Resource

Standards of Care

Standards of Care are documents written on a variety of health conditions. Standards of care written on JIA lay out the minimum levels of care that should be expected for the condition, giving guidance to healthcare professionals providing this care, as well as important information for young people and parents on the minimum level of care they should expect their child to receive.

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Standards to improve access to early diagnosis and treatment

Access to diagnosis

- 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
- All medical staff should refer all patients with suspected JIA to the paediatric rheumatology team within 6 weeks of the onset of symptoms
- The paediatric rheumatology team must see all children and young people within 4 weeks of the referral being made
- Members of the paediatric rheumatology team will have appropriate training and experience in paediatric rheumatology as defined by the appropriate professional bodies

Assessment of needs

- At diagnosis, children and young people with JIA should have a full assessment of their disease, general health, psychosocial and pain management needs. This should also include particular consideration of educational needs.
- All children and young people with JIA will have access to a paediatric 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.

Evidence-based care

- Children and young people with JIA should have safe, effective, evidence-based care and management strategies, with appropriate monitoring arrangements as defined by recognised professional bodies.

Standards to improve access to information and support

Provision of information

- Children and young people with JIA and their families should have ready access to information about JIA, treatment options and general health issues Information should be provided to enable children and young people to maximise their physical, psychosocial and emotional development within the family and the wider community

Provision of support

- Healthcare and other professionals should actively involve and support family members or carers

Standards to improve access to ongoing and responsive treatment and support

Access to health services

All children and young people with JIA:

- Should be reviewed at least annually by a designated paediatric rheumatology service
- Should be aware of and have continued access to a complete and appropriately trained named multidisciplinary team (MDT)
- Should be provided with clear details on how to contact members of the paediatric rheumatology team when necessary and should be contacted by an appropriate team member within 2 working days
- Should be able to see relevant members of the MDT if required, in addition to their paediatric rheumatologist at each clinic visit üshould have appointments with other specialists planned taking the wishes of the child and family into account
- Where aspects of health care 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
- Should be able to access support for their condition from primary care. The paediatric clinical network must provide clear pathways for advice and support for primary care

Regular specialist review

- Those children and young people with JIA, who have active disease, should have regular specialist review in accordance with BSPAR guidelines
- 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
- Children and young people with JIA should be provided by the MDT with access to information and advice to maintain good general health

Access to investigations

- 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

Access to drug treatments

- Drugs used for the treatment of JIA will be prescribed and monitored in accordance with BSPAR and/or NICE guidelines and will be available without undue delay
- Children and young people with JIA and their parents or carers should be fully informed by the MDT about the benefits and risks of taking and not taking both licensed and unlicensed treatments for JIA
- Adherence to recommended treatments should be routinely assessed and addressed. When adherence issues, which could be harmful to the health of a child or young person with JIA, arise and cannot be easily overcome referral to the paediatric clinical psychologist should be made

Access to clinical trials and long term drug safety studies

- All children and young people with JIA should be given the opportunity to be enrolled in a clinical trial or well-conducted clinical study from the point of diagnosis onwards. They should have the option of contributing towards a related, fully informed and consented Biobank for a subsequent investigation into the cause of their condition
- Clinicians should be encouraged to participate in clinical research within their clinical routine practice, in order to help improve the future care of children and young people with JIA, and be provided with the necessary and sufficient support they require to do this

Access to ophthalmology, specialist surgery and pain management

- Children and young people with JIA should be screened and managed by an ophthalmologist with experience in paediatric uveitis, linked to the paediatric clinical network, in accordance with the BSPAR and Royal College of Ophthalmology guidelines
- Specialist surgery eg orthopaedic and maxillofacial should be performed by a surgeon who has received specific training in the management of JIA and in communicating with children and adolescents and who is linked to the clinical network
- 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

Standards to improve maximising independence, inclusion and quality of life

Coping with juvenile idiopathic arthritis (JIA)

- The psychosocial wellbeing of both the child or young person with JIA and their family should be addressed by all professionals in healthcare, education and the wider community

- Children and young people with JIA and their families should be provided with support and strategies for managing any difficulties they have with unpleasant and distressing aspects of their treatment by the MDT
- Children and young people with JIA should be provided with safe and positive opportunities to meet others with similar conditions, in order to share experiences, establish social networks and have positive and challenging activities with their peers that build self-esteem, coping strategies and life skills
- Children and young people with JIA should be given the skills to disclose their arthritis to others, should they choose to do so

Home, leisure and community

- The needs of a child or young person with JIA, in terms of information, support, independent living skills, coping skills, assistive devices and impact on the family should be reviewed regularly, depending on individual requirements, but at least annually by the MDT. They may, where appropriate, include a home assessment by a member of the MDT
- The paediatric rheumatology team should encourage and facilitate age-appropriate participation in interests, sport and community life

Education and employment

- The educational setting (school and college) should ensure the full inclusion of children and young people with JIA üYoung people with JIA require the skills to move into employment. These skills need to be developed over a period of time and require a partnership approach between the young person, their families, the professionals working with them and prospective employers

Standard to improve transitional care

Access to medical, psychosocial, educational and vocational support

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

Standards for the development of services for JIA

- All health professionals involved in providing care to children and young people with JIA should be working as part of an identifiable paediatric rheumatology clinical network. The structure of individual clinical networks will vary but each will cover a defined area and should have well-publicised referral pathways, shared care protocols and a framework for clinical governance

- Commissioners of paediatric and adolescent health services must ensure that access to services for people with JIA is equitable and reaches agreed minimum standards. It is recommended that each strategic health authority identify a lead commissioner with specific responsibility for paediatric rheumatology and that services for paediatric rheumatology are commissioned at a regional level
- Children and young people with JIA should be involved by commissioners and healthcare managers in the development of services for JIA from the planning stage
- In each unit treating children and young people with JIA, a lead person should be identified to ensure guidelines are being implemented and standards of care are being adhered to
- A system for expert review of Off-label or unlicensed drugs and appropriate funding mechanisms should be in place to facilitate treatment recommendations where there is supporting evidence and a consensus of agreement within the speciality. The treatment should be started within 6 weeks of the decision to use the drug
- Each paediatric rheumatology team should have adequate staff resources to achieve its research potential

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