or social care services (NG43) February 2016
  - Tofacitinib for treating juvenile idiopathic arthritis (TA735) October 2021
  - Anakinra for treating Still's disease (TA685) March 2021

- **All Wales Medicine Strategy Group (AWMSG) guidance**
  - Appraisal of paediatric minor licence extensions - All Wales Therapeutics and Toxicology centre

- **Relevant NHS England policies**

  - Specialised Rheumatology Services (Adult) A13/S/a NHSE 2013 Paediatric Medicine: Rheumatology E03/S/b NHSE 2013
  - Complex Ehlers Danlos service (All Ages) A13/S(HSS)/b NHSE 2013
  - Clinical Commissioning Policy Statement: Biologic Therapies for the treatment of Juvenile Idiopathic Arthritis (JIA) NHSE 2015
  - Baricitinib for use in monogenic interferonopathies (adults and children 2 years and over) (210506P) [URN 1930] NHSE July 2021
  - Clinical Commissioning Policy Abatacept for refractory idiopathic inflammatory myopathies (adults and children aged 2 years and over) [211002P] (URN:1925) NHSE November 2021
  - Clinical Commissioning Policy: Anakinra for Haemophagocytic Lymphohistiocytosis (HLH) for adults and children in all ages [210701P] (1924) NHSE November 2021
  - The National Confidential Enquiry into Patient Outcome and Death. ‘The inbetweeners’ 2023. London
  - Juvenile Idiopathic Arthritis, NCEPOD, February 2025
  - Paediatric Rheumatology, GIRFT, December 2025

- **Other published documents**
  - Rheumatology GIRFT Programme National Speciality Report February 2021
  - Arthritis and Musculoskeletal Alliance. 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis ARMA
  - New and Updated Recommendations for the Treatmentof Juvenile Idiopathic Arthritis–Associated Uveitis andIdiopathic Chronic Anterior Uveitis Arthritis Care Res; doi: 10.1002/acr.24963. Epub ahead of print. PMID: 35638697 Foeldvari I, Maccora I, Petrushkin H et al. 2022
  - Development of a benchmarking toolkit for adolescent and young adult rheumatology services (BeTAR) Cai R.A., Chaplin H., Livermore P. et al, Paediatric Rheumatology 17, article 23, 2019
  - The British Society for Rheumatology guideline for the management of foot health in inflammatory arthritis, Chapman et al, Rheumatology, Vol 64, I5, P2355-2368, May 2025

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission the service of specialist rheumatology for children (aged up to 16 years), in line with the criteria identified in this specification.

2.1 Access Criteria

Pathways need to be clear and robust in each Health Board to avoid delays as the service will accept referrals from secondary and tertiary care clinicians[4] for a child aged 0-16 years who has either:

- a confirmed or suspected diagnosis of an inflammatory or non-inflammatory rheumatic condition
- secondary care is unable to make clear diagnoses; complex musculoskeletal or multi-system syndromes with no clear diagnosis
- Prolonged fever, rash, arthritis, weakness, weight loss, anaemia raised inflammatory markers or generalised malaise, fatigue, anorexia or joint swelling and stiffness
- Rashes in the presence of any of the above, or vasculitic or typical rheumatological rash e.g. of systemic lupus erythematous (SLE) or systemic onset JIA
- Undefined autoimmune disease e.g. complex autoimmune thrombocytopenia.
- Raynaud’s phenomenon (when there are features of underlying conditions)
- Juvenile idiopathic uveitis
- Child protection cases presenting with rheumatological features
- Patients with emerging new diagnoses which would benefit from the expertise of a paediatric rheumatologist.

For patients between the age of 16 and 18 years at the time of referral, new referrals should be made to adult services. Adult clinicians can liaise with Paediatricians if required depending on the nature of the young adult’s presentations. The arrangements for transitional care noted in section 2.11.

Referrals into the rheumatology service will be handled by the receiving service according to the decisions made by the rheumatology consultants in conjunction with the multidisciplinary team.

All care and treatment decisions should be based on shared decision making between the service user (patient), their family and the clinician.

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[4] In rare instances with prior approval from the Consultant Team, referrals from primary care will be accepted.

