

Standards of Care
for children and
young people with

Juvenile Idiopathic Arthritis





Contents

The Background	1
About these Standards	3
The Standards of Care:	
Standards to improve access to early diagnosis and treatment	5
Standards to improve access to information and support	10
Standards to improve access to ongoing and responsive treatment and support	13
Standards to improve maximising independence, inclusion and quality of life	21
Standards to improve transitional care	27
Standards to improve the development of care for JIA	30
References	31
Appendix 1: The Paediatric Rheumatology MDT	33
Glossary	34
Acknowledgements	36

ARMA is the umbrella organisation for the UK musculoskeletal community. ARMA is a registered charity No 1108851. Our member organisations are:

- Arthritis Care
 - Arthritis Research UK
 - BackCare
 - Birmingham Arthritis Resource Centre
 - British Chiropractic Association
 - British Health Professionals in Rheumatology
 - British Institute of Musculoskeletal Medicine
 - British Orthopaedic Association
 - British Osteopathic Association
 - British Sjogren's Syndrome Association
 - British Society for Paediatric & Adolescent Rheumatology
 - British Society for Rheumatology
 - British Society of Rehabilitation Medicine
 - Chartered Society of Physiotherapy
 - Children's Chronic Arthritis Association
 - COT Specialist Section - Rheumatology
- Early Rheumatoid Arthritis Network
 - Fibromyalgia Association UK
 - Lupus UK
 - MACP
 - McTimoney Chiropractic Association
 - National Ankylosing Spondylitis Society
 - National Association for the Relief of Paget's Disease
 - National Osteoporosis Society
 - National Rheumatoid Arthritis Society
 - Podiatry Rheumatic Care Association
 - Primary Care Rheumatology Society
 - Psoriasis Scotland Arthritis Link Volunteers
 - Psoriasis Association
 - Rheumatoid Arthritis Surgical Society
 - RSI Action
 - Scleroderma Society

Photographs on front cover reproduced by kind permission of Arthritis Care.

© April 2010 Arthritis and Musculoskeletal Alliance.
Any part of this publication may be freely reproduced for non-commercial purposes and with the appropriate acknowledgement.

The contents of this document and further resources including contact details for our member organisations, further information about our work and this project, including additional examples of good practice and resources to support implementation, are available on the ARMA website at www.arma.uk.net.

The Standards of Care project has been managed by ARMA. This document received funding from an anonymous donor, and has been funded through an unrestricted educational grant from Wyeth Pharmaceuticals, a wholly-owned subsidiary of Pfizer Inc. Wyeth has had no input into or influence over the content of this document and any opinions contained therein are not necessarily those of Wyeth Pharmaceuticals. For details of contributors, please see Acknowledgements on page 36.

Introduction

This is an exciting time in paediatric rheumatology. The past ten years have seen a revolutionary change in how children and young people with juvenile idiopathic arthritis (JIA) are treated, with an emphasis on holistic care which addresses all aspects of their lives. In addition, novel treatments have been developed which for the first time offer a realistic chance of achieving disease remission in the majority of affected children and young people. The prospect of JIA being considered a curable disease is at last on the horizon and is the ultimate goal of current research in this area. Meanwhile, it is the responsibility of providers and commissioners of healthcare, education and social services to ensure that every child and young person with JIA has access to the best currently available, evidence-based treatment, and to the support he or she requires to lead a healthy, happy, independent and ultimately fulfilling life.

These Standards of Care bring together a model of best clinical practice based on available evidence, expertise of professionals working within the specialty and an in-depth understanding of the problems experienced by children and young people with JIA.

The scale of the problem

JIA is an inflammatory condition of unknown cause which causes chronic arthritis in children and young people. In the United Kingdom, approximately 12,000 children (1 in 1,000), under the age of 16 have Juvenile Idiopathic Arthritis. JIA is one of the commonest causes of physical disability beginning during childhood.

What is the impact of JIA?

There are several different subtypes of JIA, each of which is characterised by a specific set of features. Regardless of the subtype they have, all children with JIA develop chronic arthritis, the symptoms of which are stiff, painful and swollen joints. The severity of the arthritis can vary from mild to extremely disabling. Depending on which joints are affected, difficulties can be experienced in all areas of their lives. In young children physical development can be significantly delayed. If inadequately controlled, the arthritis can lead to permanent joint damage and deformity.

JIA is also associated with a number of complications unrelated to the joints, some of which can be more problematic for the child or young person than the arthritis itself. In addition to the physical problems caused by JIA, the disease can also affect the child or young person's emotional well-being, social development and educational attainment. Difficulties in these areas can be experienced at any age but often become more apparent during adolescence.

The diagnosis of JIA does not only affect the child or young person but impacts on the whole family and society. The cost to the individual, the family and society should not be underestimated.

Why we need Standards of Care

The management of JIA requires a holistic approach, and whilst control of disease activity is clearly a major goal, attention should also be focused on general health, mental wellbeing and functional, educational, social and employment outcomes.

All children with JIA have the right to equitable access to the highest quality of clinical care, based on current evidence and delivered by appropriately resourced and experienced multi-disciplinary teams. These Standards of Care are designed to help and support children and young people with JIA and their families and all professional teams, by providing a statement of the minimum standards of care required by such children and young people. The Standards of Care can also be used by parents and Third Sector organisations to negotiate with healthcare commissioners and providers about delivery of care for children in their area.

The aim is to provide the best quality of care for all children and young people with JIA and their families irrespective of their geographical location. Fundamental to this is the engagement and empowerment of children or young people with JIA and their families who should be central to the management of their condition and to the planning of services.

ARMA Standards of Care are intended to:

- improve the quality of life for children and young people with JIA and their families or carers
- improve functional, educational, social and employment outcomes
- promote equality of access to diagnosis and management by an appropriately resourced and experienced multidisciplinary team
- promote access to information, support and knowledge appropriate to children or young people with JIA and their families
- promote consistent standards of ongoing and responsive treatment and support
- involve the child or young person with JIA and their family or carers in the management of their illness and how their care is delivered

Looking beyond healthcare – the holistic approach

Healthcare is only one factor in the holistic approach to maximise the potential of all children and young people affected by JIA. The ARMA Standards are intended to support those affected by JIA to lead independent lives and reach their full potential. The Standards define which services are appropriate and suggest ways of providing them effectively and in a measurable way. A detailed rationale for the Standards draws on available evidence and examples of good practice drawn from ARMA's ongoing call for good practice: a database giving details of these and other examples is available at www.arma.uk.net.

The Standards acknowledge the fact that those planning and delivering services around the UK face differing demographic, geographical and economic factors, which will affect how the Standards are implemented in each locality. We hope that the Standards will act as a tool for all stakeholders – service users, providers, commissioners and policy-makers – to work together to review and improve their local musculoskeletal services.

The Standards are not guidelines, or algorithms of care, though they refer to those where available.

How the Standards were developed

This set of Standards for children and young people with JIA, like previous Standards published by ARMA, are the result of extensive collaboration. They have included input from young people with arthritis, their parents, Community and Voluntary Sector leaders and a wide range of clinicians and other health professionals who are recognised experts in their field.

The Standards were developed by an expert working group, facilitated by ARMA and the British Society for Paediatric and Adolescent Rheumatology (BSPAR). The group included experienced service users, providers and experts from many professions from around the UK. Starting with a review of the needs of people with JIA, the group met 5 times between 2008 and 2010 to determine evidence-based Standards to meet those needs, consulting widely and publicly on the drafts. The Acknowledgements on page 36 give details of the working group membership.

Clinical experts have identified the evidence base, including relevant guidelines for the management of JIA. Evidence has not been graded for the purposes of this document. For further details on the evidence base, please refer to the references quoted in the document.

The resulting Standards are therefore based firmly on the experiences and preferences of children and young people with JIA, and on evidence of good practice where this is available.

ARMA plans to review these Standards in 2013, or sooner if there are significant developments in care for children and young people with JIA.

Next steps

The publication of these Standards is part of an ongoing programme to improve musculoskeletal services for all. These Standards will be circulated to children and young people with JIA and their families, doctors, allied health practitioners, providers and commissioners of health services, voluntary organisations and policy makers. Audit tools will be published to support the Standards implementation. Examples of good practice will be made accessible to everyone through ARMA's online database.

All stakeholders are invited to make a commitment to implementing the Standards. First steps might be to:

- audit existing services
- work in partnership with all stakeholders, including national and local voluntary organisations, to involve service users in designing and developing services.

