



PAEDIATRICS

**A NATIONAL MODEL
OF CARE FOR PAEDIATRIC
HEALTHCARE SERVICES
IN IRELAND
CHAPTER 43:
PAEDIATRIC
RHEUMATOLOGY**



Féidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Clinical Strategy and Programmes Division



**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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43.0 INTRODUCTION

The spectrum of paediatric rheumatological disorders of childhood are varied and often complex in nature. Recognition of the sub-speciality itself is relatively new to paediatrics, however given its broad base and often multisystem involvement it is frequently at the centre of care in many chronic and acute medical illnesses. A crude overview of the speciality would divide childhood musculoskeletal conditions into inflammatory and non-inflammatory disorders.

Juvenile Idiopathic Arthritis (JIA) is the commonest inflammatory disorder of childhood and in the Caucasian population has an annual incidence of 1/10,000, and a prevalence of 1:1000 in children less than 16 years of age. There are seven subtypes of JIA of which Oligoarticular JIA is the most frequently seen affecting over 50% of patients. Systemic JIA, which accounts for 10% of the patient cohort, is typically an aggressive subtype of JIA that can prove fatal in some. It is estimated that there are over 1,000 children less than 16 years in Ireland with JIA. Uveitis, a potentially sight threatening disease, is the most common extra-articular complication of JIA. It can affect up to 30% of patients, and is typically asymptomatic requiring patients to attend for regular (4-6 monthly) slit lamp examinations.

Other inflammatory disorders such as autoinflammatory syndromes or autoimmune/connective tissue disorders (CTD) are less common and often affect multiple systems. They are chronic and potentially life threatening. Many are associated with profound disability in function and mobility. These disorders can impact severely on the education of the children, and on the educational and vocational abilities of young adults/adolescents. The majority of these disorders require immunosuppressant therapy which in itself requires frequent monitoring and assessment.

Conditions recognised and actively managed by the paediatric rheumatology service

JIA	<ul style="list-style-type: none"> Oligoarticular JIA Polyarticular JIA (RF negative/positive) Systemic JIA Enthesitis-related JIA Psoriatic JIA Undifferentiated JIA
CTD	<ul style="list-style-type: none"> Juvenile dermatomyositis (JDM) Systemic lupus erythematosus Mixed connective tissue diseases (MCTD) Scleroderma – systemic and localised/linear morphea Sjogren's syndrome Overlap CTD

Vasculitis	<p>Systemic vasculitis</p> <p>Polyarteritis nodosa</p> <p>Undifferentiated systemic vasculitis</p> <p>GPA/Wegner's Disease</p> <p>Behcet's syndrome</p> <p>Atypical Kawasaki disease</p> <p>Atypical Henoch Schonlein purpura</p> <p>Takayasu's arteritis/GCA</p> <p>Hypocomplementemic vasculitis or hypersensitivity vasculitis</p> <p>Cerebral vasculitis</p> <p>Post-infectious vasculitis</p>
Systemic autoinflammatory disorders	<p>Periodic fever syndromes (HIDS, PFAPA, CINCA, MWS, FCUS, FME, TRAPS)</p> <p>Chronic recurrent multifocal osteomyelitis</p> <p>DIRA</p> <p>CANDLE syndrome</p>
Reactive (post-infective) arthritis	<p>Lyme disease with arthritis</p> <p>Post-streptococcal arthritis</p> <p>Post-infectious arthritis</p> <p>Relapsing polychondritis</p>
Patients requiring immunosuppressant therapy	<p>(under guidance of Rheumatology)</p> <p>Uveitis – idiopathic, other</p> <p>Lymphoproliferative disease</p>
Other arthritis associated with systemic disease	<p>Cystic fibrosis-related arthropathy</p> <p>Inflammatory bowel-related arthropathies</p> <p>Anti-phospholipid syndromes</p> <p>Osteoporosis (Idiopathic/Iatrogenic)</p>
Genetic syndromes associated with stiff joints, arthralgia, arthritis	<p>Skeletal dysplasia</p> <p>CACP</p> <p>Down's arthropathy/arthritis</p>
Metabolic disorders with arthropathy	<p>Mucopolysaccharodosis</p> <p>Hurlers</p>
Non-inflammatory disorders	<p>Benign hypermobility and hypermobility related to underlying syndromes (Ehlers Danlos Syndrome, Marfan's syndrome, Larsen's syndrome, Sticklers etc.)</p> <p>Pain amplification syndrome / chronic pain syndrome</p> <p>Reflex sympathetic dystrophy and complex regional pain syndromes</p> <p>Cold-induced injury</p> <p>Over use syndromes</p> <p>Erythromyelalgia</p>
Joint disease associated with other medical conditions	<p>Complex, immunodeficiency, neoplasm, infectious disease, endocrine disorders, genetic, post-transplantation, and arthritis associated with birth defects</p>

