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Welsh Health Specialised  
Services Committee (WHSSC)

# **Specialised Services Service Specification: CP172**

## **Specialised Paediatric Rheumatology Service**

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*Version 1.0*



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## **Statement**

Welsh Health Specialised Services Committee (WHSSC) 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 WHSSC has reviewed the requirements and standards of care that are expected to deliver this service.

## **Disclaimer**

WHSSC 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.

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

## 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. This service will only be commissioned by the Welsh Health Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales.

### 1.1 Background

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 and then maintain normal physical, social, educational, vocational and emotional growth and development
- minimize chronic disability and deformity
- achieve and maintain remission of disease
- provide appropriate ongoing care.

The diagnosis of rheumatological disorders can be difficult and delay in appropriate referral can affect outcomes (including, but not limited to, joint damage, risk of blindness, and risk of significant morbidity associated with untreated systemic inflammatory disease), particularly for inflammatory arthritides and for inflammatory disorders in general<sup>1</sup>.

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. As a consequence patients may remain under the care of paediatric rheumatology services for most of their childhood years.

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<sup>1</sup> [NHS England SSNDS Definition no26 Specialised Rheumatology Services 2010](#)

Common inflammatory conditions are:

- 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.

These diseases are highly significant with potential for organ damage if not adequately treated<sup>2</sup>.

Non-inflammatory conditions include a wide range of chronic pain syndromes for example, hypermobility associated with pain, complex regional pain syndrome (CRPS), which although often very disabling for patients can be medically unexplainable in terms of definitive pathology.

Specialist paediatric rheumatologists may be asked to assess patients with unexplained fever, pain or multisystem critical illnesses. In addition osteogenesis imperfecta, juvenile idiopathic osteoporosis and metabolic bone disease may be managed by specialist rheumatology teams. The full list of conditions can be found 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. Even the more common JIA has incidence of 1 in 10,000 and a prevalence of 1 in 1,000<sup>3,4</sup>. Conditions such as Juvenile Dermatomyositis (JDM) are extremely rare.

It is estimated<sup>5</sup> there are:

- 12,000,000 children <18yrs in England and Wales
- at any one time there are >12,000 children with JIA

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<sup>2</sup> [NHS England SSNDS Definition no26 Specialised Rheumatology Services 2010](#)

<sup>3</sup> [NHS England \(2010\) SSNDS Definition no26 Specialised Rheumatology Services](#)

<sup>4</sup> [NICE \(2015\) TA 373 Abatacept, adalimumab, etanercept and tocilizumab for treating juvenile idiopathic arthritis](#)

<sup>5</sup> [NHS England \(2015\) Clinical Commissioning Policy Statement: Biologic Therapies for the treatment of Juvenile Idiopathic Arthritis \(JIA\)](#)

- half of these will go on to have arthritis in adulthood
- 1 in 3 will not have arthritis in adulthood but will have sustained permanent damage to one or more joints.

### **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<sup>3</sup>.

### **Population Covered**

This service specification is aimed at delivering safe and effective care for children and young people aged between 0 – 16 years with suspected and confirmed 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.

### **Current Services**

Many conditions require specialist multi-disciplinary care, and the specialist team work 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 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

- Paediatric Rheumatology Service, Noah's Ark Children's Hospital for Wales, Cardiff

Cwm Taf Morgannwg University Health Board (CTMUHB)

- Paediatric Rheumatology Service via a monthly satellite clinic at the Royal Glamorgan Hospital
- Paediatric Rheumatology Service, Noah's Ark Children's Hospital for Wales, Cardiff

#### Aneurin Bevan University Health Board (ABUHB)

- Paediatric Rheumatology Service, Noah's Ark Children's Hospital for Wales, Cardiff

#### Powys Teaching Health Board (PTHB)

- Paediatric Rheumatology Service, Noah's Ark Children's Hospital for Wales, Cardiff
- Birmingham Children's Hospital, Birmingham Womens and Children's NHS Foundation Trust

#### Swansea Bay University Health Board (SBUHB)

- Paediatric Rheumatology Service, Noah's Ark Children's Hospital for Wales, Cardiff
- Service is supported by Consultants from Bristol tertiary Paediatric Rheumatology service, and two all day clinics twice a year in Swansea, Morriston.
- 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.

