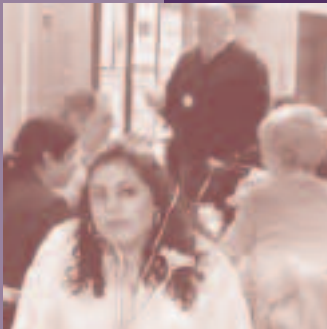




Standards of Care
for people with

Inflammatory Arthritis





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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 Campaign
- BackCare
- British Chiropractic Association
- British Coalition of Heritable Disorders of Connective Tissue
- British Health Professionals in Rheumatology
- British Institute of Musculoskeletal Medicine
- British Orthopaedic Association
- British Scoliosis Society
- British Sjögren's Syndrome Association
- British Society for Paediatric and Adolescent Rheumatology
- British Society for Rheumatology
- British Society of Rehabilitation Medicine
- Chartered Society of Physiotherapy
- Children's Chronic Arthritis Association
- CHOICES for Families of Children with Arthritis
- Early Rheumatoid Arthritis Network
- Lupus UK
- Manipulation Association of Chartered Physiotherapists (UK)
- Marfan Association (UK)
- National Ankylosing Spondylitis Society
- National Association for the Relief of Paget's Disease
- National Association of Rheumatology Occupational Therapists (NAROT)
- National Osteoporosis Society
- National Rheumatoid Arthritis Society
- Podiatry Rheumatic Care Association
- Primary Care Rheumatology Society
- Psoriatic Arthropathy Alliance
- Raynaud's and Scleroderma Association
- Rheumatoid Arthritis Surgical Society
- Royal College of Nursing Rheumatology Nursing Policy and Practice Group
- Scleroderma Society
- Society for Back Pain Research

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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

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Inflammatory arthritis: the size of the problem

Inflammatory arthritis is the term used to describe a range of conditions, including rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis (JIA). These are autoimmune diseases, in which the body's immune system attacks the joints and causes them to become inflamed. Inflammatory arthritis can affect almost any joint: often the hands and feet, and also knees, shoulders, elbows, hips, the neck and other joints. It can also affect other parts of the body.

It is not known exactly what causes a person to develop inflammatory arthritis. Various factors may be relevant, including the environment, infection, trauma and a person's genetic make-up.^[1] There are other risk factors that increase the risk of developing rheumatoid arthritis, such as smoking,^[2] obesity and prior blood transfusion.^[3]

Around 387,000 adults in the UK have rheumatoid arthritis, the most common form of inflammatory arthritis. It affects around three times as many women as men.^[4] There are approximately 200,000 people in the UK who have ankylosing spondylitis.^[5] For psoriatic arthritis estimates vary, between 84,000 and 177,000.^[6]

Inflammatory arthritis affects thousands of children, as well as adults. Around 12,000 children under 16 are affected by juvenile idiopathic arthritis (JIA).^[7] It is one of the commonest causes of physical disability that begins during childhood.^[8]


What is the impact of inflammatory arthritis?

Inflammatory arthritis is usually a progressive condition. Its pattern and progression vary greatly between individuals, and it is impossible to predict the impact it may have on any one person's life.

For a small minority of people, inflammatory arthritis remains relatively mild, or may even go into 'remission' for a period of time. For others it causes damage to a number of joints, which can be severe. Many people experience disabling pain, stiffness and reduced joint function, which has a huge impact on quality of life for them and for their families. It can affect other organs as well as the joints, and severe inflammatory arthritis significantly shortens life expectancy. (Inflammatory arthritis, particularly rheumatoid arthritis, can shorten life expectancy by around 6-10 years, which equates to the impact of diabetes, Hodgkin's disease, strokes and triple vessel coronary artery disease.^{[9] [10]}) This has a direct economic effect on society as well as affecting the individual and their family.

For children who are affected, and their families, juvenile idiopathic arthritis can be an isolating and lonely experience, as the fluctuating nature of the condition is often particularly misunderstood.

The costs to the NHS, as well as to individuals and their families, are high. In 2000, for example, there were 1.9 million GP consultations for inflammatory arthritis, and nearly 46,000 hospital admissions.^[11] The cost to the NHS of managing rheumatoid arthritis and complications of treatment, e.g. osteoporosis is an estimated £240 million per year,^[12] and the total annual cost of treating rheumatoid arthritis (including health costs and lost working days) is estimated to be £1.3 billion.^[13]



Work-related disability is particularly common for rheumatoid arthritis, with around 206 million working days having been lost overall to arthritis in the UK in 1999-2000, with rheumatoid arthritis alone accounting for around 9.4 million of these – equivalent to £833 million in lost production.