2.2 Service description

In addition to the standards required within the Contract, specific quality standards and measures will be expected. The specialist provider must also meet the standards as set out below.

The Paediatric Rheumatology Service delivered by the paediatric rheumatology consultants will be delivered through a hub and spoke model, with services being delivered in the designated specialist centre or more locally in acute hospitals. This will require strong links with local services to ensure the services meet the needs of the patients. Each paediatric service should have a named lead for linking in with the relevant local specialist paediatric rheumatology team. Each adult rheumatology team should have a named lead for linking in with the relevant local specialist paediatric rheumatology team to support transition arrangements.

The service will make use of advances in technology which allow for patients to attend virtual clinics via systems such as “T-Pro”.

In addition to the standards required within the Contract, specific quality standards and measures will be expected, detailed in section 3. The specialist provider must also meet the standards as set out below.

Facilities and equipment

The paediatric rheumatology service should have access to:

- an anaesthetic service appropriate for the age of the patient
- sufficient theatre space
- appropriate clinical environment for all aspects of the service including therapy space
- an Ophthalmologist with relevant expertise
- appropriate access to a level 3 commissioned paediatric radiology service.

Imaging

All services will be supported by a three tier imaging network. NWJCC SS161 specialist paediatric imaging service (excluding neuroimaging)(aged up to 16 years) February 2025. Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements

- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- Common standards, protocols and governance procedures will exist throughout the network
- All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development (CPD)
- All equipment will be optimised for paediatric use and use specific paediatric software.

Staffing

The provider should ensure there is access to a broad range of professionals and staffed appropriately for the size of the population.

Essential (core team)

- Paediatric Rheumatologist
- Adult rheumatologist with an interest
- Paediatric Ophthalmologist
- Paediatric Rheumatology CNS
- Paediatric Physiotherapist
- Paediatric Clinical Psychologist
- Paediatric Occupational therapist
- Podiatrist or Orthotist
- Paediatrician with a Specialist Interest in Paediatric Rheumatology in all health boards
- Paediatric pharmacy support
- Administrative support

Access to an Extended Team

- Children's community nursing team
- General practitioner
- Health visitor or school nurse
- Play specialist
- Youth worker
- Special educational needs coordinator
- Orthodontist
- Maxillofacial surgeon
- Orthopaedic surgeon
- Paediatric Endocrinologist
- Social worker

- Adult rheumatologist (for transition)
- Paediatric Immunologist
- Geneticist
- Paediatric Gastroenterology
- Paediatric Cardiologist
- Paediatric Dermatologist
- Paediatric nephrologist
- Paediatric neurologist
- Orthoptist
- Oral Health Team
- Research nurses and clinical studies support
- Relevant third sector organisations

Specialist teams

Essential

Paediatric Surgery and Anaesthesia

Joint injections under General Anaesthesia, are carried out by an appropriately trained paediatric rheumatology consultant or paediatric orthopaedic surgeon and by an anaesthetist with training and expertise in the management of children.

Where a paediatric patient requires anaesthesia for other procedures the service provider should ensure that the patient is cared for in suitable facilities and by appropriately trained and experienced members of staff.

Clinical Safety and Medical Emergency Measures

The service provider will:

- ensure they operate within a clinically safe environment, with safe practices
- have adequate levels of equipment to deal effectively with medical emergencies
- ensure that all staff are appropriately trained and accredited, and hold a Life Support certificate which meets the standards set out by the Resuscitation Council https://www.resus.org.uk/
- have at least one member of staff qualified to Intermediate Life Support (ILS) level
- ensure all medicines and tracers are managed safely and securely, in accordance with local radiological rules, the NHS Resolution and relevant consents and law
- be responsible for arranging and rehearsing medical emergency procedures on site
- ensure they have access to a medical emergency response 'crash team'
- ensure the service operates within the appropriate governance structures.

Research, Innovation and Improvement.

Appropriate research into rheumatology conditions and therapy is important and features as a core requirement of the ARMA/BSPAR Standards of Care, as well as being essential for access to emerging therapies and improving care delivery

Clinical Network

The team at the lead specialist centre will develop a clinical network with colleagues across the region, supporting education and working with the third sector in relation to patient engagement and support.