#### Hywel Dda University Health Board (HDUHB)

- Clinics in Bronglais Hospital, Aberystwyth and Wthybush Hospital Haverfordwest delivered by a Paediatrician with an interest in Rheumatology.
- Paediatric Rheumatology Service, Noah's Ark Children's Hospital for Wales, Cardiff

### **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 is to define the requirements and standard of care essential for delivering a specialist paediatric rheumatology service for children with suspected and confirmed rheumatic condition.

The objectives of this service specification is to:

- ensure a timely and correct diagnosis is made for children presenting with symptoms that could indicate a paediatric rheumatic condition
- details the requirements to deliver specialist paediatric rheumatology services for children resident in Wales with suspected and confirmed rheumatic condition
- ensure optimal standards of care are met for the use of specialist paediatric rheumatology services
- ensure equitable access to specialist paediatric rheumatology services
- identify centres that are able to provide specialist paediatric rheumatology service for children resident in Wales with suspected and confirmed rheumatic condition
- improve outcomes and quality of life for children accessing specialist paediatric rheumatology services.

## Key Elements of the Service

- Clinical assessment to establish a diagnosis
- Rapid control of the condition
- To restore and then maintain normal physical, social and emotional growth and development
- To provide safe therapeutic surveillance
- To minimise chronic disability and deformity
- To achieve and maintain remission of the condition

### 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).
  - [Clinical Trials Commissioning Policy \(CP164\)](#). December 2019
  - [Paediatric Endocrinology Commissioning Policy \(CP163\). August 2019](#)
- **Welsh Government**
  - [Welsh Government Recommended Guidelines Establishment of a Clinical Musculoskeletal Assessment Treatment Service 2017](#)
- **National Institute of Health and Care Excellence (NICE) guidance**
  - [COVID-19 rapid guideline: arranging planned care in hospitals and diagnostic service](#). NICE guideline (NG179) July 2020
  - [COVID-19 rapid guideline: rheumatological autoimmune, inflammatory and metabolic bone disorders](#). NICE Guideline (NG167). July 2020
  - [Transition from children's to adults' services for young people using health of social care services](#). NICE Guideline (NG43) February 2016
  - [Abatacept, adalimumab, etanercept and tocilizumab for treating juvenile idiopathic arthritis](#). NICE Technology appraisal guidance (TA373) December 2015
  - [Tocilizumab for the treatment of systemic juvenile idiopathic arthritis](#). NICE Technology appraisal guidance (TA238). December 2011
- **NHS England policies**
  - ['NHS Standard Contract Paediatric Medicine: Rheumatology \(2013\)'](#)
  - [Canakinumab for treating periodic fever syndromes: TRAPS, HIDS/MKD and FMF \(ages 2 years and older\) 2020 NHS England Reference: 200209P, March 2020](#)
  - [Department of Health Musculoskeletal Health: A 5 year strategic framework for prevention across the life course 2019](#)

- [Clinical Commissioning Policy Statement: Biologic Therapies for the treatment of Juvenile Idiopathic Arthritis \(JIA\) 2015 NHS England](#)
- [Care Quality Commission From the pond into the sea: Children's transition to adult health services 2014.](#)
- Specialised Services National Definition Set (3<sup>rd</sup> edition) Specialised Rheumatology Services (all ages) Definition no.26 2010
- **Other published documents**
  - Davies K, Cleary G, Foster H et al. BSPAR standards of care for children and young people with juvenile idiopathic arthritis. Rheumatology 2010;49(7):1406-8
  - Foster HE, Minden K, Clemente D, et al. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. Annals of the Rheumatic Diseases 2017;76:639-646.
  - Cai, R.A., Chaplin, H., Livermore, P. et al. Development of a benchmarking toolkit for adolescent and young adult rheumatology services (BeTAR). Pediatr Rheumatol 17, 23 (2019). <https://doi.org/10.1186/s12969-019-0323-8>
  - Constantin T, Foeldvari I, Anton J, et al Consensus-based recommendations for the management of uveitis associated with juvenile idiopathic arthritis: the SHARE initiative Annals of the Rheumatic Diseases 2018;77:1107-1117.