Why we need Standards of Care

There is strong evidence that early intervention improves the long-term outlook for people with inflammatory arthritis.^[14] Yet there is enormous variation in people's experiences and in the quality of the care they receive. Many people wait too long for referral to a specialist; indeed, access to specialist care varies greatly according to where people live. Research shows that existing guidelines, including National Institute for Clinical Excellence (NICE) guidance on prescribing biologic therapies for rheumatoid arthritis, have been unevenly implemented; and there is insufficient priority given to training for health professionals involved in the care and support of people with inflammatory arthritis. This has very severe consequences for the individual and for society more widely.

Given the costs of inflammatory arthritis to the NHS and to national productivity, it is perhaps surprising that there is no National Service Framework for inflammatory arthritis and other musculoskeletal conditions. This lack of priority status is also reflected in the fact that these conditions are omitted from the Quality and Outcome Frameworks of the General Practitioners' (GPs) General Medical Services (GMS) contracts.

Yet there is much to be optimistic about. With the right care early on, people with inflammatory arthritis can look forward to a much better outlook than was thought possible in the past. Moreover, despite the lack of priority and resources attached to inflammatory arthritis services, health services in some parts of the country have identified innovative ways of improving the care they provide to people living with these conditions. These Standards aim to bring together existing evidence and best practice approaches to set out a framework for services which really meet the needs of the many people living with inflammatory arthritis. Implementation of these Standards should:

- improve quality of life for adults, children and their families who are affected by inflammatory arthritis
- identify the care and treatment which those with inflammatory arthritis can expect
- promote more consistent approaches to care
- improve access to care and treatment in places where people do not have access to a full multi-disciplinary team
- reduce the costs to the NHS, by enabling people to access effective treatment quickly, and therefore to control the progression of the disease and the associated treatment costs
- improve productivity and reduce the benefits bill, by enabling people to stay active and reducing the number of working days lost to illness.

Looking beyond healthcare

Healthcare is only part of the picture in terms of maximising independence for patients with inflammatory arthritis. Social care, aids and adaptations, employment, education, fully accessible built and external environments – including transport, buildings, homes, etc are also important parts of the larger picture.

ARMA's Standards of Care for people with inflammatory arthritis are intended to support people of all ages with inflammatory arthritis to lead independent lives and reach their full health potential through:

- access to information, support and knowledge that optimise musculoskeletal health for everyone and enable self-management
- access to the right services that enable early diagnosis and treatment
- access to ongoing and responsive treatment and support.

The Standards define what services are appropriate under these three themes and suggest ways of providing them effectively, and in a measurable way, in the form of key interventions. 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 are not guidelines, or algorithms of care, though they refer to these where available.

The Standards of Care for people with inflammatory arthritis form part of a suite of Standards; other Standards published to date are for osteoarthritis and back pain. Further Standards, for bone disease, soft tissue rheumatism and connective tissue disorders, are planned for 2005.

The Standards acknowledge the fact that those planning and delivering services around the UK face differing demographic, geographic and economic factors, which will affect how the Standards are implemented in each locality. We hope 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.

Key principles – the user-centred approach

The project has been driven by the needs of people living with musculoskeletal conditions. It began with the establishment of a set of key principles for care, developed by a group of people living with musculoskeletal conditions and consulted upon widely. These principles have underpinned the development of each set of condition-specific Standards.

The key principles, which can be found on ARMA's website www.arma.uk.net, affirm that 'patients' are individuals who need different types of advice and support at different times; and who need integrated services providing advice and support that cover all aspects of managing and living with the condition – clinical, personal, social and employment/education.

In particular, the Standards recognise that health services play a key role in supporting people to maintain or return to employment or education.

Nevertheless, while these standards focus on health services, it must be recognised that people with inflammatory arthritis and other musculoskeletal conditions have wide-ranging needs. Social care often plays a key role in ensuring people can remain as active and independent as possible. Factors such as access to transport and the built environment may have a major impact on quality of life. More work is needed to understand and meet these needs.

Musculoskeletal conditions affect families and carers as well as individuals. Indeed, many people with these conditions may be carers themselves. The Standards do not make specific recommendations on issues relating to carers: this also needs to be the subject of further work to ensure that carers' needs are understood and addressed.