Above all share your success! Tell ARMA about your initiatives; send examples of good practice; help to build a national resource for high-quality services for JIA.

This document has been jointly prepared by ARMA and BSPAR.

BSPAR

BSPAR is a charitable organisation which represents all health care professionals in the UK and Ireland involved in the care of children and adolescents with rheumatic disease, working in clinical service, educational and academic sectors. Its aim is to advance paediatric rheumatology care in the UK and Ireland, by raising the standards of clinical care, enhancing the quality of training and promoting research in order to increase understanding, improve management and ultimately create better outcomes for children with rheumatic diseases, especially JIA.

www.bspar.org.uk

Access to diagnosis

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.

Standard 2

Healthcare practitioners should refer all children and young people with suspected JIA to the paediatric rheumatology team within 6 weeks of the onset of symptoms.

Standard 3

The paediatric rheumatology team must see all children and young people with suspected JIA within 4 weeks of the referral being made.

Standard 4

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

Standard 5

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.

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).

Evidence-based care

Standard 7

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.

The rationale

- The National Service Framework for Children, Young People and Maternity Services requires a focus on early intervention, based on timely and comprehensive assessment of a child and their family's needs.¹
- Difficult 'journeys to diagnosis' have been shown to impact on how families relate to health care practitioners and subsequently adhere to treatment.^{2,3}
- Early intervention with disease-modifying drug therapy improves long-term outcomes.⁴ The earlier a child or young person is able to access treatment and support, the better are the chances of reducing the joint damage that can lead to long-term disability and loss of function. Therefore health care professionals need to refer to a specialist who can confirm diagnosis and commence treatment as quickly as possible.
- Delay in diagnosing JIA results in a delay in diagnosing the chronic anterior uveitis which can accompany it. This may result in permanent eye damage.^{5,6}

- For many children, young people and their families, the diagnosis of JIA can seem devastating. It is vitally important that diagnosis is conveyed with care and sensitivity. It should be accompanied by positive and supportive advice and information as well as details of support organisations and help lines.⁷ Children, young people and families given this diagnosis may initially find it hard to take in everything that is said. Appointments need to allow time for a full explanation of the disease and discussion of treatment options. These should be routinely followed by clinic or telephone appointments with the clinical nurse specialist or other members of the team.
- JIA can affect all aspects of a child or young person's life and development, and their wider needs, both clinical and non-clinical (eg. emotional and educational), need to be assessed and addressed.
- Children, young people and families need high-quality information to be able to balance the risks and benefits of treatment options, both pharmacological and non-pharmacological, and to make informed choices about their or their children's care.
- Disease-modifying drugs can considerably improve children and young people's lives, but they have potentially toxic side-effects which necessitate regular monitoring.⁸
- An individualised care plan can enable a child or young person and their family to have a clear understanding of what they can expect. It identifies who is responsible for which aspects of care, and promotes collaboration between the person and all the professionals involved.⁹
- JIA can affect the ability of children and young people to pursue their education or employment and participate in family life and their own social life. Appropriate adaptations to school, work place and home environments may be required. Support may need to include social services and other government agencies or voluntary organisations.

Putting the Standards into practice: **key interventions**

- i Appropriate information on musculoskeletal conditions in children and young people 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, appropriate voluntary organisations, young people and families in the development of such guidance is strongly recommended.
- ii All clinicians and allied health professionals likely to come into contact with a child or young person with JIA (for example general practitioners, paediatricians, orthopaedic surgeons, Emergency Department doctors, paediatric physiotherapists and occupational therapists) must 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 at postgraduate level, and health professionals in the paediatric rheumatology team must make training available to other professionals in their clinical network(s).

- iii All medical schools must include paediatric musculoskeletal clinical skills and knowledge as "core" teaching in their curricula to promote awareness and early recognition of JIA.
- iv Postgraduate education for all those health care professionals in primary care and secondary care (including orthopaedics, paediatrics and emergency medicine) who may be involved in the assessment of children should include and assess learning outcomes about JIA to facilitate early diagnosis and referral.
- v All children and young people with JIA should expect an initial consultation with a paediatric rheumatology consultant, or supervised trainee working with a consultant.

The appointment should be allocated a minimum of 45 minutes in the clinic schedule.

If at the initial consultation a child or young person is assessed by a trainee or another member of the clinical team, then their management should be discussed with the consultant (i.e. the same day). This should also occur at subsequent visits when appropriate.

A documented baseline assessment should be carried out when an individual's disease is diagnosed, including their general medical health and co-morbidities. This is essential to enable accurate monitoring of the effectiveness of treatment.

- vi A comprehensive record needs to be maintained of the individual's disease activity and general health, so that the efficacy of treatments can be monitored and co-morbidities can be identified.
- vii Where applicable, when commencing biologic agents, consent should be sought for inclusion on the relevant drugs registry.
- viii On diagnosis, referral to other allied health professionals within the multidisciplinary team should be made for baseline assessment, tailored education and information, advice and appropriate interventions e.g. occupational therapy, physiotherapy, podiatry and other therapies as required.¹⁰

Good Practice Example - A

A paediatric rheumatology team has developed a teaching programme to reach both general practitioners (GPs) and doctors in training. This includes teaching about the presenting features of JIA and its differential diagnoses (concentrating on symptoms and examination findings) at the regional General Practice CPD meetings every 3 years and at the Emergency Department teaching programme every 6 months. Pathways for referral to the Paediatric Rheumatology team are also explained.

Good Practice Example - B

Newcastle University has developed a simple screening examination to assess children's joints – this is called pGALS and is aimed at medical students so that all doctors of the future, whatever their career path, will know a simple approach to examining children's joints. The aim is to aid early recognition of JIA and facilitate referral to specialist care. pGALS is now taught in many UK medical schools and is taught to GPs, and other doctors in training to whom children with JIA may first present. Arthritis Research UK (formerly Arthritis Research Campaign) funded the development of pGALS and have produced free resources to help teaching and learning.

www.arthritisresearchuk.org

- ix On diagnosis, children and young people should be offered treatment in accordance with national guidelines. All children and young people with JIA will have access to intra-articular joint injections as required, with access to appropriate levels of local or general anaesthesia and appropriate imaging technology where necessary.

Intra-articular injections will be performed no later than 6 weeks after making the decision that they are required and sooner than that if clinically necessary. 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 in an age appropriate environment.

- x Children, young people and their families must be referred to a clinical nurse specialist within four weeks (core), or ideally two weeks (developmental), of their first appointment with a specialist, who will support and guide them through diagnosis and treatment options. Children, young people and their families should have ongoing access after that time to information and support, including access to a helpline (e.g. nurse-led helpline).
- xi Referrals to paediatric physiotherapy and occupational therapy should be regarded as urgent and children and young people should accordingly be placed on the acute waiting lists of these services. Waiting times to the first appointment should be no longer than 8 weeks from the time of referral or no longer than two weeks after joint injections. Urgency may in some cases be greater than this for pain management and or issues surrounding activities of daily living such as mobility.
- xii Children and young people may require input from other members of the extended multi-disciplinary team at diagnosis (see page 33).

Children and their families should be made aware at the time of diagnosis of the Children's Chronic Arthritis Association, Arthritis Care, Contact a Family and BSPAR as well as local initiatives such as paediatric rheumatology network user groups and local ARMA networks.

- xiii All children and young people with JIA will have ophthalmology reviews according to the current joint BSPAR/Royal College of Ophthalmology guidelines.¹¹ New referrals will be screened as soon as possible and not longer than 6 weeks after referral to the ophthalmology service. If symptomatic, or if the child has evidence of eye damage, in accordance with the guidelines ophthalmology review is urgent and the child should be seen within one week of the referral being made.
- xiv Each child or young person with JIA should have an individualised care plan for the management of their disease, compiled by the members of the multi-disciplinary team. The plan should include:
 - Clear pathways for ongoing care and treatment (for example, a copy of the clinic letter)
 - Information about what to do in the event of worsening symptoms, including contact details for urgent advice
 - Information about treatments
 - Information about members of the paediatric rheumatology team
 - Details of national and/or local support groups and helplines
 - Details of financial support available
 - Information for schools and employers on how to support children and young people with JIA in education and work.

Provision of 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.