## 2. Service Delivery

The Welsh Health Specialised Services Committee commission the specialist rheumatology services for children (aged up to 16 years), in-line with the criteria identified in this document.

### 2.1 Access Criteria

The service will accept referrals from secondary and tertiary care clinicians<sup>6</sup> for a child aged 0-16 years who has either:

- a confirmed diagnosis of a rheumatic condition, **or**
- Secondary care is unable to make clear diagnoses; complex 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 erythematosus (SLE) or systemic onset JIA.
- Undefined autoimmune disease e.g. complex autoimmune thrombocytopenia.
- Raynaud's phenomenon (when there are features of underlying connections).
- Juvenile idiopathic uveitis.
- Difficult 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, 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 2.3.

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.

The point at which a person with a rheumatological condition requires treatment is a shared decision between the patient and their family/carer and the treating clinician.

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<sup>6</sup> In rare instances with prior approval from the Consultant Team, referrals from primary care will be accepted.

## 2.2 Service Description

For those patients who meet the access criteria, care will be co-ordinated and delivered by a paediatric rheumatology consultants, supported by the multi-disciplinary paediatric rheumatology team, as noted in the section for [Staffing](#).

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.

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

In addition to the standards required within the Contract, specific quality standards and measures will be expected, detailed in section 3. The 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
- appropriate clinical environment for all aspects of the service including therapy space
- 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 ([‘Delivering quality imaging services for children’ Department of Health 13732 March 2010](#)). 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.

### ***Core Team (Essential)***

- 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 an interest in Paediatric Rheumatology
- 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
- Endocrinologist
- Social worker
- Adult rheumatologist (for transition)
- Paediatric Immunologist
- Geneticist
- Paediatric Gastroenterology
- Paediatric Dermatologist
- 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 rheumatology consultant or 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 ([www.resus.org.uk](http://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 Litigation Authority (NHSLA) 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. ensure appropriate research in to Rheumatology conditions and therapy.

#### **Clinical Network**

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

### **2.3 Transition care arrangements**

All children and young people with rheumatological disease need a coordinated transitional care programme leading to transfer of care to an adult rheumatologist and rheumatology MDT services at an appropriate age, under a shared care arrangement.

All 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](#).

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.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service with the support of the third sector where relevant

#### **2.4 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.

#### **2.5 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, haematology neurology, dermatology, haematology and respiratory care, and paediatric clinical psychology.

In addition, all specialist paediatric rheumatology 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.

## **2.6 Clinical Standards**

### ***Essential***

The provider needs to meet the following standards:

- [BSPAR and the RCOphth Guidelines for Screening for Uveitis in Juvenile Idiopathic Arthritis \(JIA\) \(2006\)](#)
- [ARMA Standards of Care for children and young people with Juvenile Idiopathic Arthritis \(2010\)](#)
- [NICE TA 373 Abatacept, adalimumab, etanercept and tocilizumab for treating juvenile idiopathic arthritis \(2015\)](#)
- [NICE Transition from children's to adults' services for young people using health of social care services \(2016\)](#)

## **2.7 Protocols and Procedures**

### ***Essential***

The provider needs to ensure that:

- radiological investigations and treatment are performed according to [National guidelines](#)
- 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
- protocols are in place for joint injections
- they have guidelines in place to ensure rheumatology conditions are actively managed across Wales
- they have guidelines in place for the use of biologics in the treatment of rheumatology conditions
- arrangements for transitional care.

## **2.8 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 Centre.

## **2.9 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:

- Facilitate day to day paediatric care; including the prescribing and 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.
- Support in investigations such as Radiology.

## **2.10 Exclusion Criteria**

The service will not accept new referrals for patients over 16 years of age or for conditions not outlined in [Annex i](#).