How the Standards were developed

The Standards of Care for people with inflammatory arthritis were developed by an expert working group, facilitated by ARMA. The group included people with inflammatory arthritis, representatives of user organisations, experienced service providers and experts from many professions, from around the UK. Starting with a review of the needs of people with inflammatory arthritis, the group met five times between September 2003 and June 2004 to determine evidence-based Standards to meet those needs, consulting widely and publicly on the drafts. The Acknowledgements on page 18 give details of the working group membership.

Clinical experts have identified the evidence base, including relevant guidelines for the management of inflammatory arthritis. References are shown as footnotes in the Standards. 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 people with inflammatory arthritis, and on evidence and good practice where this is available. The working group plans to review these Standards in 2007, or sooner if there are significant developments in care for people with inflammatory arthritis.

Next steps

The publication of these Standards is the beginning of an ongoing programme involving the whole community to improve musculoskeletal services.

We are circulating the Standards widely to people with musculoskeletal conditions, doctors, allied health practitioners, providers and commissioners of health services, voluntary organisations and policy makers. We will publish audit tools to support the Standards' implementation. We are also collecting and sharing examples of good practice, which are accessible to everyone through our online database.

We invite all stakeholders to make a commitment to implementing the Standards. First steps might be to:

- audit existing services
- identify champions for change in musculoskeletal services, and set up a working group to develop your local strategy and priorities
- 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 us about your initiatives; send us examples of good practice; help to build a national resource for high-quality musculoskeletal services.

Promoting musculoskeletal health

Standard 1

Health and community services should provide advice on lifestyle measures which may help to reduce people's risk of developing inflammatory arthritis, including advice on stopping smoking and weight control.

Advice on self-management and when to seek advice

Standard 2

Health and community services should provide advice that promotes self-

management, such as staying active, identifying symptoms and signs of inflammatory arthritis, managing pain and other symptoms and knowing when to seek professional advice.

Information on services, treatments and providers

Standard 3

People with inflammatory arthritis should have access to information and guidance which enables them to make informed choices of service providers, the treatments they offer and the facilities in which they are delivered.

The rationale

- Raising general awareness of musculoskeletal conditions amongst the public can help individuals to identify symptoms and signs of inflammatory arthritis and seek professional advice promptly. Early treatment is known to help prevent joint damage.^[15]
- Smoking and obesity have been identified as risk factors for rheumatoid arthritis, so strategies are needed to encourage healthier lifestyles.^[16]
- Inflammatory arthritis is a long-term condition, and there is evidence that people who are active partners in making decisions about their care may have better outcomes (that is, they are able to manage and cope better) than those who do not.^[17]
- In order for people with inflammatory arthritis to become active partners in their own care if they choose to, they need to be well informed about their condition, empowered to take responsibility for their musculoskeletal health, and able to make informed choices about treatments, providers and settings for care. The extent to which an individual is empowered to take this active role will depend on their individual circumstances, including their education and cultural background. Self-management training such as the Expert Patient Programme and Challenging Arthritis programmes can be highly beneficial for people with inflammatory arthritis.

Putting the Standards into practice: key interventions

- i Health promotion campaigns on cardiovascular disease, stopping smoking and weight control should include information about their benefits in inflammatory arthritis (alongside other conditions).
- ii Health and community services and other agencies, such as pharmacists and voluntary organisations, should make information available to the public on how to identify the symptoms and signs of inflammatory arthritis, and when, how and where to seek professional advice.



- iii People with inflammatory arthritis should have ongoing:
 - access to clear, accurate and consistent information from healthcare providers on the range of treatments, management options and settings for care. This should be available in a variety of formats and in different languages where appropriate
 - encouragement from the healthcare team to take an active role in self-managing their condition, enabling them to make informed choices about treatment options
 - access to self-management training.

- iv Healthcare providers/commissioners, social services, voluntary sector and leisure services should develop partnerships to deliver seamless services for people with inflammatory arthritis.

i For further information and resources, including details of ARMA's member organisations and other examples of good practice and information on implementation, visit www.arma.net.uk

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 - 2 Stolt P et al (2003)
 - 3 Symmons DP, Silman AJ (2003)
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Access to diagnosis

Standard 4

All people with suspected inflammatory arthritis should be seen by a specialist in rheumatology within 12 weeks of referral from their GP, to confirm diagnosis and enable prompt and effective treatment.