Table 43.1: Conditions recognised and actively managed by the paediatric rheumatology service

Early recognition and optimal treatment of JIA is associated with less morbidity and improved outcomes. Arthritis and Musculoskeletal Alliance (ARMA) / British Society of Paediatric and Adolescent Rheumatology (BSPAR) Standards of Care for children and young people with JIA (2010) recommends that all patients with suspected JIA should be seen by a paediatric rheumatologist within six weeks of the referral being made. Standards of care are not currently being met. An audit of services at the National Centre for Paediatric Rheumatology (NCPR) in 2010 confirmed that the majority of the recommended standards are not being fulfilled, including prompt access to subspecialty care and treatment. There was, and continues to be, a delay in access to care, diagnosis and clinical assessment for all patients attending or required to attend this speciality on a national and local level. Ireland has one of the lowest levels of consultant to patient ratios in Europe (2nd lowest – Paediatric Rheumatology European Society data). There are currently only two paediatric rheumatology consultant posts in Ireland. Guidance extrapolated from the British Society for Rheumatology has recommended one paediatric rheumatologist to every 200,000 children. It is therefore advised that there should be a minimum of six paediatric rheumatology consultant posts in Ireland.

43.1 CURRENT SERVICE PROVISION

The NCPR was established in 2006 in Our Lady's Children's Hospital, Crumlin (Crumlin) with the appointment of Ireland's first paediatric rheumatologist. Prior to this appointment, there was a monthly rheumatology clinic in Crumlin under the care of a general paediatrician. Complex and severe cases were sent overseas to units in the United Kingdom (UK). This national service has grown dramatically with continuous and exponential increase in patient referrals and patient assessments year on year. Patient numbers have increased by almost 400% since 2006. A second consultant paediatric rheumatologist was recruited in October 2012. The specialty of rheumatology continues to be one of the most rapidly growing services within Ireland's largest tertiary children's hospital and now accounts for the highest number medical day care patients per year.

A weekly rheumatology clinic in Children's University Hospital, Temple Street (Temple Street), was established during the 1990s. Service was initially provided by a general paediatrician and since 2008 by a consultant paediatric rheumatologist who is employed on a part time basis as a general paediatrician. Approximately 350 new patients are seen per year in Crumlin and 100 new cases per year in Temple Street. It is estimated that in excess of 2,200 outpatients were seen by the NCPR by the end of 2014. The service is largely outpatient- or day ward-delivered with only 80-90 inpatient admissions per year in Crumlin. There are patients waiting in excess of two years for a new appointment in Crumlin.