## **2.11 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.

## **2.12 Patient Pathway (Annex i)**

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

- Agree a set of referral protocols from primary care
- Identify 'red flags' to help detect conditions that would require an urgent referral to the specialist paediatric rheumatology team.
- Recognise criteria for supported self-management to highlight the need for input from third sector support.

### **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 "attend anywhere".

### **South Wales**

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

Shared Care arrangements are in place with:

- Cwm Taf Morgannwg University Health Board (CTMUHB)
- Aneurin Bevan University Health Board (ABUHB)
- Swansea Bay University Health Board (SBUHB)
- Hywel Dda University Health Board (HTHB)

Ongoing outpatient treatment where possible will be provided as close to the patients home as possible in each of the following Health Boards. Alternatively it may be possible for the patient to have ongoing outpatient care provided virtually through the use of “attend anywhere”.

### **2.13 Service provider/Designated Centre**

- **North Wales**  
Alder Hey Children’s Hospital  
East Prescott Road  
Liverpool  
L14 5AB
- **South Wales**  
Noah Ark Children’s Hospital  
University Hospital of Wales  
Heath Park Way  
Cardiff  
CF14 4XW

### **2.14 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: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

### **3. Quality and Patient Safety**

The provider must work to written quality standard 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 developed to reflect the views of parents and families. Patient Reported Outcome Measures (PROMS) and/or Patient Reported Experience Measures (PREMS) should be reported to WHSSC quarterly through the contract monitoring process.

Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

#### **3.1 Quality Indicators (Standards)**

The Specialised Paediatric Rheumatology Service should aim to deliver the following:

##### **Provider outcomes**

The lead centre will need to work with colleagues from referring hospitals to develop agreed pathways for specific conditions including uveitis. The 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.
- Minimise and reduce the short and long-term side effects of treatment.
- Consider Stem Cell transplantation for all patients who would benefit.

### **3.2 National Standards**

The provider needs to meet the following national standards:

- The National Standards for [Paediatric Medicine Rheumatology Quality Dashboard 2019/20](#)

### **3.3 Quality requirements**

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 the Delivery Unit/ Welsh Government and to WHSSC within 48 hours feedback of outcomes from any serious incidents and learning from these.
- 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 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 WHSSC 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 dashboard and submit these to WHSSC on a quarterly basis through the contract monitoring processes.

Providers will submit a quarterly audit report detailing their ability to meet the standards, [quality dashboard](#) and KPI's to the WHSSC quality team. This approach will allow commissioners to consider any service changes in line with the WHSSC planning cycle.

## 4. Performance monitoring and Information Requirement

### 4.1 Performance Monitoring

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

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

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

WHSSC 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	<ul style="list-style-type: none"> <li>• All Children and young people will receive an initial consultant appointment with the paediatric rheumatologist which will be a minimum of 45 minutes.</li> <li>• All Children and young people requiring a follow-up appointment should have an appointment of 20 minutes.</li> <li>• 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.</li> <li>• All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team if required.</li> <li>• Patients with an active rheumatological condition should be seen at clinic at intervals of no greater than 4 months apart.</li> </ul>

Clinical Nurse Specialist	<ul style="list-style-type: none"> <li>All Children and young people and their families will be referred to the Clinical Nurse Specialist within 4 weeks.</li> <li>All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team.</li> <li>Ophthalmology appointment within 6 weeks of referral.</li> </ul>
Physiotherapist	<ul style="list-style-type: none"> <li>All paediatric physiotherapy regarded as urgent will have a maximum waiting time to 1<sup>st</sup> appointment of no more than 8 weeks.</li> <li>All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team, if required.</li> </ul>
Occupational Therapist	<ul style="list-style-type: none"> <li>All paediatric occupational therapy regarded as urgent will have a maximum waiting time to 1<sup>st</sup> appointment of no more than 8 weeks.</li> <li>All patients will have an Annual review by the paediatric rheumatology Multidisciplinary team, if required.</li> </ul>
Ensuring that people have a positive experience of care	<ul style="list-style-type: none"> <li>Total number of children of any age who started treatment with a DMARD or Biologic agent within the reporting period</li> <li>Total number of rheumatology appointments for children with JIA in outpatients</li> <li>Total number of children with newly-diagnosed JIA</li> <li>Number of children with JIA who receive Intra-Articular steroid injections under General Anaesthesia</li> <li>Total number of children with newly-diagnosed JIA</li> <li>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</li> </ul>
Administration	<ul style="list-style-type: none"> <li>Audit the timeliness the issuing of appointments to patients</li> <li>Audit the timescale for typing medical notes</li> </ul>