Children and young people in whom juvenile idiopathic arthritis (JIA) is suspected should be seen within a maximum of 4 weeks.

Developmental: All people with suspected inflammatory arthritis should be seen by a specialist in rheumatology within 6 weeks of referral from their GP, to confirm diagnosis and enable prompt and effective treatment.

Assessment of needs

Standard 5

On diagnosis, people should have a full assessment of their disease, general health, psychosocial and pain management needs. This should also include vocational advice and referral to social services to identify other needs if appropriate. The assessment should involve the full rheumatology multi-disciplinary team and any other relevant specialities. Family and carers should be involved where appropriate.

For children and young people, particular consideration should be given to education and social development needs.

Evidence-based care

Standard 6

People with inflammatory arthritis should have access to safe, effective, evidence-

based care and management strategies, with appropriate monitoring arrangements.

People should have access to personalised education programmes to enable them to make informed choices about treatment options, including recognised self-management programmes.

Individualised care plans

Standard 7

People should be offered an individualised care plan for ongoing care.

Developmental: People should have access to a health advisor or facilitator who can support them in accessing information and services.

Support to remain in or return to work or education

Standard 8

People should be supported to remain in or return to employment and/or education, through access to information and services such as occupational therapy, occupational support and rehabilitation services.

Advice should be offered on benefits.

Involvement of people with inflammatory arthritis in service development

Standard 9

Healthcare organisations should involve people with inflammatory arthritis in the planning and development of services for inflammatory arthritis and other musculoskeletal conditions.

The rationale

- Early intervention with disease-modifying drug therapy improves long-term outcomes.^[18] The earlier the 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



GPs need to refer to a specialist who can confirm diagnosis and commence treatment as quickly as possible.

- 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.^[19]
- People with inflammatory arthritis report that receiving a comprehensive diagnosis as soon as possible is valued and allows them to begin the process of coming to terms with the condition and learning to better manage living with the condition.
- For many people and their families, the diagnosis of inflammatory arthritis can seem devastating. It is vitally important that diagnosis is conveyed with care and sensitivity. It should be accompanied by constructive messages and with positive and supportive advice and information as well as details of support organisations and helplines (see ARMA website www.arma.uk.net). People given this diagnosis may initially find it hard to take in everything that is said and to understand the implications for their future. Appointments need to allow time for a full explanation of the disease and discussion of treatment options.
- 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.^[20]
- Inflammatory arthritis can affect all aspects of a person's life and development, and their wider needs, both clinical and non-clinical, need to be assessed and addressed. For example, depression is associated with inflammatory arthritis,^[21] and some people may require psychosocial support to help them manage this. Evidence,^[22] and indeed the experiences of people with inflammatory arthritis, shows that services are most effective when they are delivered through a full and well-established multi-disciplinary team. Other healthcare professionals, including pharmacists, can play a valuable role in directing individuals to appropriate support and advice. Support also needs to be available for those who do not wish to self-manage.
- 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.
- People 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 care.
- Disease-modifying drugs can considerably improve people's lives, but they have potentially toxic side-effects which necessitate regular monitoring.^[23] Monitoring is usually most convenient for the patient in a primary care setting.
- An individualised care plan can enable a person with inflammatory arthritis and their carers 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.

- Inflammatory arthritis can significantly affect a person's ability to work and learn. Juvenile idiopathic arthritis can affect the ability of children and young people to pursue their education. However, with support and appropriate adaptations to working practices and environments, many individuals can continue in employment or education.^[24] This support can include social services and other government agencies or voluntary organisations.
- People with inflammatory arthritis should be involved in helping to plan and develop services at both local and national level. Their perspective on service delivery can lead to imaginative solutions and improvements to healthcare services, helping services to meet people's real needs.

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

- v Rheumatology departments and local GPs should agree and implement local referral protocols to ensure that people with symptoms of inflammatory arthritis are seen by a specialist within 12 weeks of referral from their GP and children should be seen within four weeks. This specialist will usually be a rheumatologist, or a GP with a special interest in rheumatology working as part of the local rheumatology team. As inflammatory arthritis can involve other organs, the specialist should be able to refer for other specialist opinions (for example from chest, skin, heart and kidney specialists) as required.

Developmental: Rheumatology departments and local GPs should agree and implement local referral protocols to ensure that people with symptoms of inflammatory arthritis are seen within six weeks of referral from their GP. GPs should refer as soon as a diagnosis of inflammatory arthritis is suspected.