43.1.1 Rheumatology outpatient clinics

Rheumatology Teen Clinic (Monday morning in Crumlin)

- Ethos – encourage self advocacy and independence skills
- Active transition process (early / mid / late)
- Additional time, each patient seen individually and then again with parents
- MDT support, Teen CNS
- Age 12 years plus
- 12 approximately (2-3 new, 9-10 return)

Rheumatology General Clinic x2 – 2 x consultants in attendance (Tuesday morning in Crumlin)

- Inflammatory and non-inflammatory joint disease, auto-immune, vasculitis, hypermobility, pain syndromes
- Patients 12 years and less
- MDT support
- Approximately 24-28 patients (6 new, 16-20 return)

<p>Rheumatology General Clinic – 1 x consultant in attendance (Wednesday morning in Temple Street)</p>	<ul style="list-style-type: none"> • Inflammatory and non-inflammatory joint disorders, AID, CTD • All age groups • CNS / physiotherapist in attendance • Approximately 12-14 patients (3 new, 10 return)
<p>Biologic Clinic (Friday morning in Crumlin)</p>	<ul style="list-style-type: none"> • Biologic therapy new and return • Yearly detailed assessment • 6-8 patients • MDT supported
<p>Urgent Clinic (Wednesday in Crumlin)</p>	<ul style="list-style-type: none"> • Any urgent/new outpatient referred patient not accommodated in routine clinic times • Patients are accommodated wherever space is available, including OPD, MDU, physiotherapy department.
<p>Young Adult/Adolescent Transition Clinic (Bi-monthly in St. Vincent's University Hospital-Crumlin)</p>	<ul style="list-style-type: none"> • Mid/late transition • Unique model of care • 9-10 patients • Combined paediatric/adult rheumatology support • Generally accessible to Dublin/Leinster patients only
<p>Combined Connective Tissue Disease Clinic (Quarterly in Crumlin)</p>	<ul style="list-style-type: none"> • Quarterly joint dermatology/ rheumatology clinic • Approximately 12-15 patients seen jointly by both teams

Table 43.2: Rheumatology outpatient clinics

There is daily activity in the medical day units in both Crumlin and Temple Street, including:

- Biologic Infusions
 - Twice weekly or more infusion list
 - Patients see by medical team, consultant and clinical nurse specialist (CNS)
 - In addition are reviewed by further MDT members as necessary
 - Approximately 4- 5 patients seen each clinic (8-10 weekly)
- Pre-Joint Injection Clinic
 - Run in advance of joint list for patients who have not been recently seen or who have had therapeutic change in the interim
 - Monthly (as required)
 - CNS-led clinic
 - Physiotherapy review of all patients
- Urgent patient reviews- new/return
- Joint injections – weekly
 - Entonox sedation
 - Local anaesthesia
 - General anaesthesia (these occur twice per month. There is a long waiting list for these procedures)
 - There is inconsistent physiotherapy support due to lack of resources

- Theatre activity – general anaesthesia required for joint injections, radiological support (imaging intensifier screening required)
 - Crumlin: Bi-monthly list, 12 patients approximately
 - Temple Street: Monthly list, six patients approximately

Outside the greater Dublin area, there a very limited number of services available to children with rheumatological conditions. There is a bi-monthly clinic run by the adult rheumatology services in Galway. There is no paediatric input to this clinic. A similar clinic is held in Waterford on a monthly basis (estimated 40 patients attending based on personal correspondence). The vast majority of the approximate 1200 children / adolescents with JIA, as well as the many others with various musculoskeletal complaints, have their diagnosis established/confirmed and their treatment planned in Dublin.

43.1.2 Current staffing in Crumlin

Consultant	1.7WTE consultant 0.3WTE St. Vincent's University Hospital/Our Lady's Hospice
Non-consultant hospital doctor (NCHD)	1WTE Registrar 1WTE Senior House Officer
Clinical nurse specialist (CNS)	2WTE CNS Grade 1
Physiotherapy	1.4WTE
Occupational therapy	0.5WTE
Psychology	No dedicated time (crisis/emergency support only)
Social work	Temporary / limited support (general hospital on-call social worker)
Podiatry	No service provision
Youth worker	No dedicated support
Dietitian	No dedicated support