Provision of support

Standard 10

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

The rationale

- The National Service Framework for Children, Young People and Maternity Services requires services to give children and their families information about the treatments that they receive.¹¹ It also requires the promotion of the health and well-being of all children and young people wherever possible.
- Being provided with information about JIA and treatments enables children and young people and their families to make informed decisions about their management. This encourages a partnership between the family and the multi-disciplinary team, which aids adherence to treatments and improves patient and family satisfaction.
- Young people express a clear preference to be able to access general health information from all healthcare professionals rather than have to make a separate visit to their GP. One of the 'You're Welcome' quality criteria for young people is that staff members should be trained to discuss all relevant health issues.¹²
- The vision of Every Child Matters¹³ is central to the requirement of children and young people and their families for information to enable them to maximise their development and participation.
- 'Healthy Lives, Brighter Future' states that 'Better support in the early years and through childhood and adolescence will lay the foundation for better health and life chances into adulthood'. The document is clear that support is required for ongoing physical and psychological problems.¹⁴

- The diagnosis of JIA can be devastating for children and young people and their families. The implications are far-reaching; physical, emotional and financial. The child or young person and their family will require intensive support immediately, and also in the longer term, from all professionals in their sphere.
- Support from other children and young people with JIA and their families can also be invaluable and may be provided in a variety of formats. Children and young people and families should have choice over the support offered to them.¹⁵ Parents require support that reflects their lives.¹⁶

Putting the Standards into practice: key interventions

- Information should be provided by the Paediatric Rheumatology team about JIA, medical treatments including drugs and joint injections, and therapies including physiotherapy, occupational therapy, podiatry and orthotics, pain management, clinical psychology and play specialists.
- Information should be provided about the members of the multi-disciplinary team and how to access them.
- Information should be provided about general health including diet, exercise, alcohol, drugs, smoking, sexual health, travel and immunisations and transition to adult care.
- Information about financial help should be provided.
- Sign-posting to other agencies and sources of help should be provided.
- Information should be in clear, simple language, avoiding jargon.
- Information should be developmentally appropriate; i.e. the content and style should be appropriate for every stage of a child or young person's life.¹⁵
- Information should be up-to-date¹⁵ and the need for information regularly revisited. Health professionals

Good Practice Example - C

The Children's Chronic Arthritis Association (CCAA) runs an annual JIA Family Support Weekend which provides for the child or young person with arthritis and the whole family a unique opportunity, not only to meet other families in the same situation, but to gain up-to-date information and support from a wide range of health professionals on coping with everyday life with their disease. The weekend also provides a wide range of recreational activities for the children or young people with JIA and their siblings, which helps build their confidence and self-esteem.

Good Practice Example - D

In Northern Ireland, Arthritis Care's Family and Youth Work Service has developed a series of residential weekends in partnership with the local paediatric rheumatology team. These weekends include supervised physical activities, positive future workshops and body image workshops. A number of the young people have progressed to become youth leaders themselves on the project, acting as mentors, peer support and role models to newly diagnosed young people with JIA.

should document which leaflets, etc have been given to children and young people and their families.

- ix Information should be easily accessible to families in which English is not their first language, using interpreting services when needed.
- x Information should be available in a variety of formats, for example leaflets, DVDs, web-based.
- xi Access to a dedicated Telephone Helpline managed by the Paediatric Rheumatology Nurse Specialist for non-urgent queries is advocated in order to provide information and support. This should be provided in accordance with the RCN (2006) guidance on telephone helplines.¹⁷
- xii Face-to-face support should be provided by the MDT
- xiii Written support should be provided where indicated; for example advocating for children and young people to participate in school trips, medical reports for Disability Living Allowance
- xiv Support may be provided by other children or young people and families in the form of workshops or activity weekends.

Access to health services

Standard 11

All children and young people with juvenile idiopathic arthritis should be reviewed at least annually by a designated paediatric rheumatology service.

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 (see Appendix 1).

Standard 13

Each child or young person with JIA should be provided with clear details on how to contact members of the paediatric rheumatology team when necessary and should expect to be contacted by an appropriate team member within 2 working days.

Standard 14

Children and young people with JIA should be able to see relevant members of the MDT if required, in addition to their paediatric rheumatologist at each clinic visit.

Standard 15

Appointments with other specialists e.g. ophthalmologists, should be planned taking the wishes of the child and family into account. Where preferred and convenient for the child and family these should be scheduled to take place on the same day as the rheumatology clinic visit.

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.

Standard 17

Children and young people with JIA should be able to access support for their condition from primary care. The paediatric rheumatology clinical network must provide clear pathways for advice and support for primary care.

Regular specialist review

Standard 18

Those children and young people with JIA, who have active disease, should have regular specialist review in accordance with BSPAR guidelines.

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.

Access to Investigations

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.

Access to drug treatment

Standard 22

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.

Standard 23

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.

Standard 24

Adherence to recommended treatments should be routinely assessed and addressed. Where 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

Standard 25

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 point of diagnosis onwards. They should have the option of contributing towards a related, fully informed and consented Biobank for subsequent investigation into the cause of their condition.

Standard 26

Clinicians should be encouraged to participate in clinical research within their clinical routine practice, in order to help improve 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

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.¹⁸

Standard 28

Specialist surgery e.g. orthopaedic and maxillofacial surgery 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.

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 need for physiotherapy and occupational therapy involvement in JIA is ongoing throughout the course of the disease. The practice of discharging patients after a 6 week block of treatment is inappropriate for JIA and should not be part of the management strategy.
- JIA can be unpredictable and the disease can flare up suddenly with little warning. In addition complications can arise as a result of its treatment. Children and young people with JIA and their families therefore require rapid and direct access to the appropriate members of their paediatric rheumatology team.
- In order for health professionals working outside the immediate tertiary paediatric rheumatology service to provide safe and effective care to children and young people with JIA, ongoing access to support from the tertiary service is required. This includes access to clinical support, training and continuous professional development (CPD)

Regular specialist review

- Children and young people with JIA should be able to expect their clinic reviews to provide ongoing and responsive support for every aspect of their disease. Goals of frequent review are to ensure disease is adequately controlled, to make sure the child or young person is getting the support he or she needs to maximise their quality of life, and to ensure they have access to the information and guidance required for a healthy lifestyle. Reviews need to be frequent enough to ensure that problems can be addressed before any long term damage is sustained.
- The multidisciplinary nature of the management of JIA results in the need for frequent appointments with various team members and associate specialists. This can be extremely disruptive and inconvenient for the children or young people and their families and can affect all aspects of their lives.

Access to investigations

- Children are not simply small adults – they have different anatomy, physiology and normal reference values. Professionals performing and interpreting investigations in children with JIA should be aware of these differences and should have expertise in both performing and interpreting the results of any investigations they undertake. Where this expertise is unavailable the child or young person should be referred to a centre where it is available. Appropriate sedation and distraction (e.g. involving play therapists where appropriate) should also be available.

Access to drug treatment

- Inflammation of the joints in JIA causes pain, swelling and muscle wasting, all of which can interfere with activities of daily life. Ongoing inflammation can lead to permanent joint damage and growth disturbance (for example, legs of unequal length). Therefore the primary goal of the medical treatment of JIA is to suppress disease activity as rapidly as possible and bring about disease remission.
- Major advances have taken place in recent years in our understanding and the evidence-base of JIA. Important steps have taken place in improving treatment of JIA.¹⁹ A core set of criteria

The rationale

Access to health services

- Optimal management of JIA requires the ongoing involvement of a highly skilled paediatric rheumatology MDT. Although it may be appropriate for some care to be provided by local practitioners with generic skills and with some training in paediatric rheumatology, every child and young person with JIA should remain under the care of a designated paediatric rheumatology service by which they should be reviewed at least annually by all team members involved in their care.

have been developed through international consensus to facilitate standardisation of measures of change in JIA which can be very useful in clinical practice.^{20, 21} More recently, the bar has been raised in the expectations both clinicians and families have of outcome in JIA. Definitions of clinical remission both on and off medication and minimum disease activity become important targets to achieve in clinical practice.^{22, 23} The advent of biologic therapies has opened a major new era in the medical management of JIA.²⁴

- At the same time, many newer drugs commonly used in adult medicine do not have a license to be used in children or young people. In addition, because JIA is a relatively rare condition, there is often limited published evidence to support the use of drugs which have been successfully used in adults with arthritis. This means that NICE are often unable to carry out an appraisal of a drug which may help in JIA. As a result paediatric rheumatologists often have to recommend the use of medicines that are currently not licensed for use in JIA and/or for which there is no NICE guidance. In such situations the drug should be prescribed in accordance with best available evidence and only if there is a professional consensus of opinion that the treatment is appropriate and with no reasonable alternatives. In such cases it is essential that the child (if appropriate) or young person and their families are fully informed that the treatment is unlicensed for JIA and do consent to its use.