2.3 Response Time and prioritisation

The tertiary provider needs to ensure that all Paediatric Rheumatology services are delivered in a timely manner and in accordance within the core standards for the service which are identified in section 3. Treatment will be prioritised according to clinical need and where children have the same clinical need, who gets the treatment first will be decided through chronological waiting list management provided this does not contravene agreed treatment protocols. Any diagnostic test and investigations will be completed within any target dates established by NHS Wales.

2.4 Interdependencies with other services or providers

Many children and young people with rheumatic conditions may have more than one body system involvement. The key interdependencies include, paediatric intensive care, renal services, immunology and infectious diseases, paediatric and adult orthopaedics, emergency care, neurology, dermatology, haematology, respiratory care, ophthalmology, persistent pain service and paediatric clinical psychology.

In addition, all specialist paediatric rheumatology centres are required to work closely with paediatric radiology, chemical pathology and clinical genetic services for diagnosis and management.

All specialist interdependent services will be provided from the specialist centre treating the patient’s rheumatological condition.

2.5 Clinical Standards

- Guidelines for Screening for Uveitis in Juvenile Idiopathic Arthritis (JIA) produced jointly by BSPAR and the RCOphth 2006
- Arthritis and Musculoskeletal Alliance. 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis ARMA
- Abatacept, adalimumab, etanercept and tocilizumab for treating juvenile idiopathic arthritis (TA373) December 2015

- Transition from children’s to adults’ services for young people using health or social care services (NG43) February 2016

2.6 Protocols and Procedures

Essential

The specialist provider needs to ensure that:

- access to radiology across all health boards with the same protocols according to national policies.
- access to theatre lists with a wait no longer than 4 weeks across all health boards
- access to eye screening within 6 weeks
- access to local support for non-inflammatory and inflammatory MSK conditions
- protocols are in place to cover the full range of drugs used in children with rheumatology disease. Shared protocols are available and used where indicated- no UHW Protocols using other hospitals-drafts completed due to no dedicated pharmacist to support
- protocols are in place for joint injections
- they have policies in place to ensure rheumatology disorders are actively managed across Wales
- they have guidelines in place for the use of biologics in the treatment of rheumatology disorders
- access to age-appropriate care and transition in keeping with developmental need and best practice
- ’protocols are in place to ensure each young person is fully supported through transition to adult services at an age appropriate to the individual
- they link with the local service alongside appropriate support and services from the third sector
- they link the local service to the highly specialised services
- they commit to provide specialised multi-disciplinary paediatric rheumatology support as part of a hub and spoke / visiting clinic’s arrangements.
- they provide education and training for upskilling local services and staff around MSK conditions.

2.7 Clinical Responsibility

The provider is responsible for all the risks arising in connection with the provision of paediatric rheumatology services (whether arising directly or indirectly) under the terms of this specification.

Where the service is delivered through a hub and spoke model in Local Health Board facilities, clinical governance and accountability will remain with the Specialist Centres.

2.8 Shared Care Arrangements

The specialist centres will have established shared care arrangements with the Acute Hospitals in the Health Boards, which allows patients to receive agreed treatments closer to home by the secondary care team.

The Specialist centre will:

- Lead on all aspects of care for the rheumatological disorder.
- Communicate quickly and efficiently with other members providing shared care through telephone, email support or video conferencing.
- Provide information sheets and a link to appropriate websites for other professionals as well as parents and patients.
- Be flexible in providing alternative solutions.
- Refer to other specialists locally when appropriate.
- Act as advocates for patients.
- Maintain an efficient service.
- Offer radiological and therapeutic measures on the same day where possible.