Table 43.3: Current Staffing in Crumlin

43.1.3 Current staffing in Temple Street

Consultant	0.3WTE
NCHD	No dedicated staffing
Clinical nurse specialist (CNS)	0.5WTE
Physiotherapy*	0.6WTE
Occupational therapy	No dedicated support
Psychology	No dedicated support
Social work	No dedicated support
Podiatry	No dedicated support
Youth worker	No dedicated support
Dietitian	No dedicated support

Table 43.4: Current staffing in Temple Street

* Paediatric musculoskeletal physiotherapist with a special interest in paediatric rheumatology

43.1.4 Patient journey

All new patients are assessed in the outpatient clinic or medical day unit by a consultant and their diagnosis and treatment plan is discussed with the family. Relevant investigations are undertaken, some which require the services of other specialties (e.g. radiology, renal, orthopaedic, cardiac, dermatology, haematology). A treatment care-plan is formulated, which may involve commencement of immunosuppressant therapies or chemotoxic agents. A number of these agents are only administered by the intravenous route and require admission (some weekly) to the medical day ward. Surgical procedures such as multiple intra-articular corticosteroids injections may be warranted. They also meet various components of the multidisciplinary team (MDT) including the CNS, who provides education, medication information, support to the patient and family, and liaises with support services in the community; general practitioner (GP), public health nurse (PHN), local hospital as well as the medical team. In addition, patients are given written contact information. A telephone messaging service is available to families and patients, and calls are returned within a 24-hour period. When appropriate or feasible, each new patient will meet additional members of the MDT. For the majority of patients this includes the physiotherapist and occupational therapist. Appropriate advice and education is given and follow up planned.

At follow-up visits, patients are seen by the medical team, rheumatology consultant, and rheumatology physiotherapist / occupational therapist if these services are part of their treatment plan. Written confirmation of follow-up visits is given to patients and telephone reminders are in place for all patients coming for admission, day case (joint injections) or therapy by intravenous infusions.

43.1.5 Interface with primary and secondary care

Outside Dublin

A child with a rheumatic complaint is usually referred directly by their GP, local paediatrician or local adult rheumatologist, or all three. By the time of referral they typically will have some investigations performed and radiological imaging done. On the basis of the information provided they are triaged as requiring an inpatient or outpatient review. Outpatients are triaged as 'soon', 'routine' or 'urgent'. Urgent patients are seen within six weeks, typically on the day ward, as routinely no outpatient appointments are available. There is no dedicated clinical unit for rheumatology in either Crumlin or Temple Street. If age at referral is over 16 years, they are redirected to local adult rheumatology services. If children are well enough, their parents organise transport to their local hospital or Dublin by private vehicle or public transport. If children are in critical condition, they are transported by ambulance.

Ongoing shared care for those with a chronic disease is advocated. It is typically provided by the referring physician such as the general practitioner and local paediatrician. These centres facilitate the frequent blood monitoring typically required (in accordance with written guidelines provided) for patients commenced on these immunosuppressant drugs. Local hospitals provide essential supportive care to our patients, including the management of side effects of medications, and management of general medical conditions in our immunosuppressed patients. Occasionally they will facilitate investigations or radiology requests if possible. This care is currently provided on a largely ad-hoc basis and is co-ordinated between the local medical team and the rheumatology service. In a small, but growing, number of local hospitals (with appropriate paediatric and adult rheumatology support) they administer alternating monthly/bimonthly biologic or immunosuppressive infusions.

For children living outside of the Dublin catchment area, some components of their health and social care professional input (physiotherapy / occupational therapy) could be delivered by local paediatric services. Where these services exist, the tertiary MDT liaises closely with the relevant paediatric service providers in the community to ensure appropriate joint, disease and age-appropriate therapies are delivered. Unfortunately, a dearth of paediatric primary care and disability occupational therapy and physiotherapy services exist, with resultant long waiting lists to access the relevant services in the community. The result of limited access in the community to appropriately skilled paediatric HSCPs is that this cohort of patients continues to access their ongoing therapeutic intervention in the tertiary setting.

