



**National Steering Group for Specialist Children's Services**  
**Rheumatology**  
**Executive Summary**

## **Background**

The review of children's rheumatology services in Scotland has been carried out as part of the Children and Young People's Health Support Group review of Specialist Children's Services, the process of which has been managed by the National Steering Group.

The development of Paediatric Rheumatology services in Scotland has lagged behind the rest of the UK and other paediatric specialties. An informal network of interested clinicians has developed in recent years but services are poorly developed, with many children having no access to specialist care.

The most common condition seen in paediatric rheumatology is Juvenile Idiopathic Arthritis (JIA). This is a condition previously associated with poor outcomes and long term disability (joint damage and visual impairment from associated uveitis). Changes in approach to treatment and available drug therapies over the last decade have resulted in dramatically improved outcomes in units providing optimal care. Children and young people with arthritis should now reasonably expect that their disease will be controlled and that they will enter adult life without disability.

Improved outcomes will only be achieved if all affected children have rapid access to an expert specialist service. Currently, suboptimal outcomes with disability and visual impairment are common in Scotland as a result of inadequate resources and inequity of access to specialist care.

The UK prevalence of JIA is estimated at 1:1,000 under 16 years. No accurate data exists for Scotland. 90 children with JIA have been identified in Grampian (childhood population just under 100,000) in line with the expected prevalence. Based on a childhood population of approximately 935,000 we would expect there to be over 900 children with JIA in Scotland.

Clinicians working within the current informal network for paediatric rheumatology have estimated that they are aware of around 500 affected children. Many of these are cared for in units with no specialist expertise and the known prevalence suggest that there will be several hundred more children with JIA in the country.

## **Outcomes**

All children with a rheumatology diagnosis should have access to a multidisciplinary team with appropriate specialist expertise.

Any child suspected of having an inflammatory arthritis should be seen within 4 weeks.

Ophthalmologic screening must be undertaken at recommended intervals according to UK guidelines. No child should suffer visual loss due to inadequate service provision.

Children requiring parenteral therapies should have the option of this being delivered by the family at home with the support of a specialist nurse.

Severe disability and the need for future joint replacement should be rare in children with JIA.

These outcomes are currently not being met across all Health Board areas.

Outcomes could be significantly improved with modest investment in workforce and training.

## **National / Regional / Local planning**

### Model of Care

The preferred model of care is to enable local teams to deliver evidence based treatment with support from a centrally based National team with specific Paediatric Rheumatology expertise and training. This model is evident in Wishaw and Aberdeen.

The establishment of a Managed Clinical Network (MCN) would enable a network of Paediatricians, Nurses and AHPs to develop knowledge and expertise in the management of children with rheumatology conditions. All local teams have expressed a willingness to work as part of a MCN with shared care clinics being an integral part of service delivery. A MCN proposal has been developed to support this approach

### National

A national approach is required to ensure equity of access to high quality, evidence based management for all children with rheumatological conditions in Scotland.

### Regional

Each region should work with the nationally identified clinical team within the MCN to scope and develop the service, ensuring best use of resources to deliver agreed outcomes.

## **Risks**

The greatest immediate risk is the unsustainable service in Edinburgh. Consultant input has been provided by the full time Paediatric Rheumatology Consultant in Yorkhill through a service level agreement (SLA), but input required far exceeds that provided for in the SLA. Commitments in Glasgow and across the network led to a decision in June 2007 that from January 2008, the service would be withdrawn to the level in the agreement. This will result in an immediately unsustainable service.

Failure to address and resource the networked model being advised will see the continuation of sub optimal care for many children and young people and inequalities in treatment across the country.

## **Workforce and Staffing**

A significant number of children with Rheumatology conditions are currently being managed by General Paediatricians with no training in Rheumatology, or Adult Rheumatologists with no training in Paediatrics or Paediatric Rheumatology.

3 WTE Consultant Paediatric Rheumatologists in Scotland (1 additional post immediately and the replacement on retirement of the paediatrician with an interest in Glasgow by a full time paediatric rheumatologist) would enable the development of an education and training programme for locally based Paediatricians/Adult Rheumatologists.

An increase in the provision of outreach clinics to ensure equity of access to specialist advice for all children.

There are currently 1.5 WTE Children's Rheumatology Specialist Nurses in Scotland, based in Glasgow and Edinburgh working at capacity providing education, training and support to families administering new therapies.

An additional 1.0 WTE Specialist Nurse posts are required immediately to adequately support services in Edinburgh and Aberdeen.

A Nurse Consultant working with the national team would facilitate the development of locally based nursing expertise and the safe delivery of complex treatment regimes to children in their local environment.

Children with JIA require access to physiotherapists who are regularly able to update their knowledge in this rapidly changing specialty, and ensure the provision of optimal local care. A national lead post would ensure consistency and continuity in training and regular access to advice and support.

Every District General Hospital (DGH) should have an identified local team (paediatrician, ophthalmologist, nurse and physiotherapist) to take responsibility for the care of these children, working with the national team as part of the MCN.

## Recommendations

	<b>Action</b>	<b>By when</b>
1.	Appoint 1 WTE Paediatric Rheumatologist Provide a service in Edinburgh Outreach clinics: Fife Tayside	Immediate
2.	Establish Managed Service / Clinical Network, prepare and submit bid to NSAG.	2008
3.	Appoint 0.5 WTE Specialist Nurse Grampian To establish an urgently required resource for children and families  Appoint WTE Consultant Nurse	2008  2009
4.	Appoint Consultant/advanced practitioner Physiotherapist.	2009
5.	Work via MCN to ensure implementation of ophthalmology screening guidelines for all children with arthritis via named ophthalmologist for each area.	2009
6.	Regional Planning teams to scope / establish robust data to support local service development and work with MCN in its delivery.	2009
7.	To facilitate planned development of a parent network.	2009