

Scottish Paediatric & Adolescent Rheumatology Network Guideline for a Paediatric Rheumatology Network Service

The remit of SPARN is to ensure that all children with rheumatic conditions are diagnosed promptly and managed appropriately. Care is delivered by multidisciplinary local teams with input from paediatric rheumatologist at network clinics.

The SPARN Guideline for a paediatric rheumatology network service outlines how services should be delivered to support the aims of the Network:

- To promote equity of access to the best possible care for all children with rheumatic conditions in Scotland regardless of geography
- To support local delivery of care where possible through the establishment of a network of services with locally based specialist multidisciplinary teams working in partnership with expert teams from the tertiary centres
- To ensure that care delivered meets agreed national standards of care
- To support services in improving standards of care through the establishment of continuous quality improvement

The service will meet UK agreed Standards of Care for Juvenile Idiopathic Arthritis ([ARMA Standards of care for Children and Young People with Juvenile Idiopathic Arthritis 2010](#)).

1. The SPARN Network Service will consist of:

- i) A local specialist multidisciplinary team working within the Scottish Paediatric and Adolescent Rheumatology Managed Clinical Network (SPARN)
- ii) Network clinics supported by a visiting tertiary level trained Paediatric Rheumatologist

Children with more complex rheumatological conditions eg Systemic lupus erythematosus; juvenile dermatomyositis must be managed in close liaison with the tertiary specialist teams based in Glasgow, Edinburgh and Aberdeen.

Rationale and Further Information:

Standard 1: All healthcare practitioners likely to come into contact with a child or young person with JIA require the skills to recognise the condition and support the effective management of the condition. This needs to be addressed in medical education and training programmes for other health care professionals. Clinical responsibility for the day to day management of children attending the service remains with the local Consultant and team.

Standard 16: Where aspects of the child or young person's healthcare are provided by local hospital and/or community services, care should be provided by named professionals who have experience in paediatric rheumatology and are working as part of the paediatric rheumatology clinical network.

2. A local specialist MDT team should comprise as a minimum:

- i) Link Paediatrician
- ii) Clinical Nurse Specialist (OR Children's nurse with dedicated time for paediatric rheumatology)
- iii) Physiotherapist

The local specialist team must have appropriate specialty specific training.

Rationale and Further Information:

Standard 4: Members of the paediatric rheumatology team will have appropriate training and experience in paediatric rheumatology as defined by the appropriate professional bodies.

Standard 6: All children and young people with JIA will have access to a paediatric rheumatology multidisciplinary team, the members of which should have generic experience and competence in working with children and young people in addition to paediatric rheumatology expertise. In addition Paediatric Rheumatology Nurse Specialists should have a children's nursing qualification e.g. Registered Sick Children's Nurse (RSCN) or Registered Nurse Child (RN Child).

Standard 12: All children and young people with juvenile idiopathic arthritis should have continued access to a complete and appropriately trained multidisciplinary team and be aware of this. Each child or young person with JIA should have a named paediatric rheumatologist, clinical nurse specialist, paediatric physiotherapist, paediatric occupational therapist, paediatric clinical psychologist and consultant ophthalmologist. The support of other named MDT members may be required in addition to this.

- The link paediatrician will be trained to the level specified by RCPCH for a Paediatrician with an Interest in Paediatric Rheumatology (may be appointed already trained or trained in post with support from network)
- The link paediatrician must work within the network with the support of a designated tertiary level trained consultant.
- Link Paediatricians should be members of SPARN.
- Nurses should be trained to level of competencies specified by BSPAR/RCN nursing group – see BSPAR Core competencies for Paediatric Rheumatology Clinical Nurse Specialists and Advanced Nurse Practitioners
- Nurses should be members of SPARN.
- The role of the network rheumatology nurse is detailed in SPARN Role of Paediatric Rheumatology Nurse
- Physiotherapists should be working within SPARN, with advice/support from a physiotherapist in the tertiary centres.