Within Dublin

For children living within the Dublin catchment area, the referral pathway and patient journey is similar. The exceptions include those that attend the emergency departments in Dublin, and therefore directly assess our services. The majority of children living in the Dublin catchment area have their scheduled tests including drug monitoring performed in either Crumlin or Temple Street. Patients aged 16 years and over at the point of referral are usually redirected to the Young Adult/Adolescent Transition clinic in St. Vincent's University Hospital where a consultant paediatric rheumatologist is in attendance with an adult rheumatologist, or to an adult rheumatology service in a Dublin area teaching hospital in the patient's catchment area.

Shared care with the referring clinician is at all times encouraged as most rheumatological problems are chronic in nature. Immunosuppressant therapy monitoring is requested at local level if at all possible. Transition pathways for young teens are identified as young as 11 years so care pathways can be put into place well before the transition process is completed. This model of care is almost unique to paediatric rheumatology.

43.2 PROPOSED MODEL OF CARE

43.2.1 Integration of units in Crumlin and Temple Street

With the development of the new children's hospital, it is foreseen that integration at a service level will occur prior to physical relocation of both units. This will start with the various components of service delivery including:

- A single out patient waiting list, avoiding duplicate referrals to both hospitals
- Cross-cover out of hours cover (24 hours – both sites)
- Integration of both MDTs and their outpatient waiting lists
- Single surgical waiting list for intra-articular injections
- Development of shared standards of care and protocols / best practice documentation
- Combined educational and CME sessions, journal clubs etc.

43.2.2 'Hub and spoke' model of care

Paediatric rheumatology is an ideal service in which to replicate this successful model of care. Given that the vast majority of patients have a chronic illness and many require the expertise of the unit for a considerable portion if not all of their childhood, this model develops local expertise and reduces travel for the patient to the national centre. The geographical spread of patients attending the NCPH is greatest from counties Cork, Donegal and Limerick outside the Greater Dublin area (see Figure 1). This model of care has been implemented in many units within the National Health Service (NHS) in the UK. Scotland, a country with a very similar population (over 5 million) and an even more fragmented geographical area, has a very integrated model of care from a large paediatric unit in Glasgow. It provides a network of outreach clinics from the hub unit, with clearly defined care pathways.