Access to clinical trials

- The lack of published evidence to support the use of various treatments in JIA needs to be urgently addressed.²⁵ Advances in medical treatment can only be made when a potentially superior treatment is measured against the current “gold standard” treatment. Given the relatively small numbers of people with JIA, in order to be able to make valid conclusions from the results, studies usually need to be undertaken and co-ordinated at a national or international level.
- Recent trials of biological therapies in JIA have come about only through such collaborative efforts and these significant advances need to be fostered and supported by all stakeholders concerned about the improved care of children and young people with JIA.
- Both BSPAR and the UK MCRN/arc Paediatric Rheumatology Clinical Studies Group (CSG) share the goal of advancing paediatric rheumatology care in the UK and Ireland, by raising the standards of clinical care, enhancing the quality of training and promoting research in order to increase understanding, improving management and ultimately creating better outcomes for children with rheumatic diseases. The UK MCRN/arc Paediatric Rheumatology Clinical Studies Group strategy is underpinned by the crucial question: “What are the key clinical research priorities that will change clinical practice in Paediatric Rheumatology (and especially JIA)?”.²⁶
- For several decades now, all patients with acute lymphoblastic leukaemia and a number of other childhood malignancies have been routinely given the opportunity to be included in nationally or internationally co-ordinated clinical trials of new therapeutic regimes and interventions. The result of this strategic initiative has been a stepwise and continued improvement in outcomes in these diseases. In a similar way, necessary improvement in outcomes in JIA would be expected if the paediatric oncology model was adopted in paediatric rheumatology.

- This priority for the routine access for children and young people to potential enrolment into a clinical trial or study from the time of diagnosis of JIA onwards was highlighted in a recent UK-wide consultation process carried out by the UK MCRN /arc Paediatric Rheumatology Clinical Studies Group and is outlined in its Research Strategy document.²⁶
- Research has indicated that most people with a chronic disease and their families are keen to be given the opportunity to be involved in clinical research, for both personal and altruistic reasons.^{27, 28}
- Children and young people with JIA should therefore be informed about ongoing and future clinical trials and supported in every way to participate in these if they wish and are eligible. Similarly clinicians should be encouraged to participate in clinical research and provided with all the necessary support they require to do this.

Access to ophthalmology, specialist surgery and pain management

- Uveitis is a common but serious complication of JIA which if undetected or inadequately treated can lead to visual impairment. Specific guidelines have been published by the Royal College of Ophthalmology/ BSPAR on screening for uveitis in JIA, which have been designed to minimise the risks consequent on delayed diagnosis and treatment.¹⁸
- Surgery in JIA is rarely required but in some cases specialist orthopaedic, maxillofacial or hand surgery is necessary. Surgery in JIA poses specific challenges and should be undertaken only by surgeons experienced in managing the condition and in centres where the appropriate supporting facilities are available.
- Pain can be a prominent symptom in JIA. In addition to directly limiting the child’s day to day activities, ongoing pain can profoundly affect quality of life, mental health and educational achievement. A child or young person with JIA should therefore have his/her pain levels appropriately assessed at frequent intervals and strategies to reduce the pain should be implemented.²⁹

Good Practice Example - E

A number of hospital trusts in the UK use a computerised database to record and monitor all drug treatments for their patients with JIA. The database can store blood results from other hospitals and GPs as well as the base hospital. The system flags up abnormal blood results automatically and a programme generates letters to patients who have not attended for a blood test, greatly enhancing patient safety. It is also a powerful research tool, recording demographic details, diagnosis and outcome measures.

Putting the Standards into practice: **key interventions**

Access to healthcare

- i The child or young person with JIA should have access to the full MDT and should be provided with the phone number of each of their named professionals. They should be provided with clear information on how to seek interim help when required. These details should be copied to the GP. In addition a specialist paediatric rheumatology helpline is advocated.³⁰
- ii Professionals working in primary care (including GPs, community nurses and pharmacists) should be supported by the clinical paediatric rheumatology network and expect a response to telephone enquiries within 2 working days. If an interim review is requested this should occur within 2 weeks of the request being made.
- iii A written transcript of each episode of paediatric rheumatology care will be sent to the GP of the child or young person with JIA and copied to the young person, parent or carer within 2 weeks. More urgent correspondence should be hand-delivered, e-mailed or faxed to the GP.
- iv The clinical network should provide clear and well publicised shared care guidelines and pathways for enquiries from primary care.
- v Face-to-face support for community nurses should be available from the paediatric rheumatology team where needed.

Regular specialist review

- i In accordance with BSPAR guidance CYP JIA with active disease should be seen in clinic at intervals no greater than 4 months apart.
- ii Follow-up medical consultations should be allocated at least 20 minutes in the clinic schedule.
- iii Clinics should be multidisciplinary, with all MDT members present where possible. Where required, follow-up consultations with the nurse specialist, physiotherapy, occupational therapy and podiatry should be allocated at least 30 minutes each.
- iv Children and young people with JIA should have the following measured or assessed at each review appointment:
 - Height and weight (plotted on standard growth charts)³¹
 - Urinalysis and blood pressure
 - Core outcome variables
 - Review of treatment and side effects
 - Pain and discomfort
 - Participation in activities of daily living at home, school and in the community
 - Developmental milestones
 - Social and psychological wellbeing.

Access to investigations

- i Children and young people with JIA requiring specialist radiological investigations must have these performed within 4 weeks by a service with appropriate levels of musculoskeletal expertise both to undertake the procedure and interpret the results.

Access to drug treatment

- i Standard treatments for JIA including subcutaneous methotrexate and NICE approved medication should be available within 4 weeks of the decision to treat.³²
- ii Individually funded drugs should be available within 6 weeks of the decision to treat.
- iii A safe and effective monitoring system must be demonstrable within each unit prescribing disease modifying anti-rheumatic drugs (DMARDs).^{32, 33}
- iv Systems should be in place to ensure there is no interruption in the provision of established treatments at the time of transfer to adult services. This is the responsibility of the paediatric rheumatology team.
- v Joint injections should be performed by an appropriately trained member of the paediatric rheumatology clinical network. Access to appropriate anaesthesia (including general anaesthesia and Entonox®) and appropriate radiological technology should be available. Children and young people with JIA identified as needing a joint injection should have the procedure done within 4 weeks if requiring general anaesthetic and 10 days if requiring Entonox®. Triamcinolone hexacetonide should be used in paediatric joint injections.

Access to clinical trials, pharmacovigilance and drug safety studies

- i Children and young people with JIA should be informed about ongoing and future clinical trials and supported to participate in these if they wish and are eligible. Similarly clinicians should be encouraged to participate in clinical research and provided with the support they require to do this.
- ii Written information on specific treatments and ongoing clinical research should be readily available in clinic.
- iii Working synergistically and in very close collaboration with the BSPAR community and CSG, all care givers, governmental agencies, advocacy groups and the general public should continue to work together to achieve the very highest standard of care and disease remission for children and young people across the UK with JIA.^{25, 34}
- iv Following the extremely effective model pioneered by paediatric oncology, all those concerned with the care of children and young people with JIA should foster development of a comprehensive portfolio of key research priorities for clinical trials and related studies so that all children and young people across the UK are given the possibility of participating in studies of the very latest treatments and therapies in JIA.



Access to ophthalmology, specialist surgery and pain management

- i All children and young people with JIA should have regular screening for uveitis in accordance with published BSPAR/RCOphth guidelines.
- ii A full range of pain management treatments should be available to all children and young people with JIA. This may vary from simple analgesics to a full multidisciplinary programme.
- iii Pain should be assessed with the use of age and developmentally appropriate assessment tools.

Coping with juvenile idiopathic arthritis

- Standard 30**
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
- Standard 31**
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.
- Standard 32**
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.
- Standard 33**
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

- Standard 34**
The needs of the 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.
- Standard 35**
The paediatric rheumatology team should encourage and facilitate age - appropriate participation in interests, sport and community life.