The secondary care service will:

- The roles and responsibilities of local teams should have a minimum specification and may be best achieved through co-design to ensure equitable access across Wales
- Facilitate day to day paediatric care; including the monitoring of disease modifying anti rheumatic drugs (DMARDS), prescribed by the tertiary team in the immunosuppressed rheumatology patients
- Refer to allied healthcare and social care professionals as appropriate, copying in the specialist centre.
- Support the management of infectious diseases such as chicken pox in immunosuppressed rheumatology patients liaising with specialist centre.
- Provide support to the tertiary centre with inpatient and day-case management.
- Each health board should have a named professional for paediatrics, physio (for both inflammatory and non-inflammatory conditions) and ophthalmology
- Each health board should have a clear process for transfer of care from AHP’s in the specialist service back to the patients’ local health board
- There should be a named radiologist for each Health Board, and similarly have responsibility for ensuring equity in terms of protocols and reporting.
- Provides a link with relevant third sector organisations to ensure patients are signposted to appropriate wider support and services.

2.9 Exclusion Criteria

The specialist service will not accept new referrals for patients over 16 years of age or for conditions not outlined in Annex i.

2.10 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 patient's resident in England who are registered with a GP Practice in Wales.

2.11 Transition Arrangements

Transition arrangements should be in line with Transition from children's to adults' services for young people using health or social care services NICE guidance NG43 and The Transition and Handover Guidance from Welsh Government 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 young person but will need to comply with local resources and arrangements. Every child or young person's development will be different, so plans and services need to take account of this.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service.

The manner in which this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice taken into account together with individual health board and environmental circumstances factored in.

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

2.12 Patient Pathway (Annex ii)

In collaboration across the Clinical Network the specialist provider will be required to:

- Agree a set of referral protocols from primary care

- Identify priority patients to help detect conditions that would require an urgent referral to the specialist paediatric rheumatology team.
- Develop and commit to engage in a range of community based options with robust pathways to support access.
- Ensure signposting and access to third sector support as part of the pathway.

South Wales

Children resident in South Wales will access specialist rheumatology services through Paediatric Rheumatology at the Children's Hospital for Wales.

Ensure shared Care arrangements are in place with:

- Cardiff and Vale University Health Board (CVUHB)
- Cwm Taf Morgannwg University Health Board (CTMUHB)
- Aneurin Bevan University Health Board (ABUHB)
- Swansea Bay University Health Board (SBUHB)
- Hywel Dda University Health Board (HTUHB)

Ongoing outpatient treatment where possible will be provided as close to the patients home as possible in each of the Health Boards. Alternatively, it may be possible for the patient to have ongoing outpatient care provided virtually using "T-Pro".

North Wales

Children resident in North Wales will access specialist rheumatology services through Paediatric Rheumatology at Alder Hey Children's Hospital.

Shared care arrangements are in place with:

- Betsi Cadwaladr University Health Board (BCUHB).

Ongoing outpatient treatment where possible will be provided as close to the patients home as possible in the three main acute hospitals in North Wales:

Glan Clwyd Hospital
Rhuddlan Rd
Bodelwyddan
Rhyl
LL18 5UJ

Wrexham Maelor Hospital
Croesnewydd Rd
Wrexham

LL13 7TD

Ysbyty Gwynedd
Penrhosgarnedd
Bangor
LL57 2PW

Alternatively, it may be possible for the patient to have ongoing outpatient care provided virtually through the use of “T-Pro”.

2.12 Service provider/Designated Centres

South Wales
Noah Ark Children’s Hospital
University Hospital of Wales
Heath Park Way
Cardiff
CF14 4XW

North Wales
Alder Hey Children’s Hospital
East Prescot Road
Liverpool
L14 5AB

Powys
Birmingham Children’s Hospital
Steelhouse Lane
Birmingham
B4 6NH

2.13 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. A patient experience feedback tool should be completed to reflect the views of parents and families. Patient Reported Outcome Measures (PROMS) and/or Patient Reported Experience Measures (PREMS) should be reported to NWJCC quarterly through the contract monitoring process. Provision should be made for patients with communication difficulties including their preferred language and for children, teenagers and young adults.

