Guidelines

BSPAR Standards of Care for children and young people with juvenile idiopathic arthritis

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See page 1213 for the editorial comment on these guidelines (doi:10.1093/rheumatology/kep459)

Key words: Adolescent rheumatology, Juvenile idiopathic arthritis, Paediatric rheumatology, Rehabilitation, Health policies.

Executive summary

Introduction

The publication of Standards of Care for juvenile idiopathic arthritis (JIA) has been a major priority for BSPAR for sometime. Both delay in diagnosis due to failure of early recognition of the condition and inequity in subsequent service provision are frequently reported by patients and their parents/carers.

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

These BSPAR Standards of Care for JIA have been designed to help paediatric rheumatology teams to improve the service they provide, by providing a statement of the minimum standards of care required by children and young people with JIA. Fundamental to this are:

- the engagement and empowerment of patients with JIA and their carers;
- adequate training of all professionals likely to come into contact with a patient with JIA;
- a holistic approach with focus on functional and psychosocial outcomes in addition to control of disease activity and development of clinical networks for paediatric rheumatology.

The standards were developed in accordance with the objectives set out in the Children’s National Service Framework [1]. Patient and carer organizations were consulted widely throughout the process. The standards have been designed to complement and be used alongside the user-centred Arthritis and Musculoskeletal Alliance Standards of Care for children and young people with JIA, which are due to be published in April 2010.

This article is an executive summary of the BSPAR Standards of Care for JIA, which were published on the BSPAR website in January 2009 (www.bspar.org.uk/pages/clinical_guidelines.asp).

Summary of the standards

Empowering patients with JIA and their carers

- Patients with JIA and their families will be encouraged to participate in the management of their disease and must have access to information and guidance to allow them to make informed choices about their treatment.

Identification of JIA

- All clinicians and allied health professionals who are likely to come into contact with a child with JIA should have the appropriate knowledge and clinical skills to recognize JIA and be aware of the need for prompt referral to a paediatric rheumatology team.

Referral to the paediatric rheumatology service

- Patients with incident or suspected JIA will be managed by a specialist paediatric rheumatology...
multidisciplinary team. The structure of the multidisciplinary team will vary depending on local arrangements. In some cases the entire team will be based in a single paediatric tertiary referral centre. In other cases some elements of care will be delivered in district general hospitals and in community settings by professionals working as part of a formal paediatric rheumatology clinical network.

- Children with suspected JIA will be referred to the paediatric rheumatology team without undue delay, and seen within 10 weeks of onset of symptoms and within 4 weeks of the referral.
- The initial consultation will last as long as is required. The appointment should be allocated 45 min in the clinic schedule.

Access to the paediatric rheumatology multidisciplinary team

- All children and young people with JIA will have access to a full multidisciplinary team, the members of which have appropriate skills and experience for managing children with arthritis [2] (Fig. 1).
- All members of the multidisciplinary team will have appropriate training and experience in paediatrics and 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 must be working within a paediatric rheumatology clinical network.

Fig. 1 Essential members of the paediatric rheumatology multidisciplinary team.

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<thead>
<tr>
<th>CORE MULTIDISCIPLINARY TEAM</th>
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<tr>
<td>(Access to named member required by every child or young person with JIA):</td>
</tr>
<tr>
<td>- Paediatric rheumatologist*</td>
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<tr>
<td>- Paediatric rheumatology clinical nurse specialist</td>
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<tr>
<td>- Ophthalmologist</td>
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<tr>
<td>- General practitioner</td>
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<tr>
<td>- Paediatric physiotherapist</td>
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<td>- Paediatric Clinical Psychologist</td>
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<tr>
<td>- Paediatric Occupational Therapist</td>
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<tr>
<td>- Podiatrist</td>
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<td>- Health Visitor or School nurse</td>
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<tr>
<th>EXTENDED MULTIDISCIPLINARY TEAM</th>
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<tr>
<td>(Access to named member required if clinically indicated):</td>
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<tr>
<td>- Community nursing team</td>
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<td>- Play therapist</td>
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<td>- Youth worker</td>
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<td>- SENCO</td>
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<td>- Orthodontist</td>
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<td>- Maxillofacial surgeon</td>
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<td>- Orthopaedic surgeon</td>
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*May work in conjunction with a paediatrician with an interest in paediatric rheumatology or an adult rheumatologist with an interest in paediatric rheumatology (operating within a formal paediatric rheumatology clinical network). SENCO: Special Educational Needs Co-ordinator.

Access to treatment

- 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 and National Institute for Health and Clinical Excellence guidelines.
- Monitoring of therapy, where required, will be undertaken in accordance with BSPAR guidelines.
- Where subcutaneous drug administration is indicated, an appropriately trained health care professional (either a paediatric rheumatology nurse specialist or an appropriately trained member of the paediatric community or hospital nursing team) will be available to provide necessary advice, administer the drug and where appropriate, to train the patient or a carer to safely administer the injections at the patient’s home [3, 4].
- All patients with JIA will have access to IA joint injections as required, with access to Entonox, general anaesthesia and appropriate imaging technology where necessary.
- IA injections will be performed no later than 6 weeks after the decision that they are required is made.
- Joint injections will be performed by an appropriately trained clinician, preferably a member of the paediatric rheumatology team.

Regular review

- ‘Tight’ clinical control is advocated to patients with active disease being assessed at intervals no greater than 4 months apart.
- At least 20 min for follow-up consultations should be allocated in the clinic schedule.
- Patients will have prompt access to interim assessment when required.
- Access to a dedicated telephone helpline managed by the Paediatric Rheumatology Nurse Specialist for non-urgent queries is advocated.

Ophthalmology screening

- All patients will have ophthalmology reviews according to the current joint BSPAR/Royal College of Ophthalmology guidelines [5].
- 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, the patient should be seen within 1 week.

Clinical networks and arrangements for shared care

- Each hospital with clinical services for children in the UK 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.
- Out of hours consultant paediatric rheumatology advice should be accessible to every hospital.
Each hospital with clinical services for children should have a named consultant to link with the paediatric rheumatology clinical network. The named consultant will either be a paediatrician or an adult rheumatologist with appropriate training [2].

Care of adolescents with JIA

- All young people with JIA should have a planned, co-ordinated transition from the paediatric to the adult service.
- Young people with JIA will have access to information and advice appropriate for their age and understanding on all generic health issues they may be affected by.
- The adult service will include a rheumatologist, experienced in the care of adults with JIA.

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References