Good Practice Example - A

A hospital trust working in collaboration with primary care providers has developed a programme of initiatives to improve access to services for people with musculoskeletal conditions. Musculoskeletal clinics, based at five different locations, are run by rheumatology consultants, GPs with special interest (GPwSI's) and extended scope physiotherapists. The teams work to locally developed clinical algorithms for the common musculoskeletal conditions to ensure that patients receive care to agreed standards. Teams can also directly list patients for surgery. Initially a limited pilot project with only a few GP practices involved, the approach has now been rolled out to all GPs in the area and is also used by GPs in nearby trusts.

- vi Services should allow up to 45 minutes for a person's first consultation with the specialist, to establish diagnosis and initiate treatment. Some of this time may be spent with a specialist nurse or allied health practitioner.
- vii 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.
- viii On diagnosis, people should be offered treatment in accordance with national guidelines, such as Scottish Intercollegiate Guidelines Network (SIGN) guidelines and British Society for Rheumatology (BSR) guidelines for rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis. In outline, current evidence supports early aggressive treatment with single or combination DMARDS and, if they fail, biologic agents such as anti-TNFa in order to prevent joint damage. For full details refer to SIGN and BSR guidelines.

Good Practice Example - B

A rheumatology unit serving a population spread across a very wide and often remote geographical area has introduced a self-medication scheme for patients including patients using parenteral drugs such as sub-cutaneous methotrexate and the new biologic agents. Nursing staff have a lead role in assessing and delivering the programme. The inpatient programme educates participants about their medication and familiarises them with the expected benefits and potential hazards of their prescription. The staff liaise with the patient's own GP and practice nurse who then take on the role of monitoring blood test results. This has greatly enhanced patients' motivation and self-confidence, and has led to better concordance.

- xi Rheumatologists and GPs should agree shared-care protocols to enable monitoring to take place in a community setting where possible, particularly for people who are taking disease-modifying drugs.
- xii Each person with inflammatory arthritis 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
 - information about treatments, care providers and services
 - access to self-management advice if required
 - details of national and/or local support groups and helplines
 - details of social services and employment services
 - information about what to do in the event of worsening symptoms, including contact details for urgent advice
 - information for schools and employers on how to support people with inflammatory arthritis in education and work.
- xiii All people with inflammatory arthritis should have access to continuous and co-ordinated services. These include healthcare, social care, benefits advice, housing assistance if necessary, transport, education for children and young people, and support for people of working age to help them remain in or return to work. Assistive devices should also be considered. Health professionals should direct people to the appropriate services.
- xiv Clinical governance teams should ensure that there is access to training on the needs and care

- ix People should be offered the opportunity to talk to a clinical nurse specialist or other specialist allied health professional, within four weeks (core), or ideally two weeks (developmental), of their first appointment with a specialist, in order to enable a more in-depth discussion than may have been possible when the diagnosis was first given. Children and young people and their families may need more time for this appointment. People should have ongoing access after that time to information and support, including access to a helpline (e.g. nurse-led helpline).
- x People should be referred to other specialist allied health professionals within the team e.g. occupational therapy, physiotherapy, podiatry, for assessment, advice and intervention as indicated to identify predisposing factors to deformity and other aspects specific to their disease.

- xv of people with inflammatory arthritis for all professionals involved in their care and support. Whenever possible a named individual within the healthcare team should be responsible for providing on-going support and information.
- xvi People with arthritis should be involved in helping to plan and develop services at both local and national level.
- xvii Advice should be available on modifying working practices and on adapting workplaces and educational establishments. People should have access to information on the steps that can be taken to support them. Employers should seek advice from various sources, for example from health professionals and government agencies, including Health & Safety Executive (HSE), access to work and disability employment advisors. For children and adolescents attending educational establishments, support and advice should be provided by special needs advisors and through the annual statementing process if this applies to the child/adolescent.

Developmental: Occupational health services, where available, should provide advice to employers.

- xviii Health services should provide access to vocational rehabilitation services.

i For further information and resources, including details of ARMA's member organisations and other examples of good practice and information on implementation, visit www.arma.net.uk

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The multi-disciplinary team

Standard 10

People with inflammatory arthritis should have ongoing access to the local multi-disciplinary team, whether this is based in secondary care or in the community.

Self-management

Standard 11

People with inflammatory arthritis should have access to ongoing information, advice and support for self-management. This could include:

- a local nurse-led helpline
- appropriate national and local voluntary organisations
- opportunity to receive self-management training.