3.1 Quality Indicators (Standards)

Specialist provider outcomes

The specialist centre will need to work with colleagues across the health care ecosystem to develop agreed pathways for specific conditions including uveitis. The specialist tertiary provider will:

- Ensure all patients must have an annual review of their management.
- Maintain a good patient (and family) experience of treatment including:
  - Children with established rheumatic diseases (and their carers) should be counselled by a Paediatric Rheumatology Clinical Nurse Specialist before starting treatment with a DMARD or Biologic.
  - Children with Juvenile Idiopathic Arthritis (JIA) should have access to a dedicated paediatric rheumatology clinic for all follow-up appointments.
  - Children with Juvenile Idiopathic Arthritis should have access to a specialist paediatric rheumatology service from new diagnosis within 4 weeks of referral.
  - Children with Juvenile Idiopathic Arthritis who need to have intra-articular steroid injections should wait no longer than 4 weeks and have them done on a Paediatric General Anaesthetic list.
  - Children with considered / suspected Juvenile Idiopathic Arthritis should have access to Uveitis screening within 6 weeks of diagnosis.
- Ensure access to research trials
- Ensure access and/or signposting to relevant third sector support services
- Ensure access to specialist paediatric rheumatology MDT support on an ongoing basis. This could be at the 'specialist centres' or where that might be geographically distant from the patients, local AHPs could be upskilled as leads for paediatric rheumatology in local hospitals.
- Ensure mental health support is available
- Minimise and reduce the short and long-term side effects of treatment.

- Consider Stem Cell transplantation for all patients who would benefit.
- Consider CAR T-cell therapy for all patients who would benefit.

3.2 National Standards

The provider is required to meet the following standards:
NHSE Paediatric Medicine Rheumatology Quality Dashboard

3.3 Other quality requirements

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

The provider should work to written quality standards to meet the requirements of the Health Board, Trust and Lead commissioners including:

- regular updates within SLA meetings
- reporting of any serious untoward incidents to NHS Performance and Improvement, health board of residence and the NWJCC as soon as possible. Outcome and learning to be shared with the health board of residence and the NWJCC
- service quality improvements and initiatives outcomes from audits against national standards
- Patient experience feedback and the development of PROMS and PREMS to demonstrate and reflect the service provided and the development of action plans to meet any concerns addressed within these
- The need to engage with the third sector to provide information, peer support and other service available from voluntary organisations to children and families
- Annual Multi-Disciplinary Peer review with providers across the Network.

3.4 Clinical Governance

The provider will ensure that all staff adheres to its policies, procedures, clinical guidelines and the requirements detailed within this service specification.

Every patient requiring treatment at a specialist centre will have a named consultant responsible for their care. A member of the team will be offered as a keyworker to support families throughout the clinical pathway if required.

Any complaints, claims or serious incidents including never events relating to contracted services need to be reported by the provider directly to NWJCC within 48 hours of the event.

Providers will report any failure to meet the required standards detailed within this service specification.

Providers will monitor against the NHSE Paediatric Medicine Rheumatology Quality Dashboard and submit these to NWJCC on a quarterly basis through the contract monitoring processes.

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.

In particular, the provider will be expected to monitor against the following target outcomes:

Indicator	Outcome measures
Rheumatology Consultant Session, Specialist Centre	• All Children and young people will receive an initial consultant appointment with the paediatric rheumatologist which will be a minimum of 45 minutes. • All Children and young people requiring a follow-up appointment should have an appointment of 20 minutes. • All children and young people with a suspected new inflammatory rheumatological condition will be seen by the specialist paediatric rheumatology team within 4 weeks of the referral being made. • All patients will have an Annual review of their management by the paediatric rheumatologist and a Multidisciplinary team review if required. • Patients with an active rheumatological condition should be seen at clinic at intervals of no greater than 4 months apart. • Ophthalmology appointment within 6 weeks of referral

Clinical Nurse Specialist	• All Children and young people and their families will be seen by Clinical Nurse Specialist within 4 weeks. • All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team. •
Physiotherapist	• All paediatric physiotherapy regarded as urgent will have a maximum waiting time to 1st appointment of no more than 8 weeks. • All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team, if required.
Occupational Therapist	• All paediatric occupational therapy regarded as urgent will have a maximum waiting time to 1st appointment of no more than 8 weeks. • All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team, if required.
Ensuring that people have a positive experience of care	• Total number of children of any age who started treatment with a DMARD or Biologic agent within the reporting period • Total number of rheumatology appointments for children with JIA in outpatients • Total number of children with newly-diagnosed JIA • Number of children with JIA who receive Intra-Articular steroid injections under General Anaesthesia • Appropriate PREMS to be collected - Development of a national audit tool for juvenile idiopathic arthritis: a BSPAR project funded by the Health Care Quality Improvement Partnership. Rheumatology (Oxford) 2018; 57(1):140-151
Administration	• Audit the timeliness of issuing appointments to patients • Audit the timescale for typing medical notes

4.3 Date of Review

This document is scheduled for review every three years, unless information is received which indicates that the policy requires revision.