Education and employment

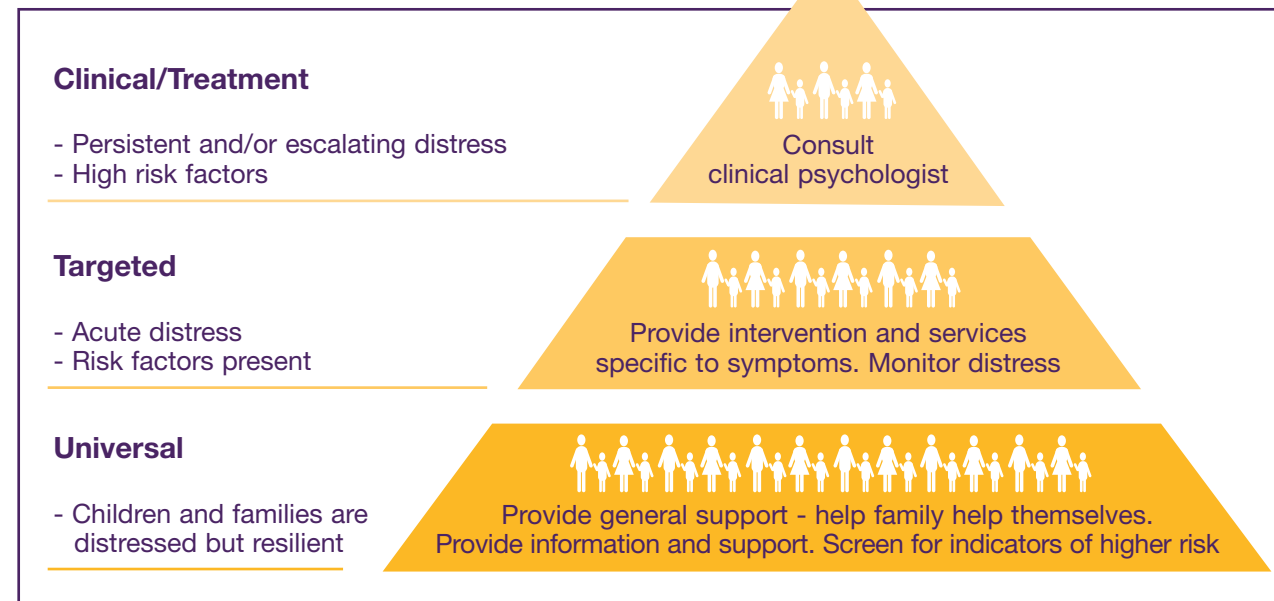
- Standard 36**
The educational setting (school and college) should ensure full inclusion of children and young people with JIA
- Standard 37**
Young people with JIA require the skills to move into employment. These skills need to be developed over a period of time and require a partnership approach between the young person, their families, the professionals working with them and prospective employers.

The rationale

Coping with juvenile idiopathic arthritis

- All families are likely to experience some difficulties managing the challenges which come with a diagnosis of JIA. Emotional and behavioural difficulties may develop which include:
 - Difficulties adjusting positively to this chronic medical condition. Children and young people may experience anxiety, depression, low self-esteem, stress and altered body image
 - Behavioural difficulties that impact on home life, functioning in school or the effective management of the condition
 - Parental anxiety regarding diagnosis and managing ‘normal’ family life
 - Parental difficulties coping with a child who may have emotional and/or behavioural difficulties
 - Family dynamics, including disagreements between parents or sibling rivalry which may interfere with medical treatment

Paediatric Psychosocial Preventative Health Model



- Families differ in their level of need for psychosocial assistance. This is captured in the Paediatric Psychosocial Preventative Health Model (Kazak, 2006).³⁵ Some will require targeted assistance from the paediatric rheumatology team. Other families, often those who have pre-existing vulnerabilities, experience high and persistent levels of distress and will require help from a Clinical Psychologist or from specialist mental health services.
- It is the responsibility of the paediatric rheumatology team to address these issues in partnership with the child or young person with JIA and their families or carers. Some children, young people and their families may find aspects of the treatment of their condition difficult to cope with at times. These difficulties may include:
 - Child or parental anxiety related to the hospital environment and clinic visits
 - Fear of injections/blood tests or other procedures
 - Difficulties understanding the disease process, medical terminology and the reasons for particular treatments
 - Difficulties adhering to treatment plans
 - Trying to live a normal life with an unwanted medical condition and/or whilst being in pain
- Children and young people with JIA, their families and those working with them may experience low expectations of their ability to progress both socially and educationally while hoping for the same things as their peers. An often-heard phrase is “you can’t have arthritis – that’s an older person’s disease”. There is often a stigma attached to developing arthritis, therefore the need to increase integration and reduce feelings of ‘being different’ are crucial to the overall future development of a child or young person with JIA. They should be made aware of all support services available to them which may enhance their quality of life.
- Children and young people with JIA and their families have a right to equal opportunities for the provision of health and social care and education. It is important for children and young people with JIA and their families to be made aware of the services available to them which enhance their quality of life. This is important at school, college or work in order to get support under the Disability Discrimination Act (2005).³⁶

Home, leisure and community

- A child or young person with JIA can experience difficulties participating in everyday activities for a number of reasons including limited psychological and personal capabilities. These may be temporary or permanent.
- Interventions are available to maximise participation, including skills training, advice and support as well as environmental modification.
- Waiting times for specialist equipment can have an adverse effect on participation and inclusion in every day activities at home, school and in the community. This may impact significantly on emotional wellbeing and quality of life.
- Children and young people with rheumatic diseases tend to be less physically active than their peers. Poor conditioning, rather than disease activity, may interfere with participation in Physical Education and leisure activities. Children and young people with JIA may also experience a variety of barriers to participation in play and leisure activities.
- Participation in sports and other activities are essential for a child or young person with JIA in order to:
 - improve bone health, reducing the risk of osteoporosis.
 - improve feelings of wellbeing, moderate the effects of pain, boost energy levels and provide opportunities to increase social interaction.
 - increase strength and stamina enabling participation in normal activities of daily life.
 - improve cardiovascular fitness and reduce the risk of coronary heart disease.
 - prevent obesity and reduce the risk of Type II Diabetes.
 - improve sleep due to physical activity during the day.

Education and employment

- A child or young person with JIA may experience academic, social or mobility difficulties at school. These can result in absenteeism, teasing/bullying or emotional problems. Provisions should be made for a child or young person with JIA so that they can:
 - access the full curriculum, including PE and other practical subjects such as Drama and Design and Technology.
 - engage in all aspects of school life.
 - access the school site in line with the Disability Discrimination Act (2005).
- Young people with JIA should have the same opportunities afforded to them when applying for a job as their non-disabled peers. If the young person is already in employment, employers have a responsibility to make reasonable adjustment to enable them to remain in post and carry out their role effectively.³⁶

Good Practice Example - F

A hospital trust annually arranges a trip for young people with chronic rheumatic disease which provides opportunities to participate in a range of self-care tasks and adventure activities as well as providing an opportunity to meet similar others. The programme is organised by the young people themselves who determine menus, house rules and activity schedules. The programme is perceived as a valuable experience by the young people and offers an opportunity to develop friendships which last beyond the trip.

Putting the Standards into practice: **key interventions**

Coping with JIA

- i Practitioners should build an equal partnership with children, young people and their families so that psychosocial issues can be discussed openly and ensure that young people and their families do not feel that they are being judged. This will be aided by the creation of a welcoming environment suited to children and young people and their families.
- ii There should be ongoing assessment and discussion, by all professionals within the paediatric rheumatology team, of the level of family risk and distress in order to build an optimal fit between the child's and the family's needs and the level of psychosocial care required. This information should be communicated to the GP.
- iii Clinical Psychology services should be run in parallel with JIA clinics. Clinical Psychologists should support other team members in psychological aspects of their casework and help the child or young person and their families with strategies to manage all aspects of their symptoms. Potentially distressing aspects of treatment should be addressed by all professionals in the paediatric rheumatology team in each consultation.
- iv The clinical psychologist should identify any co-morbid mental health needs. These may require referral to specialist Child and Adolescent Mental Health Services or risk assessment.
- v There should be access to a play specialist in clinic for the engagement and education of children through therapeutic play. This may include the preparation of the child for procedures and the familiarisation of the child with equipment used.
- vi The team should ensure that children and young people with JIA and their families are made aware of local forums/network meetings outside the medical setting which will enable them to learn about available support services and to share ideas and learning.
- vii Knowledge of other agencies, both voluntary and statutory, and their referral and eligibility criteria should be made available through the paediatric rheumatology clinic.
- viii Referrals to workshops for children and young people with JIA to enhance their knowledge and experience of self management, improve their self image and expand their social network should be considered by the MDT as part of the overall health plan.
- ix At the appropriate time, information should be given to children and young people with JIA and their families on their rights under the Disability Discrimination Act. Many voluntary sector organisations can provide this service.
- x Approaches used should recognise the barriers, real or perceived, from the children and young person's point of view and develop skills with them to counter the negative experiences.
- xi The child or young person with JIA should be empowered to evaluate the risk and benefits of disclosure in order that they are able to make informed decisions about whether or not to disclose their condition to other people.