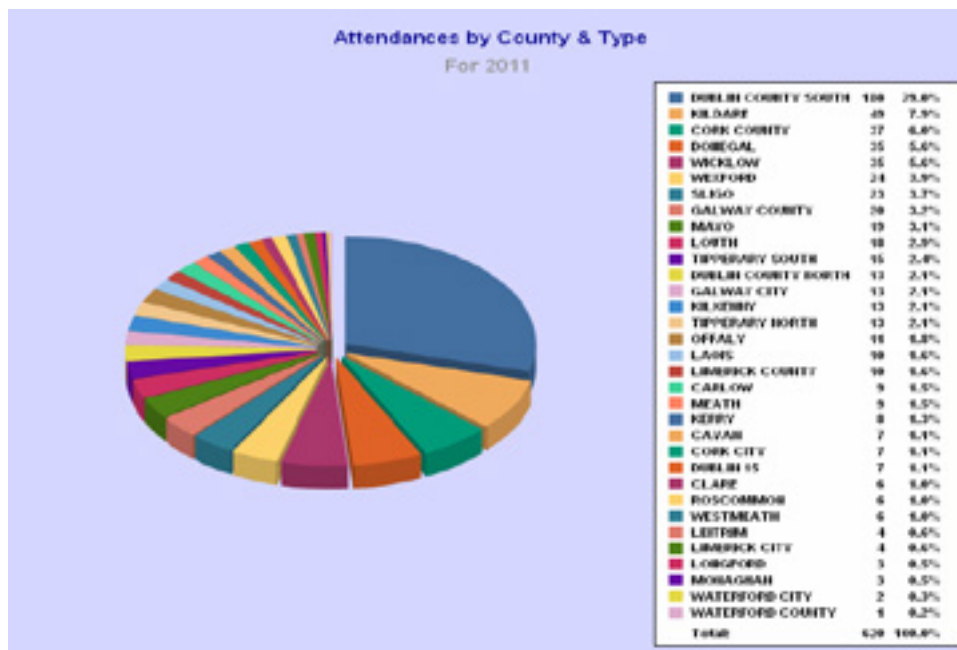


Figure 43.1: Rheumatology outpatient attendances by county 2011

A network would promote service delivery at the most local point of contact supported by agreed clinical standards and a service model. It will facilitate effective service interfaces and support good practice in a multidisciplinary approach.

- National referral process – a single referral document, available online to all clinicians and primary care providers, will be completed and sent by post or online
- Referrals triaged as urgent, soon or routine
- Referrals triaged on age (general clinic or teen transition clinic)
- Point of referral identified, if outside greater Dublin area linked with outreach clinic minimum of twice yearly, initial assessment to occur in NCPR
- Non-inflammatory conditions are assessed in hub unit or outreach clinic. All non-inflammatory conditions will be followed up locally if required.

It is proposed that the hub centre will provide an outreach clinic on a quarterly basis to the following areas:

- a) Cork
- b) Limerick
- c) West/Northwest - Galway

This clinic will be attended by a paediatric rheumatologist with a local physician (either a consultant general paediatrician or an adult rheumatologist). Ideally, both will be in attendance as this would allow for replication of the already successfully award-winning model of care provided by the combined Crumlin/SVUH Transition Clinic in Dublin. As the outreach service develops, a separate transition clinic quarterly in each of the centres is expected to be needed. A local adult rheumatologist link in each outreach hospital will be required to ensure successful implementation of this model of care.

There will be a robust system for information sharing across a pathway of care and shared care guidelines and protocols to deliver good practice.

Outpatient care in the hub centre (new children's hospital) will remain unchanged with four-weekly outpatient clinics. There will be a requirement for further development of formal transition services across the greater Dublin area in addition to the SVUH Transition Clinic. Inpatient and day ward services will be provided in a dedicated paediatric clinical area within the new children's hospital (plans in process). A dedicated biologic and infusion suite will be part of this.

MDT care/input:

- Physio triaged non-inflammatory clinics (specialist physiotherapist)
- Nurse-led OPDs – biologic assessment and pre- injections
- Nurse-administered joint injections
- MDT-led non-inflammatory care programme
- Clinical specialist physiotherapy and occupational therapy triaged non-inflammatory clinics
- Physiotherapy – administered joint injections

43.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

43.3.1 Infrastructure

There is currently no dedicated clinical space in either Crumlin or Temple Street for paediatric rheumatology. Offices are fragmented and the MDT is dispersed throughout the hospitals. A dedicated clinical area is required including OPD rooms, joint injection / entonox room, infusion / biologic suite, offices, admin space, NCHD and research space, and an education area.

The inpatient bed requirement is three to four dedicated bed-spaces. A day-ward facility is needed, with dedicated infusion suite and joint injection area (ideally within the paediatric rheumatology clinical area), as well as surgical day ward bed requirements for general anaesthetic (GA) joint injection lists. For outpatient clinics, again ideally within the dedicated clinical space, rooms must be large enough for full musculoskeletal (MSK) assessment including gait analysis, and sufficient number of rooms to facilitate attendance of MDT (estimated at six rooms).

43.3.2 Equipment and technology

- MSK Ultrasound Machine
- Entonox Delivery System
- Appropriate physiotherapy assessment tools, e.g. treadmill, age-appropriate gym equipment
- OT splinting equipment and wax therapy bath
- Hydrotherapy pool
- Capillaroscope x 4
- Appropriate information technology (IT) equipment and support for all staff members
- Dedicated national database and website with appropriate administrative and IT support, within the unit

43.3.3 Human resources

The minimum requirements for a specialist team delivering paediatric rheumatology care are described by Baildam and Davidson, 2008. The following is applicable for the Children's Hospital Group.

