



## **STANDARDS OF CARE FOR CHILDREN AND YOUNG PEOPLE WITH JUVENILE IDIOPATHIC ARTHRITIS**

Prepared by the Clinical Affairs sub-committee of the BSPAR, and adapted from the British Society of Rheumatology Standards of Care for Rheumatoid Arthritis (1). The standards were ratified by the Executive Committee of BSPAR in January 2009.

### **PHILOSOPHY**

BSPAR believes that all children with JIA have the right to equitable access to the highest quality of clinical care, based on current evidence and where evidence is lacking, consensus, delivered by experienced multidisciplinary teams.

This document is designed to help and support paediatric rheumatology teams by providing a statement of the minimum standards of care required by children and young people with JIA. The aim is to provide the best quality of care for all patients irrespective of their geographical location. Fundamental to this is the engagement and empowerment of patients with JIA and their carers who should be involved at every step both in the management of their disease and the planning of services.

The management of JIA requires a holistic approach, and whilst control of disease activity is clearly a major goal, attention should also be focussed on the improvement of functional, educational, social and ultimately employment outcomes.

The standards have been developed in accordance with the objectives set out in the Children's National Service Framework, published by the Department of Health in 2004 (2).

## **THE STANDARDS**

### **1. EMPOWERING PATIENTS WITH JIA AND THEIR CARERS**

- All patients with JIA will be encouraged to participate, as fully as is appropriate for their age and understanding, in the management of their disease.
- Age appropriate information and materials about their disease and treatment options will be readily available.
- Patients and their carers will also have access to information and guidance to allow them to make informed choices about their treatment.
- Patients and their families should be made aware at the time of diagnosis of the CCAA and BSPAR as well as local initiatives such as paediatric rheumatology network user groups and local ARMA networks.

### **2. IDENTIFICATION OF JIA**

- All clinicians and allied health professionals likely to come into contact with a child with JIA (for example general practitioners, paediatricians, orthopaedic surgeons, A&E doctors, paediatric physiotherapists and occupational therapists) should acquire appropriate clinical skills and knowledge about early recognition of JIA and the need for prompt referral to a paediatric rheumatology team. This needs to be addressed in the relevant specialty training across the professional bodies (3).
- Appropriate information on musculoskeletal conditions in children and adolescents should be included in electronic information systems designed to aid GPs and other health professionals in order to facilitate diagnosis and to “signpost” further management. The involvement of BSPAR in the development of such guidance is strongly recommended.

### **3. REFERRAL TO THE PAEDIATRIC RHEUMATOLOGY SERVICE**

- All patients with incident or suspected JIA will be managed by a specialist paediatric rheumatology multi-disciplinary team. This will either be a tertiary paediatric referral centre or a team working within a formal paediatric rheumatology clinical network.
- Children with incident or suspected JIA will be referred without undue delay, defined as being seen by the paediatric rheumatology team within 10 weeks of onset of symptoms and within 4 weeks of the referral.
- Referrals to paediatric physiotherapy and occupational therapy should be regarded as urgent and patients should accordingly be placed on the acute waiting lists of these services. Waiting times to first appointment will vary between trusts but should be no longer than 8 weeks from the time of referral.

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#### 4. THE MULTIDISCIPLINARY TEAM

- All children and young people with JIA will have access to a multidisciplinary team, the members of which have appropriate skills and experience for managing children with arthritis.
- Medical members of the paediatric rheumatology team will have appropriate training and experience in paediatric rheumatology as defined by the appropriate professional bodies.
- Adult rheumatologists, paediatricians and orthopaedic surgeons involved in the care of children and young people with JIA, will be working within a paediatric rheumatology clinical network.
- Allied Health Professionals should have generic experience and competence in working with children and young people in addition to rheumatology expertise (4). 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) (5).
- The extended team is likely to include one or more of the following:

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- General Practitioner,
- Consultant Paediatric Rheumatologist
- Consultant Rheumatologist with an interest in paediatric and/or adolescent rheumatology\*
- Consultant Paediatrician with an interest in rheumatology\*
- Paediatric rheumatology nurse specialist,
- Paediatric Physiotherapist,
- Occupational therapist,
- Play therapist,
- Podiatrist/orthotist,
- Pharmacist,
- Paediatric dentist and orthodontist,
- Social worker,
- Consultant ophthalmologist,
- Consultant paediatric orthopaedic surgeon (see also 8),
- Hand/ plastic surgeon,
- Paediatric pain service.

\* Working within a formal paediatric rheumatology clinical network

- Access to child psychology and child and adolescent psychiatry services, youth workers, complementary therapy and dietetics will also be available.
- The Paediatric Rheumatology Nurse has a pivotal role within the Paediatric Rheumatology Team. His/her remit should include the following aspects of care:
  - To ensure the effective co-ordination of care for children and young people with rheumatological illnesses within the specialist paediatric rheumatology team.