If an update is carried out, this version of the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EIA) 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. Listening to People

6.1 Complaints, Incidents and Redress Process

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

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

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to Listening to People, The NHS Wales Complaints, Incidents and Redress Process – People's Guidance 2026. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure, with a copy of the concern being sent to NWJCC.

Annex i List of Rheumatology Conditions

Rheumatology Conditions

- Connective tissue diseases including systemic lupus erythematosus, juvenile dermatomyositis, mixed connective tissue diseases, scleroderma – systemic and localised/linear morphoea, Sjogren's syndrome.
- Patients receiving immunosuppressive, cytotoxic or biologic therapies
- Reactive (post infectious) arthritis
- Diagnostic evaluation and long-term management of chronic inflammatory arthritis to include:
    - JIA and its subtypes (i.e. oligo articular (persistent or extended), Psoriatic and enthesitis related arthritis), Polyarticular (rheumatoid factor positive or negative) JIA, Systemic onset JIA.
    - Other arthritis associated with inflammatory bowel disease or chronic inflammatory diseases
    - Raynaud's phenomenon (when there are features of underlying connections)
    - Lyme disease with arthritis
    - Chronic multifocal osteomyelitis/chronic non-bacterial osteitis
    - Auto-inflammatory syndromes
    - Post-infectious arthritis
    - Relapsing polychondritis
    - Uveitis
    - Osteoporosis due to underlying rheumatology condition

Chronic vasculitis

- Polyarteritis nodosa
- Atypical Kawasaki disease
- Atypical IgA vasculitis
- Granulomatosis with polyangiitis (GPA) Eosinophilic granulomatosis with polyangiitis (EGPA)
- Behcet's syndrome
- Takayasu's arteritis
- Hypocomplementemic vasculitis or hypersensitivity vasculitis
- Cerebral vasculitis
- Post-infectious vasculitis
- Anti-phospholipid syndromes
- Acute rheumatic fever
- Sarcoidosis