Staff Category	Current (WTE)	Proposed (WTE)
Consultant	2.1	6
Specialist Registrar	1	3
Registrar	0	1
SHO	1	3
Specially trained nurses	0	6
Advanced nurse practitioner	0	2
Clinical nurse specialist	2	4
Dietitian	0	1
Physiotherapist	2.4	6*
Occupational Therapist	0.5	4^
Psychologist	0	4
Podiatrist	0	2
Social Worker	0	3
Hydrotherapist	0	2
Youth Worker	0	1
Administrative Support	2	4
Data Manager	0	1

Table 43.5: Human resources

- * Proposed Physiotherapy: 6 WTE
 - Clinical Specialist (Triage) Physiotherapist: 2 WTE
 - Senior Physiotherapist: 3 WTE
 - Basic Grade Physiotherapist: 1 WTE

- ^ Proposed Occupational Therapy: 4 WTE
 - Clinical Specialist (Triage) Occupational Therapist: 1 WTE
 - Senior Occupational Therapist: 2 WTE
 - Basic Grade Occupational Therapist: 1 WTE

43.3.4 Education and training

- Medical:
 - MSK ultrasound training for clinicians
- Nursing:
 - Development of advanced nurse practitioner posts
 - Joint injection procedure training for clinical nurse specialists
 - Postgraduate training, e.g. Diploma in Rheumatology Nursing, for all clinical nurse specialists
- Health and social care professionals:
 - Access and funding for international postgraduate training in paediatric rheumatology and specialist areas

43.3.5 Interdependencies with other clinical programmes

Ophthalmology:

All children with JIA require regular uveitis screening, and thus ophthalmology services for all patients attending the unit are required. An integrated care pathway should ideally include an ophthalmology assessment as part of the MDT rheumatology visit. Access to this critical service is patchy and unreliable, both in tertiary units and many local clinics (due to demands on that service), which is in breach of international standards of care for this patient group.

Dermatology:

A successful quarterly clinic takes place in Crumlin for connective tissue disease patients. There is a demand for increased frequency of this clinic.

Infectious diseases / Immunology:

While no formal arrangement / clinic are in place currently, there is a large overlap of cross-specialty care. It is proposed that a combined clinic is developed between rheumatology and infectious diseases / immunology to address specifically complex overlapping patients such as AID.

Orthopaedics:

A large volume of patients each year are referred and reviewed between both services. A more formal joint clinic / conference would be welcomed through which a more integrated approach to these patients is applied.

Renal/Haematology/Oncology:

There are a significant number of patients each year that require integrated care across these subspecialties – vasculitis, malignancies, haematologic presentations of CTD.

PICU:

A significant burden of care, particularly at first presentation is in the PICU setting for complex autoimmune disorders.

Radiology:

This is a critical component for diagnostic and therapeutic decision making in the care of rheumatology patients. All modalities of imaging are required, including intraoperative screening for patients undergoing joint injections. Currently, there are long waiting lists for radiology services which impacts on clinical treatment decisions and diagnostics for patients under the rheumatology service. This can be detrimental to the patient's condition and quality of life in these patients can occur when not treated within a timely manner.

43.4 PROGRAMME METRICS AND EVALUATION

It is imperative that data, including minimum data sets, clinical outcomes and ongoing metrics be held on a professionally administered database. This would allow for ease of assessment and access of data/statistics from the significant wealth of clinical data in the National Rheumatology Service. Key to programme metrics and evaluation is not just the compilation and collection of data, but the means to store and retrieve these data in a manner which makes them beneficial in terms of retrieval and analysis, thus increasing the cost benefit and advancing service development and research.