### 4.3 Date of Review

This document is scheduled for review in 2024 where any new evidence will be considered.

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 Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

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

## **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 WHSSC.

### **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: [Welsh Health Specialised Services Committee \(WHSSC\) | Individual Patient Funding Requests](#)

## **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
- Periodic fever syndromes
- Reactive (post infectious) arthritis
- Diagnostic evaluation and long-term management of chronic inflammatory arthritis to include:
  - JIA and it’s 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
  - Lyme disease with arthritis
  - Chronic recurrent multifocal osteomyelitis Auto-inflammatory syndromes
  - Post-infectious arthritis Relapsing polychondritis Uveitis
  - Osteoporosis
  -

### **Chronic vasculitis**

- Polyarteritis nodosa
- Atypical Kawasaki disease
- Atypical Henoch Schonlein purpura
- Wegner’s granulomatosis
- Behcet’s syndrome
- Takayasu’s arteritis
- Hypocomplementemic vasculitis or hypersensitivity vasculitis
- Cerebral vasculitis
- Post-infectious vasulitis
- Anti-phospholipid syndromes
- Acute rheumatic fever Sarcoidosis

Genetic syndromes associated with stiff joints or severe hypermobility  
e.g. Ehlers Danlos and Marfan's syndrome

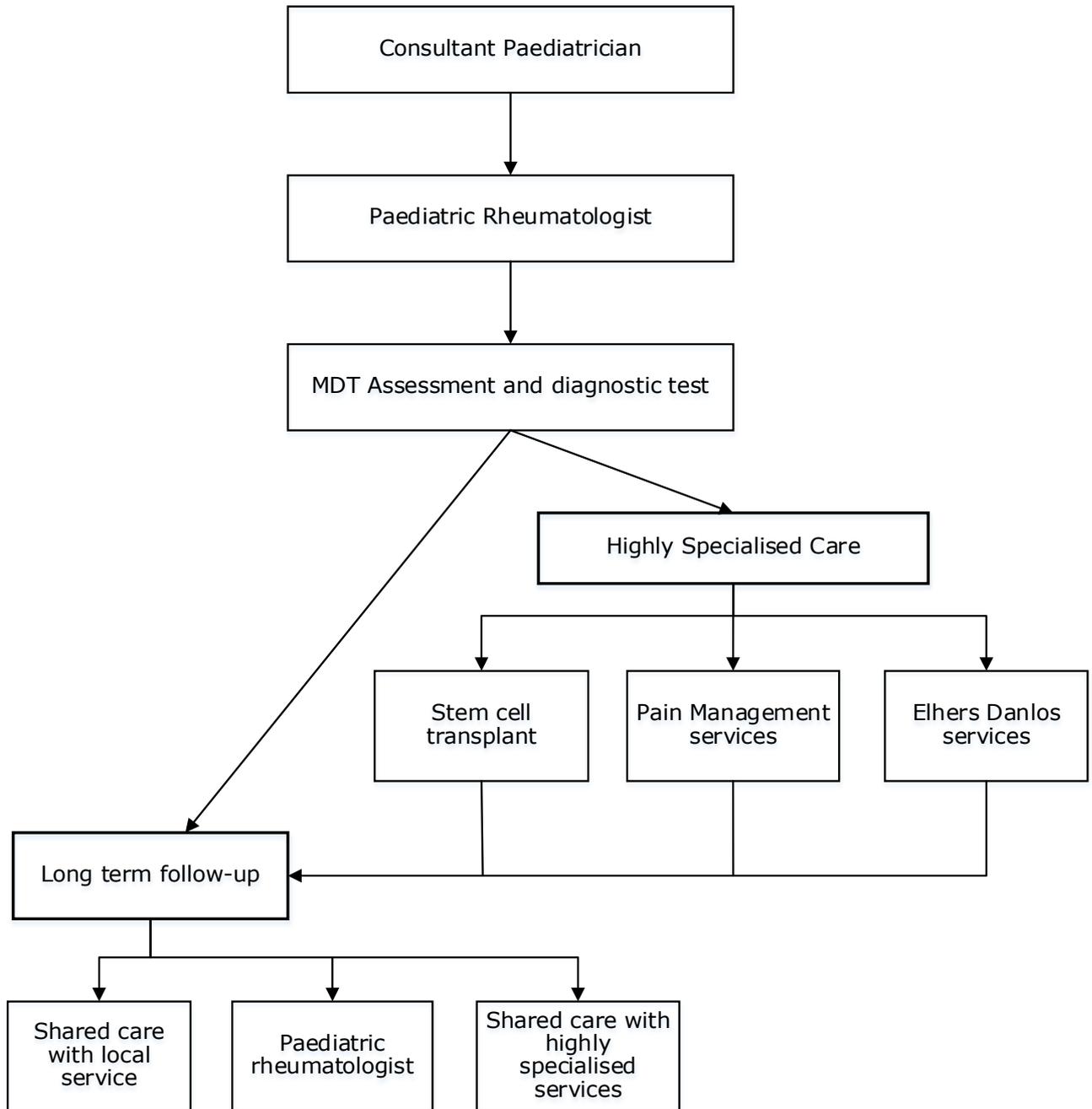
Joint disease associated with other medical diagnoses e.g. inflammatory bowel disease, cystic fibrosis, complex cyanotic heart disease, Down's syndrome, immunodeficiency, neoplasm, infectious disease, endocrine disorders, genetic and metabolic disease, post transplantation, and arthritis associated with birth defects.