- Holistic disease education / management for child, family, parents, carers and others involved in care and consequences of rheumatological diseases and their management
- Knowledge and experience in the care of patients who are immunosuppressed
- Psychosocial support of the child, family and/or carers
- Knowledge of treatment modalities, monitoring requirements (eg NICE guidance)
- Assessment of disease activity (use of core outcome variables e.g. childhood Health assessment questionnaire) response to treatment
- Liaison as appropriate with Primary & secondary Care Teams, Education, Social Services and voluntary agencies
- Facilitation of effective transition to adult care / life

## 5. ACCESS TO INVESTIGATIONS

- All children and young people with JIA will have ready access to investigations as clinically required. This may be as part of their initial investigation to establish the diagnosis as well as to monitor ongoing disease activity progression and assessment for complications (such as osteoporosis).
- Investigations required may include one or more of the following:
  - Radiological investigations:
    - Plain Radiography
    - Ultrasound
    - CT
    - MRI (with use of appropriate contrast medium e.g. gadolinium where indicated)
    - Nuclear Medicine
    - DEXA
  - Laboratory investigations:
    - Autoantibodies (such as ANA, Rheumatoid factor)
    - HLA typing (HLA B27)
- Where radiological investigations are required it is essential that these can be performed by units experienced in the assessment of children and interpreted by an appropriately trained radiologist with experience in JIA. Where this facility is not available locally, it is recommended that collaborative links are established with an appropriate radiology department within the clinical network.

## **6. ACCESS TO TREATMENT**

### **6.1 Access to drug therapy**

- All children and young people with JIA will have prompt access to the drugs required to control their disease, by the route that their clinician believes most medically appropriate and given in accordance with BSPAR guidelines (6). Drugs that may be required include non-steroidal anti-inflammatory drugs (NSAIDs), methotrexate and in some cases other disease modifying anti-rheumatic drugs (DMARDs), corticosteroids, “biological therapies” including anti-TNF agents and other immunosuppressive drugs.

### **6.2 Monitoring of Therapy**

- Monitoring of therapy, where required, will be undertaken in accordance with BSPAR guidelines (6) .

### **6.3 Anti-TNF Drugs and Related Agents**

- In accordance with NICE guidance, patients receiving etanercept and related biologic agents will be managed by a specialist paediatric rheumatology team or within an established paediatric rheumatology clinical network and, subject to informed consent being obtained, all patients receiving etanercept will be registered with the BSPAR Biologics Registry.

### **6.4 Subcutaneous Drug Administration**

- Where subcutaneous drug administration is indicated, an appropriately trained health care professional with paediatric experience will be available to administer the drug and where appropriate to train the patient or a carer to safely administer the injections at the patient’s home (7,8). This health care professional will be either a paediatric rheumatology nurse specialist or an appropriately trained member of the paediatric community or hospital nursing team.

### **6.5 Advice To Families Of Children Taking Immunosuppressive Drugs**

- Appropriate advice (verbal and written) will be available to families of children taking immunosuppressive agents (e.g. corticosteroids, methotrexate, biological agents) on the following:
  - Immunisations (see standard 14)
  - Foreign travel
  - Opportunist infection
  - Management of contact with chickenpox or shingles.

- Patients receiving potentially immunosuppressive drugs will be encouraged to wear a means of identifying this such as a Medicalert® bracelet or necklet.
- Patients receiving systemic corticosteroids will in addition be provided with a steroid card.

## **6.6 Joint Injections**

- All patients with JIA will have access to intra-articular joint injections as required, with access to entonox, general anaesthesia and appropriate imaging technology where necessary.
- Intra-articular injections will be performed no later than 6 weeks after the decision that they are required is made, although urgency may in some cases be much greater than this.
- Joint injections will be performed by an appropriately trained clinician with the skills to assess joint activity and select appropriate joints for injection at the time of the procedure. This will preferably be a member of the paediatric rheumatology team.

## **7. MONITORING OF DISEASE ACTIVITY**

- All patients will have regular assessments of disease activity, based on current consensus and evidence based practice, in order to optimally monitor response to treatment and for potential side effects or complications of treatment.
- Monitoring assessments will be performed by appropriately trained personnel within the paediatric rheumatology team, such as the Paediatric Rheumatology Nurse Specialist and following agreed protocols or guidelines based on evidence or local consensus within the clinical network.

## **8. REGULAR REVIEW**

- “Tight” clinical control is advocated, with patients with active disease being assessed at intervals no greater than 4 months apart, although the clinical team may decide that more frequent review is necessary.
- Patients will have prompt access to interim assessment by the paediatric rheumatology team or clinicians within the clinical network (in accordance with agreed clinical guidelines) when required.
- Access to a dedicated Telephone Helpline managed by the Paediatric Rheumatology Nurse Specialist for non-urgent queries is advocated. This should be provided in accordance with the RCN (2006) guidance on telephone helplines (9).

## **9. OPHTHALMOLOGY SCREENING**

- All patients will have ophthalmology reviews according to the current joint BSPAR/Royal College of Ophthalmology guidelines (10).
- New patients will be screened as soon as possible and not longer than 6 weeks after referral to the ophthalmology service.
- If symptomatic, or the patient has evidence of cataract or posterior synechiae, in accordance with the guidelines ophthalmology review is urgent and the patient should be seen within one week.