Minimum data set

- Demographics
- Diagnosis
- Medications
- Investigations to date - ideally linked to lab and x-ray systems
- MDT / other providers (documented list of individual's personal team)
- +/- Relevant family/social history

All fields to be flexible to allow for constant update.

Clinical outcome variables:

General

CHAQ: Childhood Health Assessment Questionnaire (all patients)

Physicians Global Assessment

Joint counts – active and restricted (Stickman Diagram)

Pain scores – visual analog scales

PedQL

Disease-specific

JIA

JAQQ: Juvenile arthritis Quality of Life Questionnaire

JAFAR: Juvenile Arthritis Functional Assessment Report for Parents

Myositis

CMAS: Childhood Myositis Assessment Scale

SLE

SLICC/Damage Index

SELDAI/ Activity Score

BILAG Index: British Isles Lupus Assessment Group

Spondyloarthropathy

BASDAI: Bath Ankylosing Spondylitis Disease Assessment Index

(ref.: http://www.rheumatology.org/Practice/Clinical/Forms/Clinical_Forms/ concise overview of above outcome measures, and online versions of those unavailable for download)

Management and service planning

- Outpatient numbers, including DNA
- Waiting lists – duration and nature of complaint, referral source
- Bed occupancy
- Theatre usage
- Incident reporting
- Clinical governance

Clinical audit

Key areas in the fields of clinical care and service development should continue to be identified and audited. Clinical audit should be performed based on the HSE '5 Stage' clinical audit guidelines: identifying audit area and stakeholders, defining standards and criteria, measuring performance, making improvements and maintaining improvements including re-audit (HSE, 2013).

43.5 KEY RECOMMENDATIONS

- Increase the paediatric rheumatology multidisciplinary team staffing levels in order to provide a safe, accessible and effective service.
- Implement the BSPAR / ARMA standards of care
- Develop the hub and spoke model of rheumatology service provision
- Establish a dedicated clinical area for rheumatology services
- Build links with adult rheumatologists to facilitate the transition from paediatric to adult rheumatology services
- Develop data collection capability
- Develop specialist physiotherapy triage clinics to alleviate waiting lists (assessment of non-inflammatory conditions)
- Develop a joint clinic for slit lamp eye reviews, which is an essential part of management to take place on a three to four monthly basis.

43.6 ABBREVIATIONS AND ACRONYMS

AID	Autoinflammatory disease
ARMA	Arthritis and Musculoskeletal Alliance
BSPAR	British Society of Paediatric and Adolescent Rheumatology
CACP	Camptodactyly arthropathy coxa vara pericarditis
CINCA	Chronic infantile neurological cutaneous and articular syndrome
CME	Continuing medical education
CNS	Clinical nurse specialist
CTD	Connective tissue disorders
DIRA	Deficiency of IL-1receptor antagonist
FCUS	Familial cold autoinflammatory syndrome
FMF	Familial Mediterranean syndrome
GCA	Giant cell arthritis
GP	General Practitioner
GPA	Granulomatous polyangitis
HIDS	Hyper Ig D syndrome
IT	Information technology
JDM	Juvenile dermatomyositis
JIA	Juvenile idiopathic arthritis

MCTD	Mixed connective tissue diseases
MDT	Multidisciplinary team
MDU	Medical day unit
MSK	Musculoskeletal
MWS	Muckle-Wells Syndrome
NCPR	National Centre for Paediatric Rheumatology
NHS	National Health Service
OPD	Outpatients department
OT	Occupational therapy
PFAPA	Periodic fever with aphthous stomatitis, pharyngitis and adenitis
PHN	Public health nurse
PICU	Paediatric intensive care unit
SVUH	St. Vincent's University Hospital
TRAPS	TNF receptor associated periodic syndrome
UK	United Kingdom

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Useful links

www.arthritisresearchUK.org

www.bspar.org.uk

www.nice.org.uk