Home, leisure and community

- i A child or young person with JIA experiencing difficulties participating in everyday activities should be referred to an occupational therapist for assessment and intervention.
- ii Assessment of daily activities should occur within the child/young person's own environment (i.e. home and school or work) to identify the unique challenges they face.
- iii All interventions should be carefully considered with the child or young person and their family to encourage adherence and ensure they are acceptable.
- iv Provision of developmentally appropriate interventions including assistive devices, mobility aids and equipment which maximise independence, promote skills and provide independence should be made by social services within 6 weeks of referral.
- v The child or young person with JIA should be encouraged to normalise participation in activities as much as possible, despite suffering from symptoms which are potentially disabling.
- vi Creative strategies should be discussed with the child or young person to enable them to be physically active at moderate levels of intensity. This should include weight bearing or resisted activities to maintain bone health.
- vii Advice should be given to children, young people and their families in order to enhance play and leisure activities.
- viii With the consent of the family and/or the child or young person with JIA, appropriate advice and information should be offered to sports coaches, social clubs etc. to facilitate participation.
- ix The child or young person with JIA should be signposted to organisations offering social and recreational activities.

Education and employment

- i With the consent of the family and/or the child or young person with JIA, schools should be provided by the MDT with information on the nature of the condition, medication and management, as well as the potential impact on mobility, academic performance and social life at each educational stage in order to maximise inclusion. All parties to whom this information is disclosed should ensure that such information is treated confidentially.
- ii With consent, a key worker from the paediatric rheumatology team should liaise with the child's family and Special Educational Needs Coordinator (SENCO) and/or the school nurse to optimise participation, in accordance with SENCO Code of Practice 2008. Such liaison might include a full school assessment and the provision of appropriate equipment.
- iii Schools and colleges should be encouraged by the MDT to contact the key worker to request specific information on the child or young person with JIA, provided there is consent from the patient and/or family.
- iv With the consent of the family and/or the child or young person with JIA, a member of the

paediatric rheumatology team should alert the SENCO of any significant change or deterioration in symptoms, so that the appropriate additional support for inclusion is provided.

- v A designated member of the paediatric rheumatology team or a local community occupational therapist should do a full school assessment on a needs basis. Agreement needs to be sought with the family and the SENCO on implementation and where additional support is indicated the paediatric rheumatology team should give expert advice on the nature of the additional support required.
- vi School counsellors may help a child or young person with JIA with some of the emotional burdens of the condition and the way the condition impacts on their school life.
- vii Upon leaving school, support should be provided to ensure a smooth transition to further/higher education in order to maximise participation in all aspects of the student experience (academic, domestic and social). With consent, liaison should occur with the college, student services, and accommodation officer to ensure needs are met. Young people should be sign posted to SKILL (national bureau for disabled students) for advice on a range of issues including finance.
- viii Most children or young people with JIA should be encouraged to have the same aspirations regarding employment as their peers without JIA.
- ix Young people with JIA should be enabled to develop a career plan during transition from paediatric to adult care. This should be a collaboration between the young person, the MDT and educational establishments.
- x Work experiences for young people with JIA should be appropriate and relevant to their aspirations for future employment.³⁷
- xi Young people with JIA should be given the skills to discuss their health condition with a prospective employer.
- xii Opportunities should be made available to enable young people to meet peers with a similar health condition who have experience of successful employment and independent living.

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

The rationale

- Transition from paediatric to adult care is a multifaceted process, which includes the event of transfer to adult Rheumatology services, involving both paediatric and adult rheumatology services and attends to the medical, psychosocial and educational/vocational needs of such young people and the needs of their parents/caregivers. The aims of transition are to:
 - Provide high quality, coordinated, uninterrupted health-care that is patient-centred, age and developmentally appropriate and culturally competent, flexible, responsive and comprehensive with respect to all persons involved;
 - Promote skills in communication, decision-making, assertiveness and self-care, self-determination and self-advocacy;
 - Enhance the young person's sense of control;
 - Provide support and information for the families of the young person during this process and help them facilitate and encourage the young person's self-advocacy and independence;
 - Maximise lifelong functioning and potential;
- Good transitional care has been shown to improve health related quality of life, patient and parent satisfaction, knowledge, vocational readiness, documentation of adolescent health issues,^{38, 39} stable and/or improved disease control^{40, 41} and attendance at follow up appointments both prior to and after transfer to adult care.^{42, 43}

Good Practice Example - G

A hospital trust has a dedicated weekly adolescent clinic supported by a multidisciplinary team meeting. Age and developmentally-appropriate transitional care plans are used to focus consultations from the age of 11 years. Young people are seen alone when appropriate. The adolescent team supports 2 young adult clinics (age 16-25) at neighbouring trusts.

- A key skill for young people with JIA is the ability to see health professionals independently of parents. This has been shown to be predictive of successful transfer and is associated with improvements in health related quality of life. Preparation for this should include explanation and assessment of understanding of confidentiality, consent and chaperones. Transitional care needs of the parents should also be addressed including their role in promoting appropriate autonomy

- ix There should be appropriate information transfer⁵⁰ including provision of medical and multidisciplinary summaries, a hand-held summary for the young person's own use, and efficiently organized appointments, aiming to minimise absence from school and college. A personal health record developed by the young person themselves (for example 16+ years: www.healthspace.nhs.uk or any age: www.sickkids.ca/myhealthpassport) are helpful strategies. During transition, copies of clinic letters should be sent to the young person concerned as well as the families with careful attention to confidentiality etc.
- x The use of formalised transition checklists are advocated⁴⁹ in addition to the development of a tracking mechanism post transfer to ensure successful transfer, e.g. confirmation sent to the paediatric service of attendance at the 2nd adult clinic appointment.⁴⁹
- xi Primary care involvement is vital^{49, 50} and should include a named GP.

Putting the Standards into practice: **key interventions**

- i An adolescent rheumatology service which meets the “You’re Welcome” quality criteria for young person friendly services⁴⁴ should be provided. This includes provision of an age-appropriate environment and opportunities for young people to be seen independently of their caregivers: this has been shown to be called for by young people themselves⁴⁵ as well as being a predictor of improvement in health related quality of life³⁸ and of successful transfer.⁴⁶
- ii All staff coming into contact with young people should receive training on communicating with young people, seeing young people on their own, consent and confidentiality, and promoting attitudes and values that are young person friendly. (www.e-lfh.org.uk/ah)
- iii Development and evaluation of transitional care should involve consultation with and participation of users – young people and their families.⁴⁷
- iv Individualised transitional care planning should start by age 11-12 years, be young person-centred and include the identification of the necessary skill-set to enable the young person to function in the adult clinic.^{48, 49}
- v Written information about transition for young people and their caregivers as well as details of the adult services should be provided in clinic settings from early adolescence.^{44, 50}
- vi There should be an agreed (with paediatric and adult rheumatology teams) written policy on timing of transition and transfer.⁵⁰
- vii Interested and capable adult services should be identified which have close links with the paediatric service, an understanding of the developmental needs of young adults and participate actively in transition. They should also ensure that social, psychological, education and employment needs are addressed.^{50, 51}
- viii A transition coordinator within the paediatric rheumatology team should be identified who will ensure coordination (particularly of complex patients under multiple consultants) as well as regular audit and evaluation of the transition process.⁵⁰

Standard 39

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.

Standard 40

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 regional level.

Standard 41

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.

Standard 42

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.

Standard 43

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 specialty. The treatment should be started within 6 weeks of the decision to use the drug.

Standard 44

Each paediatric rheumatology team should have adequate staff resources to achieve its research potential

Good Practice Example - H

An annual parents' day organised by the West Midlands Paediatric Rheumatology network includes a series of workshops designed to allow parents and young people to comment on their experiences and help design better services for the future. One of the initiatives that has arisen as a result of these workshops is the production of a DVD which highlights the difficulties in accessing appropriate care. The DVD has been widely circulated and has received positive feedback from a number of influential organisations and won the prestigious NRAS "Patients In Focus" award in 2010.