## **10 MAINTENANCE OF BONE HEALTH**

- All patients with JIA and in particular those taking oral corticosteroids for at least three months will be given appropriate advice regarding calcium intake, maximising weight bearing exercise and optimal vitamin D exposure.
- Revisions of this document will incorporate any new evidence on the use of specific agents for the prevention of osteoporosis (e.g. bisphosphonates) in JIA.

## **11. PAIN MANAGEMENT.**

- The paediatric rheumatology team will have knowledge of and access to appropriate medications and alternative techniques of pain management (e.g. joint protection, warmth and behavioural approaches).
- Patients and families will be encouraged to participate in the choice of optimal pain management and this should be addressed with a multidisciplinary team approach.

## **12. PAEDIATRIC ORTHOPAEDIC SURGERY / HAND SURGERY**

- As appropriate patients should have access to a paediatric orthopaedic surgeon and hand/ plastic surgeon who has experience of treating children with arthritis, although surgical interventions are rarely needed in current practice.
- Young people requiring joint replacements should be referred to centres with appropriate experience.

### **13. CARE OF ADOLESCENTS WITH JIA**

- **Transitional Care**

- All young people with JIA should have a planned, coordinated transition from the paediatric to adolescent service, and also from the adolescent to the adult service (11-13). A system should be in place to ensure that there is no interruption in the provision of established treatments such as biological agents which should be continued for as long as clinically necessary.
- The adult service will include a rheumatologist experienced in the care of adults with JIA and liaise with the local paediatric rheumatology team to facilitate transition and transfer to adult services.
- BSPAR strongly recommends that named adult rheumatologists with the appropriate skills and experience are identified within local clinical networks to take on the care of these patients.
- Care should include frequent and comprehensive assessments of needs, particularly during the period of transition.

- **Generic Health Issues**

- Young people with JIA (both male and female) will have access to information and advice appropriate for their age and understanding on all generic health issues they may be affected by. This includes (but is not restricted to):
  - Sexual health and pregnancy (14)
  - Diet and exercise
  - Dental health
  - Alcohol and drug use

### **14. IMMUNISATIONS**

- Immunisations in patients with JIA will be in accordance with current RCPCH and BSPAR guidance (15).

### **15. IN-PATIENT MANAGEMENT.**

In accordance with the Childrens' National Service Framework Charter for Disabled Persons using Hospitals (16), the following will be ensured:

- All patients with JIA requiring hospital admission will be admitted to age-appropriate accommodation.

- Due account should be taken of patients' symptoms and disabilities due to JIA and access to specially designed facilities, appropriate to the needs of children and young people with disabilities is required, including access for wheelchairs.
- If admitted under the care of other specialists the paediatric rheumatology service should be informed.
- Out of hours consultant paediatric rheumatology advice should be accessible to every hospital and dependent on local clinical networks.

## **16. OUTPATIENT SERVICES**

- All persons with JIA should expect an initial consultation with a consultant or experienced trainee working with a consultant.
- The initial consultation will last as long as is required. The appointment should be allocated 45 minutes in the clinic schedule.
- Time required for follow-up consultations will vary but the appointment should be allocated 20 minutes in the clinic schedule.
- If at the initial consultation a patient is assessed by a trainee or another member of the clinical team, then their management should be discussed with the consultant within a reasonable timeframe (i.e. the same day). This should also occur at subsequent visits when appropriate.
- Time should be made available in the consultant's job plan to reflect the additional workload to supervise and meet the training needs of junior staff (17).

## **17. CLINICAL NETWORKS AND ARRANGEMENTS FOR SHARED CARE**

- Each hospital with clinical services for children in the United Kingdom will be linked to a Paediatric Rheumatology Clinical Network, each of which will have agreed referral pathways, guidelines for shared care and a framework for clinical governance, based on evidence as available or consensus.
- The structure of the clinical network may vary from region to region depending on local factors such as geography and regional expertise.
- It is recommended that in each hospital with clinical services for children there should be a named consultant to be the link person for the paediatric rheumatology clinical network. This will usually be a consultant paediatrician but a named consultant adult rheumatologist with appropriate training may be involved (3).
- The named consultant will work with other members of the clinical network to develop the referral protocols and shared care guidelines to suit local needs.

## ABBREVIATIONS

ANA:	Anti-nuclear antibody
Anti-TNF	Anti-tumour necrosis factor agents
A&E	Accident and Emergency
ARMA:	Arthritis and Musculoskeletal Alliance
BSR:	British Society of Rheumatology
BSPAR	British Society for Paediatric and Adolescent Rheumatology
CCAA:	Childrens Chronic Arthritis Association
CT:	Computed Axial Tomography
DEXA:	Dual-energy X-Ray Absorptiometry
HLA:	Human Leucocyte Antigen
JIA:	Juvenile Idiopathic Arthritis
MRI:	Magnetic Resonance Imaging
NICE	National Institute for Clinical Excellence
NSAIDs	Non-steroidal anti-inflammatory drugs
RCN	Royal College of Nursing
RCPCH	Royal College of Paediatrics and Child Health

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