Annual specialist review

Standard 12

People with inflammatory arthritis should be offered a comprehensive, annual specialist review that includes cardiovascular health checks such as blood pressure and cholesterol test, in accordance with British Society for Rheumatology (BSR) Guidelines,^[25] and should also assess psychosocial support needs.

Particular care should be taken to ensure that children and young people are fully supported in realising their potential as they develop and grow.

Continued access to care

Standard 13

All people with a sudden 'flare-up' in their condition should have direct access to specialist advice and the option for an early review with appropriate multi-disciplinary team members.

Standard 14

People whose disease is not well controlled should have a review at a maximum of four-monthly intervals.

This should include assessment for biologic treatments in accordance with NICE guidance, BSR guidelines and British Society for Paediatric and Adolescent Rheumatology (BSPAR) guidelines.^[26] It should be accompanied by information to support people in making choices about treatment options.

Access to surgical care

Standard 15

Individuals with inflammatory arthritis who may require specialist surgical opinion, for example those with progressive joint or tendon damage, should be offered an appointment with an orthopaedic surgeon within 13 weeks of referral. Some patients e.g. those with nerve compression or tendon ruptures, may require urgent appointments, which should be provided immediately. Information should be offered to enable informed choice of provider.

Developmental: The appointment should be within six weeks.

Standard 16

If surgery is recommended, individuals with inflammatory arthritis should be offered a pre-surgical assessment along with information on the procedure, post-operative care and an individualised discharge plan.

Rehabilitation and support

Standard 17

Rehabilitation services, including vocational support should be readily available to help people to regain independence as quickly as possible.

Standard 18

Individuals with complex conditions should have a key health worker who can support them and co-ordinate their access to the full range of health and social services, and other specialities. This should be available to people with co-morbidities and complications arising from their condition or its treatment, and/or people whose condition has become disabling.

The rationale

- The main aims of ongoing treatment are to control inflammation and to maintain and restore function. Therefore people need ongoing follow-up by the multi-disciplinary team in primary or secondary care, as appropriate. Access to a health professional trained in footwear assessment should be considered.
- People need ready access to information and support to help them remain independent and active. This may include advice to help them return to employment or education, advice on benefits, and support on a range of issues, from sexual health and family planning to advice on vaccinations when going abroad. Information should be available as part of ongoing support, and reviewed as part of a comprehensive annual review.
- For young people, a smooth transition from paediatric to adult services is very important and appropriate transitional care arrangements are essential to ensure continuity.
- Inflammatory arthritis is frequently progressive; people's needs change over time. A comprehensive annual review with a specialist rheumatology team, in accordance with BSR guidelines, enables problems to be identified, including other emerging health problems. It offers the opportunity to consider treatment options and co-morbidities; and it enables assessment of the person's wider needs, with opportunity to refer to other specialities including gastroenterology, cardiology, ophthalmology, dermatology, respiratory medicine, bone disease specialities and neurology. It is particularly important to monitor the physical and social development of children and young people to ensure that they are developing normally.
- Increased mortality in inflammatory arthritis is mainly due to cardiovascular disease. It is therefore important to assess and treat the common risk factors such as hypertension and high cholesterol levels.
- Inflammatory arthritis can be unpredictable. Many people experience sudden 'flare-ups' in their condition and therefore need rapid and direct access to health services or specialist advice.
- Services need to be flexible with choice of appointment times to limit the impact of health appointments on the rest of the person's life.
- There is evidence that uncontrolled inflammatory arthritis results in joint damage.^[27] If a person's condition is not responding to treatment, he or she may need to be reviewed urgently and considered for other therapies, including biologic therapies, in accordance with national guidelines.^[28]
- Surgery is often beneficial for people whose joints and tendons are deteriorating, and some people with inflammatory arthritis will need access to specialist surgical care. Individuals need access to information on surgeons and their areas of expertise to enable them to make informed choices about referral. It is also vital that people with inflammatory arthritis who are offered surgery give informed consent. This means giving people both information and time to consider their decision.
- Referral for joint replacement surgery should be timely and any delay should be avoided where there is a risk that the surgical outcome would be compromised.