- 1 Department of Health *National Service Framework for Children, Young People and Maternity Services: Core Standards*. 2004
- 2 Knafl K et al 'Learning from stories: parents' accounts of the pathway to diagnosis'. *Paediatric Nursing* 1986; 21(5): 411-415
- 3 Knafl K and Deatrick J 'Families and chronic illness, a synthesis of current research'. *Journal of Family Nursing* 2002; 8(3): 178-198
- 4 Wallace C A 'The use of methotrexate in childhood rheumatic diseases' *Arthritis Rheum* 1998; 41 (3): 381-91
- 5 Edelsten C et al 'An evaluation of baseline risk factors predicting severity in juvenile idiopathic arthritis associated uveitis and other chronic anterior uveitis in early childhood'. *Br J Ophthalmol* 2002;86 (1): 51-6
- 6 Zulian F et al 'Early predictors of severe course of uveitis in oligoarthritis juvenile idiopathic arthritis' *J Rheumatol* 2002; 29:2446-53
- 7 Royal College of Nursing (2006) *Telephone advice lines for people with long term conditions: guidance for nursing practitioners*. London: RCN
- 8 Royal College of Nursing *Assessing, managing and monitoring biologic therapies for inflammatory arthritis; guidance for rheumatology practitioners*. 2003.
- 9 *Etanercept for the treatment of juvenile idiopathic arthritis*. National Institute for Health and Clinical Excellence TA35, 2002
- 10 BSPAR *Position Statement on Professional working in Paediatric Rheumatology* 2007. www.bspar.org.uk/downloads/clinical_guidelines
- 11 *The National Service Framework for Children, Young People and Maternity Services*. Department of Health 2004.
- 12 *You're Welcome Quality Criteria*. Department of Health 2007
- 13 *Every Child Matters: Change for Children*. Department for Children, Schools and families 2004
- 14 *Healthy Lives, Brighter Futures*. Department of Health 2009
- 15 *Aiming High for Disabled Children*: www.dcsf.gov.uk/everychildmatters/healthandwellbeing
- 16 DCSF (2007: 28) *The Children Plan, Building brighter futures*.
- 17 Royal College of Nursing (2006) *Telephone advice lines for people with long term conditions: guidance for nursing practitioners*. London: RCN
- 18 BSPAR and RCOphth: *Guidelines for Screening for Uveitis in Juvenile Idiopathic Arthritis* 2006. www.bspar.org.uk/downloads/clinical_guidelines/
- 19 Beresford MW, Baildam E. New advances in the management of juvenile idiopathic arthritis - 1: Non-Biological therapy. *Arch Dis Child Educ Pract Ed* 2009;94:144-150
- 20 Giannini EH, Ruperto N, Ravelli A, Lovell DJ, Felson DT, Martini A. Preliminary definition of improvement in juvenile arthritis. *Arthritis Rheum* 1997;40:1202-1209
- 21 Albornoz MA. ACR formally adopts improvement criteria for juvenile arthritis (ACR pediatric 30). *ACR News* 2002;21:3
- 22 Wallace CA, Ruperto N, Giannini E. Preliminary criteria for clinical remission for select categories of juvenile idiopathic arthritis. *J Rheumatol* 2004;31:2290-2294
- 23 Magni-Manzoni S, Ruperto N, Pistorio A, Sala E, Solari N, Palmisani E, Cugno C, Bozzola E, Martini A, Ravelli A. Development and validation of a preliminary definition of minimal disease activity in patients with juvenile idiopathic arthritis. *Arthritis Rheum* 2008;59:1120-1127
- 24 Beresford MW, Baildam E. New advances in the management of juvenile idiopathic arthritis - 2: The Era of Biologicals. *Arch Dis Child Educ Pract Ed* 2009;94:151-156
- 25 Thornton J, Beresford MW, Clayton P. Improving the evidence base for treatment of juvenile idiopathic arthritis: the challenge and opportunity facing the MCRN/ARC Paediatric Rheumatology Clinical Studies Group. *Rheumatology* (Oxford) 2008 May;47(5):563-6].
- 26 www.arc-research.org.uk/med_director/paedrheumcsg.asp
- 27 Mattson ME, Curb JD, McArdle R. Participation in a clinical trial: the patients' point of view. *Control Clin Trials*. 1985 Jun;6(2):156-67.
- 28 Madsen SM, Mirza MR, Holm S, Hilsted KL, Kampmann K, Riis P Attitudes towards clinical research amongst participants and nonparticipants.. *J intern med* 2002 Feb;251(2):156-68.
- 29 Predictors of pain in children with established juvenile rheumatoid arthritis. *Arthritis & Rheumatism* 2004 51: 222-227.
- 30 *Royal College of Nursing: Telephone advice lines for people with long term conditions: guidance for nursing practitioners*. RCN, London 2006.

- 31 Tanner J.M., Whitehouse R.H., Takaishi M. Standards from birth to maturity for height, weight, height velocity and weight velocity: British children 1965. *Archives of Disease in Childhood* 1966; 41: 454–471, 613–635
- 32 Royal College of Nursing (2004) *Administering Subcutaneous methotrexate for inflammatory arthritis. RCN guidance for nurses* London: RCN
- 33 Royal College of Nursing (2009) *Assessing, managing and monitoring biologic therapies for inflammatory arthritis: guidance for rheumatology practitioners*. London: RCN
- 34 Wallace CA. Developing standards of care for patients with juvenile idiopathic arthritis: An opportunity to improve care and disseminate knowledge. *Rheumatology* (Oxford). 2010 Feb 19. [E-pub ahead of print]
- 35 Kazak, A.E, Rourke, M.T., Alderfer, M. A., Pai, A., Reilly, A.F., and Meadows, A.T. ‘Evidence-based Assessment, Intervention and Psychosocial Care in Paediatric Oncology: A Blueprint for Comprehensive Services across Treatment.’ *Journal of Pediatric Psychology*, October 2007: 32: 1099 - 1110
- 36 *The Disability Discrimination Act* 2005. The Stationary office, London.
- 37 *Freedom to Live*. Rachel Christophides 2008, Livability
- 38 McDonagh JE, Southwood TR, Shaw KL. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Arthritis and Rheumatism* : 2007; 46(1):161-8
- 39 Robertson LP, McDonagh JE, Southwood TR, Shaw KL. Growing up and moving on. A multicentre UK audit of the transfer of adolescents with Juvenile Idiopathic Arthritis JIA from paediatric to adult centred care. *Ann Rheum Dis* 2006; 65:74-80
- 40 Orr, D.P., Fineberg, N.S., & Gray, D.L. Glycaemic control and transfer of health care among adolescents with insulin dependent diabetes mellitus. *J Adol Health* 1996;18:44-47.
- 41 Duguépérrou I, Tamalet A, Sermet-Gaudelus I, Le Bourgeois M, Gérardin M, Desmazes-Dufeu N, Hubert D.. Clinical changes of patients with cystic fibrosis during transition from pediatric to adult care. *J Adol Health* 2008; 43: 459-465.
- 42 Kipps S, Bahu T, Ong, K, Ackland FM, Brown RS, Fox CT, Griffin NK, Knight AH, Mann NP, Neil HA, Simpson H, Edge JA, Dunger DB. Current methods of transfer of young people with type 1 diabetes to adult services. *Diabetic Medicine* 2002; 9:649-654.
43. Vanelli, M., Caronna, S., Adinolfi, B., Chiari, G., Gugliotta, M., & Arsenio, L. Effectiveness of an uninterrupted procedure to transfer adolescents with type 1 diabetes from the paediatric to the adult clinic held in the same hospital: eight-year experience with the Parma protocol. *Diabetes Nutr Metab* 2004;17(5): 304-8.
- 44 Department of Health. *You're welcome quality criteria. Making health services young people friendly*. October, 2007 (www.dh.gov.uk)
- 45 Shaw KL, Southwood TR, McDonagh JE on behalf of the British Paediatric Rheumatology Group. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)*. 2004 Jun;43(6):770-778.
- 46 Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Sui SC, Webb GD. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* 2004;113(3):197-205.
- 47 Shaw KL, Southwood TR, McDonagh JE. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child: Care, Health & Development* 2007;33(4):368-79.
- 48 McDonagh JE, Southwood TR, Shaw KL. Growing up and moving on in rheumatology: development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *J Child Health Care* 2006;10(1):22-42.
- 49 Department of Health. *Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services*. Department of Health Publications, 2006, London www.dh.gov.uk/transition
- 50 Department of Health. *Getting the right start: National Service Framework for Children, Young People and Maternity Services: Standard for Hospital Services*. April 2003
- 51 Royal College of Physicians of Edinburgh. *Think Transition: Developing the essential link between paediatric and adult care*. Royal college of Physicians of Edinburgh, Edinburgh 2008

Core members

- Paediatric rheumatologist
- Ophthalmologist
- Paediatric rheumatology clinical nurse specialist
- Paediatric physiotherapist
- Paediatric clinical psychologist
- Paediatric occupational therapist
- Podiatrist or orthotist

The extended team

- Children's community nursing team
- General practitioner
- Health visitor or school nurse
- Play specialist
- Youth worker
- Special educational needs coordinator
- Orthodontist
- Maxillofacial surgeon
- Orthopaedic surgeon
- Endocrinologist
- Social worker
- Adult rheumatologist (once formal transition process occurs)

The extended team 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).