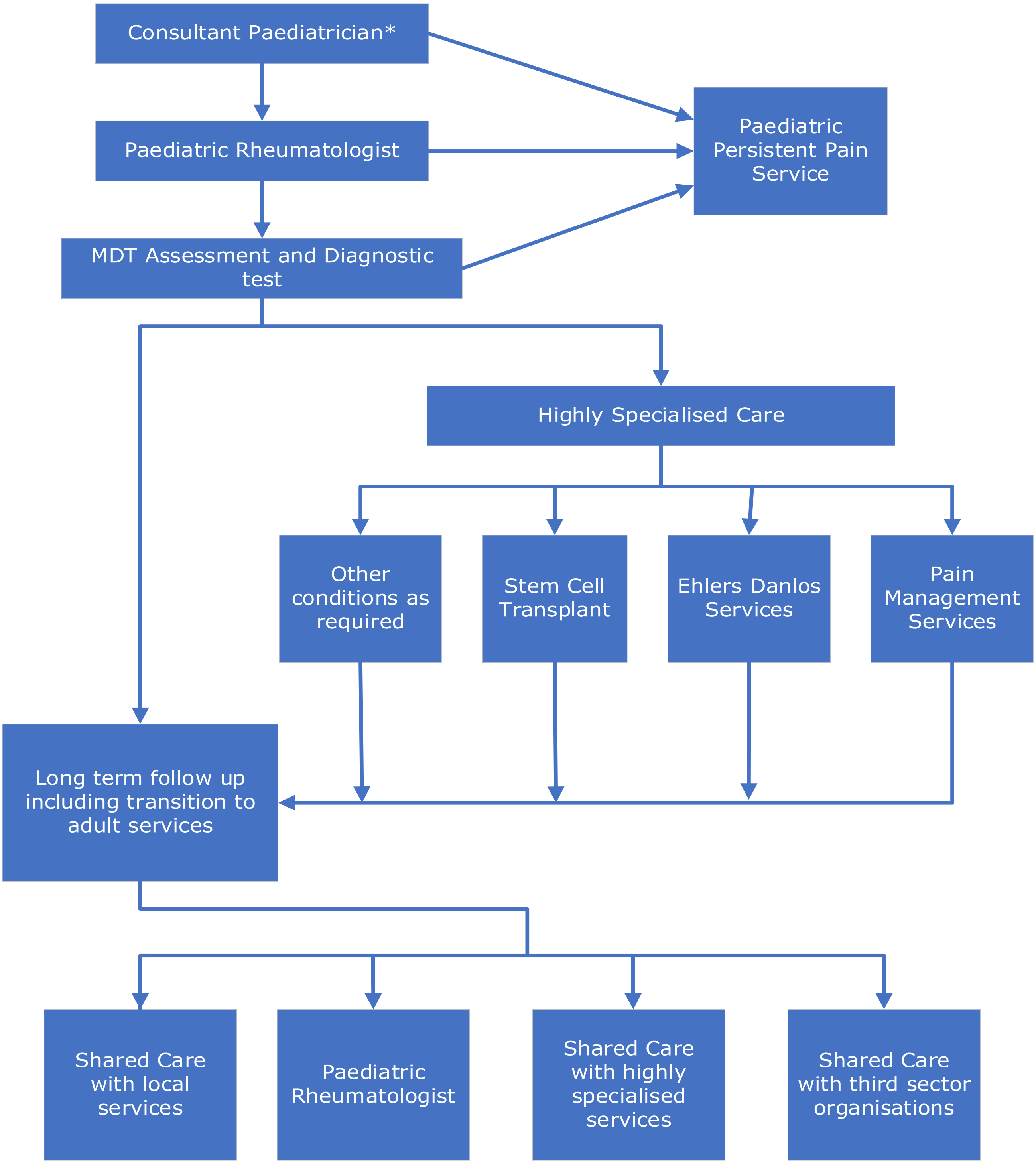
Joint disease associated with other medical diagnoses e.g. inflammatory bowel disease, cystic fibrosis, complex cyanotic heart disease, Down’s syndrome, immunodeficiency, neoplasm, infectious disease, endocrine disorders, genetic and metabolic disease, post transplantation, and arthritis associated with birth defects. These patients require shared specialist care and where possible should be managed in joint specialist MDT clinics for care to be coordinated/optimised and to reduce the health economic burden.

Surgery

Children with juvenile idiopathic arthritis with cervical spine involvement will require a specialist opinion from a specialised paediatric surgery and anaesthesia services. Maxillo-facial surgery for patients with TMJ disease and the role of plastic surgery/maxilla-facial for patients with disfiguring conditions such as scleroderma.

Joint injections under General Anaesthesia, are carried out by an appropriately trained rheumatology consultant or orthopaedic surgeon and by an anaesthetist with training and expertise in the management of children.

Annex ii Patient Pathway



*Referrals can be made from primary care, although primary care may initially refer to the secondary care service

Annex iii Glossary

Autoimmune Disease
An autoimmune disease is an illness that causes the immune system to produce antibodies that attack normal body tissues.

Highly Specialised care
Highly Specialised services are provided to a smaller number of patients compared to Specialised services; usually no more than 500 patients per year. For this reason they are typically best delivered nationally through a very small number of centers of excellence.

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.

Multi-Disciplinary Team (MDT)
An MDT is a group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients.

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.

Rheumatology
Rheumatology is a branch of medicine devoted to the diagnosis and therapy of rheumatic diseases.

Rheumatic Disease
Rheumatic Disease conditions affecting joints tendons, ligaments, bones, and muscles.

Specialised care
Specialised care requires highly specialised equipment and expertise.

Contact Us

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

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

Email:

NWJCC consultation mailbox – NWJCC.Consultation@wales.nhs.uk

Telephone:

General Enquiries – 01443 433112

Website:

Contact us - NHS Wales Joint Commissioning Committee

Writing:

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

South Wales 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.