### **Surgery**

Children with juvenile idiopathic arthritis with cervical spine involvement will require a specialist opinion from a specialised paediatric surgery and anaesthesia services.

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



## Annex iii Codes

<b>Code Category</b>	<b>Code</b>	<b>Description</b>
Treatment Specialty Code	262	Paediatric Rheumatology

## **Annex iv Abbreviations and Glossary**

### **Abbreviations**

<b>ABUHB</b>	Aneurin Bevan University Health Board
<b>ARMA</b>	Arthritis and Musculoskeletal Alliance
<b>AWMSG</b>	All Wales Medicines Strategy Group
<b>BCUHB</b>	Betsi Cadwaladr University Health Board
<b>C&amp;VUHB</b>	Cardiff and Vale University Health Board
<b>CNS</b>	Clinical Nurse Specialist
<b>CPD</b>	Continuous Professional Development
<b>CTMUHB</b>	Cwm Taf Morgannwg University Health Board
<b>HDUHB</b>	Hywel Dda University Health Board
<b>IPFR</b>	Individual Patient Funding Request
<b>JIA</b>	Juvenile Idiopathic Arthritis
<b>JSLE</b>	Juvenile Systemic Lupus Erythematosus
<b>JDM</b>	Juvenile Dermatomyositis
<b>NICE</b>	National Institute of Clinical Excellence
<b>PREM's</b>	Patient Reported Experience Measures
<b>PROM's</b>	Patient Reported Outcome Measures
<b>SMC</b>	Scottish Medicines Consortium
<b>SBUHB</b>	Swansea Bay University Health Board
<b>SLE</b>	Systemic Lupus Erythematosus
<b>WHSSC</b>	Welsh Health Specialised Services

### **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 centres of excellence.

#### **Individual Patient Funding Request (IPFR)**

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that

fall outside the range of services and treatments routinely provided across Wales.

### **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.

### **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.

### **Welsh Health Specialised Services Committee (WHSSC)**

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