- Network physiotherapists should be encouraged to become members of SPARN.
- Competencies for therapists (Occupational Therapists and Physiotherapists) involved in the care of children and young people (C & YP) with rheumatology conditions are outlined in BSPAR Paediatric Rheumatology AHP Competencies

3. All children with JIA should have access to a full multidisciplinary team including:

i) Ophthalmology

Paediatric ophthalmologists should usually be the key lead delivering screening for JIA uveitis in each region, however screening can be done by other appropriately trained staff where they are properly supported, and have immediate access to the lead ophthalmologist where there are concerns.

ii) The following must be available locally:

- Paediatric Occupational therapist (a named link therapist for the service is desirable)
- Clinical Psychology

iii) The following should be available either locally or via the network:

- Paediatric pharmacist
- Orthotics
- Podiatry
- Play therapy
- Pain team
- Orthopaedic surgeon
- Maxillofacial surgeon
- Dietician
- All other paediatric speciality services for children with multisystem rheumatological disorders

Rationale and Further Information:

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Standard 27: Children and young people with JIA should be screened and managed by an ophthalmologist with experience in paediatric uveitis, linked to the paediatric rheumatology clinical network, in accordance with the BSPAR and Royal College of Ophthalmology guidelines.

Screening for uveitis should be according to UK Guidelines: 'Guidelines for Screening for Uveitis in Juvenile Idiopathic Arthritis (BSPAR/RCPOph 2006)'/Management of uveitis should be according to Scottish Guidelines: 'SUN (Scottish Uveitis Network) Treatment Guidelines: Appendix 6 Paediatric Guideline' <https://www.sparn.scot.nhs.uk/wp-content/uploads/2016/11/uveitis-treatment-guideline-sep-201011-final-appendix-6.pdf>.

All professionals seeing children with JIA must have paediatric training. They should be working within SPARN and should be supported to attend appropriate SPARN and other education days. They should be aware of any BSPAR Guidance relevant to their role.

4. Support for the provision and administration of medication will include:

- i) Provision of subcutaneous methotrexate and other drugs at home or elsewhere in the community.
- ii) Equitable and timely access to Biologic Therapies.
- iii) A biologic drug should normally be commenced within 4 weeks of the decision being made to start.

Rationale and Further Information:

Drugs used for the treatment of JIA will be prescribed and monitored in accordance with [SPARN Guidelines](#) where available and will be available without undue delay.

Provision of subcutaneous methotrexate and other drugs at home or elsewhere in the community is usually supported by clinical nurse specialist/specialist children's nurse and/or local community children's nursing team.

[Methotrexate use in paediatric and adolescent rheumatology Information for health professionals](#)

[Administering disease modifying anti rheumatic drugs \(DMARDs\) and biologic therapies to children and young people with rheumatological conditions¹](#)

[SMC Guidelines](#)

Patients should be informed of appropriate research opportunities where these are available. Appropriate access to cohort studies, drug trials and other research opportunities should be open to all patients where possible. It is acknowledged that some families would therefore have to travel to take advantage of some research opportunities.

5. Timely access to appropriate service for intra-articular steroid injections and subsequent post procedural care:

- i) All units should ensure reasonable access to entonox to facilitate joint injections in older children. If not delivered locally this should be provided via clinic within a reasonable travel distance.
- ii) Access to joint injections requiring image guidance or general anaesthetic (GA) may be local or via the network depending on local expertise and availability.
- iii) Joint injections under GA should be performed where possible within 6 weeks of the decision to inject as per UK standards: [ARMA Standards of care for Children and Young People with Juvenile Idiopathic Arthritis 2010](#).
- iv) Children and young people with functional impairment due to arthritis for whom IA joint injections are indicated and appropriate, should be referred to OT/PT, for follow up review /treatment. There is a requirement to ensure consistency of the response time from OT/PT for therapy follow up to ensure that this helps the child /young person to return to optimum strength, joint range of movement and function. Where possible SPARN would recommend that patients requiring OT or Physio review post joint injections were assessed within 2 weeks of their procedure.
- v) To ensure effective communication, and allow timely planned review by OT or PT, network teams should be informed in advance of the date when patients under their care are booked for joint injections and informed within 24 hours by email or telephone that the procedure has taken place and which joints were injected.