Biologic therapies or ‘biologics’

Therapies used in the treatment of rheumatoid and other forms of inflammatory arthritis.

Care plan

A written statement about a person’s health needs; the treatment, support and advice they should have; and who should provide these and when.

Commissioners

Those that establish health needs and priorities of a population then purchase services to meet the needs of that population.

Guidelines

Official statements that define the parameters of practice.

Holistic

A concept in medical practice upholding that all aspects of people's needs, psychological, physical and social, should be taken into account and seen as a whole.

Interventions

A general term covering treatments, advice, education and other care that a practitioner may give.

Maxillofacial

Maxillofacial refers to the area of the mouth, jaws, face, skull, and associated structures.

Multi-disciplinary team

A healthcare team that includes professionals from different disciplines, working together to provide a comprehensive service for people with musculoskeletal problems.

NICE

The National Institute for Health and Clinical Excellence is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

Normal reference values

A reference value (or range) is a set of values of some measurement that a physician or other health professional can use to interpret a set of results for a particular patient.

Off-label

Off-label use is the practice of prescribing drugs for an unapproved indication.

Orthotics

Devices intended to alter or stabilise the mechanical function of a joint or limb. This includes a range of splints, insoles and braces.

Paediatric Rheumatology

The diagnosis and treatment of diseases and disorders of the joints, muscles, bones, tendons and other body tissues such as juvenile idiopathic arthritis.

Pathway

A person’s route or journey through care which can include a range of different treatments and services.

Podiatrist

A podiatrist is a clinician who specialises in the evaluation and treatment of diseases of the foot. In the UK, a podiatrist should be registered with the Health Professions Council.

Primary care

Care services available in the community, for example through a community pharmacist or the care provided by a GP. This is often a person’s first point of contact for advice, information and treatment.

Providers

Organisations responsible for delivering care and treatment, such as NHS trusts. Also called healthcare providers, service providers.

Psychosocial support

Professional care which addresses a person’s psychological and social health needs; this may include support to reduce a person’s distress, fear or ability to cope, support for social and family relationships, and support/ advice about employment or benefits.

Rheumatology

Diagnosis and treatment of diseases and disorders of the joints, muscles, bones and tendons such as arthritis and degenerative joint disease. Rheumatological conditions are a subset of the broader group of musculoskeletal problems.

Secondary care

Care available usually in a hospital setting. People generally need a referral from a professional in primary care.

Service user

A person who accesses healthcare services.

Stakeholder

A person, group, organisation, or system which affects or can be affected by an organisation's actions.

Standards

A set of expected norms and acceptable outcomes (see guidelines).

Strategic health authority

NHS strategic health authorities (SHA) are part of the structure of the National Health Service in England. Each SHA is responsible for enacting the directives and implementing fiscal policy as dictated by the Department of Health at a regional level. In turn each SHA area contains various NHS trusts which take responsibility for running or commissioning local NHS services. The SHA is responsible for strategic supervision of these services.

Tertiary services

Specialised health services that are provided by a few hospital trusts on a regional basis.

The Standards of Care project has been managed by the Arthritis and Musculoskeletal Alliance (ARMA) working with the British Society of Paediatric Rheumatology (BSPAR). A wide range of individuals and organisations, including ARMA member organisations, have generously given time, expertise and other support in kind.

We would like to acknowledge the contributions of those involved in this project. ARMA thanks all those who have been involved in the project working groups and who have taken the time to comment on the consultation drafts of these documents; also those who have contributed examples of good practise. We welcome further contributions and feedback.

ARMA is a registered charity (no. 1108851).

Steering Group

Dr Peter Prouse
(Chair)
Consultant Rheumatologist, Basingstoke and North Hampshire NHS Foundation Trust

Dr Karen Davies
Consultant Paediatric Rheumatologist, New Cross Hospital, Wolverhampton and Chair, BSPAR Clinical Affairs Committee

Dr Carrie Britton
Board Member of ARMA and parent of young person with JIA

Sue Murray-Johnson
Chief Executive BHPR

Kate Fleck
Northern Ireland Director, Arthritis Care

Brenda McGrath
Chair, Children's Chronic Arthritis Association

Development Group

Dr Karen Davies
(Joint Chair)
Consultant Paediatric Rheumatologist, New Cross Hospital, Wolverhampton

Dr Penny Davis
(Joint Chair)
Consultant Paediatric Rheumatologist, Birmingham Children's Hospital NHS Foundation Trust

Dr Nick Wilkinson
Consultant Paediatric Rheumatologist, Oxford Paediatric & Adolescent Rheumatology Centre, Nuffield Orthopaedic Centre, Oxford

Dr Konrad Jacobs
Consultant Clinical Psychologist, Dept of Paediatric Psychology, Oxford Paediatric and Adolescent Rheumatology Centre, Nuffield Orthopaedic Centre, Oxford

Steve Mainwaring
Clinical Auditor, Royal National Hospital for Rheumatic Diseases, Bath

Caroline Cox
General Secretary, Children's Chronic Arthritis Association

Jill Ferrari
Specialist Podiatrist at Great Ormond Street Hospital and Senior Lecturer at University of East London

Janine Hackett
Occupational therapist specialising in Paediatric Rheumatology, Occupational Therapy Dept, University of Derby

Jan Scott
Principal Physiotherapist (Rheumatology), Birmingham Children's Hospital NHS foundation Trust

Pam Whitworth
Senior Clinical Nurse Specialist, Birmingham Children's Hospital NHS Foundation Trust

Nicky Freeman
Clinical Nurse Specialist, Birmingham Children's Hospital NHS Foundation Trust

Emma Inness
Clinical Nurse Specialist, Oxford Paediatric and Adolescent Rheumatology Centre, Nuffield Orthopaedic Centre NHS Trust, Oxford

Claire Bigham
Community Paediatric Physiotherapist

Laura Hunter
Community Children's Rheumatology Nurse, Kingfisher Children's Unit, Grantham and District Hospital

Laura Staines
Head Paediatric Physiotherapist, City Care Centre, NHS Peterborough

Elaine Parsons
Clinical Nurse Specialist, Oxford Paediatric and Adolescent Rheumatology Centre, Nuffield Orthopaedic Centre NHS Trust, Oxford

Sharon Weightman
Leader for Learning Support, The Beaconsfield School, Buckinghamshire

Other contributions

Liz Hutchinson
Clinical Nurse Specialist, Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust

Sally Watt
Service user with JIA

Tracey Malkin
Programme Manager Children's Services Commissioning, NHS Stoke on Trent

Robert Field
Podiatrist, Rheumatology Services, Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust

Dr Maggie Lawrence
General Practitioner, White Horse Medical Practice, Farringdon

Dr John Jackman
General Practitioner, Langford Medical Practice, Oxford

Caroline Strange
Specialist Teacher from Bucks County Specialist Teaching Service

Dr Michael W Beresford
Senior Lecturer, University of Liverpool, Honorary Consultant Paediatric Rheumatologist, Chair, UK MCRN/ARC Paediatric Rheumatology CSG

Dr Gavin Cleary
Consultant Paediatric Rheumatologist, Alder Hey Children's NHS Foundation Trust, Liverpool, BSPAR Convenor

Helen Foster
Professor of Paediatric Rheumatology, Newcastle University, Newcastle upon Tyne

Dr. Helen Venning
Consultant Paediatric Rheumatologist, Queen's Medical Centre, Nottingham

David and Louise Haston

We are also grateful for the input from the following organisations

Arthritis Research UK

Arthritis Care


British Orthopaedic Association

Children's Chronic Arthritis Association

West Midlands Paediatric Rheumatology Network Parent's Group

LUPUS UK

Standards of Care
for children and
young people with



Juvenile Idiopathic Arthritis



Arthritis and Musculoskeletal Alliance

Bride House
18-20 Bride Lane
London
EC4Y 8EE

Tel: +44 (0) 20 7842 0910
info@arma.uk.net
www.arma.uk.net

Registered Charity No: 1108851
Registered Company No: 5380237