Rationale and Further Information:

Standard 29: Patients with JIA and their parents or carers should be encouraged to participate in the choice of optimal pain management strategies, the full range of which should be available.

The individual trained to undertake joint injections may be link paediatrician, physiotherapist, or nurse.

In some units a local orthopaedic surgeon may be willing to administer intraarticular steroids. However the paediatric rheumatology team should be available to confirm the joints to be injected on the day and should specify the dose and preparation of steroid to be administered.

SPARN joint injection referral proforma available if referral to tertiary unit for joint injection indicated.

6. An appropriate clinical environment for children and young people will be provided:

- i) Clinics should be held in a children's OP department with play materials for younger children, appropriate equipment for monitoring growth and suitable rooms for MDT clinics
- ii) All teams should have local access to appropriate day case facilities for administration of parenteral therapies as necessary.
- iii) Access to appropriate paediatric inpatient care locally and via the network

Rationale and Further Information

Standard 19: In addition to the assessment of disease activity, all aspects of the current physical and psychological health of a child or young person with JIA must be assessed and addressed by members of the MDT.

Standard 20: Children and young people with JIA should be provided by the MDT with access to information and advice to maintain good general health.

7. Paediatric Radiology will include:

- i) Local access to routine x-ray and u/s
- ii) Access to MRI, CT and DEXA locally or via network

Rationale and Further Information

Standard 21: Investigations required for the management of JIA must be performed within appropriate timeframes by services with the necessary expertise both to perform the investigation and interpret the results.

- National PACS facility to enable review of imaging by tertiary radiology consultant with paediatric MSK expertise if necessary.
- Local MRI should be done with acceptable paediatric protocols including contrast if required to facilitate correct age-appropriate interpretation.

8. Transition to adult services will include:

- i) Each unit identifying a named adult 'link' professional to facilitate transition for older teenagers.

Rationale and Further Information

Standard 38: Age and developmentally appropriate individualised transitional care for children and young people with JIA, which addresses medical, psychosocial, educational and vocational issues, should take place reflecting early, mid and late phases of adolescent development.

- Adult rheumatology team to provide a welcome leaflet describing and introducing their service to young people.
- The paediatric team must provide appropriate transitional care including generic adolescent health advice to meet the needs of the young person moving to adult services.

9. Information and advice includes:

- i) All newly diagnosed children with JIA should be provided with the network approved JIA information packs and with names and contact details of their local team members
- ii) All services should provide patients and families with appropriate written information regarding diseases and drugs
- iii) Each network service must offer a telephone helpline for families and ensure that they know how to access it
- iv) All local services should have knowledge of, and provide information regarding, appropriate family support networks
- v) The local team will undertake to disseminate information re patient support and information activities as requested.

Rationale and Further Information

Standard 8: Children and young people with JIA and their families should have ready access to information about JIA, treatment options and general health issues.

Standard 9: Information should be provided to enable children and young people to maximise their physical, psychosocial and emotional development within their family and the wider community.

Standard 10: Healthcare and other professionals should actively involve and support family members or carers.

SPARN agreed information packs for newly diagnosed patients with JIA is available via network office.

- Individual patient drug information and monitoring folders (which should include names and contact details of local team members) available via network office
- Contact information for SNAC (Scottish Network for Arthritis in Children) for all families of children with JIA.
- Young people over 14 years should be provided with contact details of Arthritis Care
- Families should be provide with contact details of appropriate support groups for other conditions as appropriate.
- Information for families is available on the SPARN website.

10. Other

- i) All services should be aware of and have access to protocols and guidelines to ensure service meets standards of care. SPARN must ensure that necessary guidelines are available for use within the network.
- ii) All local teams should have access to and enter data on the network Clinical Audit system to support improvements in treatment and services
- iii) Each network team should undertake an annual patient satisfaction survey

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NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.