- Pre-operative planning for discharge is critical to support people in returning to normal daily life after surgery. This requires liaison between health and social care.
- Some people require major surgery or a programme of multiple joint replacements. Rheumatology and surgical services need to liaise effectively and plan treatment, to minimise joint damage and disruption to the person's life, and to ensure that surgery is as successful as possible.
- People with inflammatory arthritis have complex needs and may have other conditions in addition to inflammatory arthritis. They may need to consult many different medical specialists. This can be difficult to manage and confusing, and it is important that one professional is responsible for co-ordinating overall care. Members of the multi-disciplinary team can help individuals to access services provided by other specialist service providers or by the multi-disciplinary team such as orthotics, wheelchair services, environmental control services (for adaptations to their environment to promote independence), assistive devices, podiatry and educational advice. There should be agreed care pathways for referral back to the specialist should this be required.

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

good practice

Good Practice Example - C

A hospital trust has developed multi-disciplinary guidelines, education and service initiatives to ensure best practice and service provision for rheumatoid arthritis and psoriatic arthritis patients on methotrexate therapy. This has included: developing guidelines for oral and parenteral methotrexate for the treatment of inflammatory arthritis; developing an education programme for patient self-administration of sub-cutaneous methotrexate; promoting methotrexate education in the community by organising study days for all health professionals. The guidelines also cover patients with inflammatory bowel syndrome using methotrexate.

xvii People with inflammatory arthritis should have a comprehensive annual review of their health in accordance with BSR guidelines including checks of blood pressure and cholesterol levels. A minimum of 30 minutes should be available for the review. This review should involve the full multi-disciplinary team, and other specialities as appropriate. In the interests of continuity of care, where possible, people should see the same specialists each time. It is particularly important to monitor the physical and social development of children and young people to ensure that they are developing normally. Additional time may be required for this group.

xx Individuals' wider psychosocial needs should be assessed and addressed, both as part of the annual review and as part of ongoing support provided by members of the multi-disciplinary team. People may need advice and support in relation to depression, social functioning, family relationships, sexual health and relationships, and family planning.

Developmental: People should also have access to a lead individual or specialist health professional with expertise in employment issues, who can help to 'bridge the gap' between people's health and employment needs.^[29]

- xxi There should be an identified clinical specialist who is responsible for transitional care when children transfer from paediatric to adult care.
- xxii People with inflammatory arthritis should have access to safe, effective and evidence-based care in accordance with national and professional guidelines such as SIGN (Scottish Intercollegiate Guidelines Network) guidelines on management of early rheumatoid arthritis.^[30]
- xxiii People with inflammatory arthritis should have access to biologic treatments, in accordance with current national guidelines.^[31]
- xxiv Services should be designed so that people with inflammatory arthritis have rapid access to information to enable them to manage 'flare-ups' of their condition. This could include access to a nurse-led helpline and/or to voluntary sector health organisations.
- xxv Self-management training such as the Expert Patient Programme and Challenging Arthritis should be available for people with inflammatory arthritis at all stages of their condition. However, not all people with inflammatory arthritis will be willing or able to take on this role, and services must also meet their needs, offering support as needed from the multi-disciplinary team.
- xxvi Rheumatology teams may offer access to specialists via combined clinics with other specialities where other organs (including skin) are involved.
- xxvii People whose joints and/or tendons are deteriorating should have a specialist surgical review. Joint clinics for rheumatology and orthopaedics are widely regarded as good models for providing care and enabling individuals to access the full range of expertise and treatment.
- xxviii A first out-patient appointment should take place within 13 weeks following receipt of referral, from primary or secondary care. Services should schedule at least 20 minutes for this appointment.
- xxix Where surgery is recommended, people should be offered a pre-operative assessment and begin the process of discharge planning in accordance with NICE guidelines. People should receive details of who to contact in the event of complications after they are discharged from hospital. Discharge planning should include appropriate specialist follow-up, particularly in complex cases. As part of discharge planning, people should have access to members of the multi-disciplinary team who will be involved in their post-operative management.
- xxx Surgical interventions should be performed in accordance with current evidence-based practices.
- xxxi If an individual with inflammatory arthritis is admitted to hospital for any reason, the healthcare team responsible for their care should have access to a multi-disciplinary rheumatology team who can advise other health professionals on their rheumatological needs.

Good Practice Example - D

A hospital trust has established a practitioner-led (both nurse and physiotherapist) ankylosing spondylitis follow-up clinic. The patients are seen by the practitioner for 30 minutes and then the physiotherapist for 30 minutes. This allows for a medical assessment and any ongoing problems to be resolved or treatment planned at the time of appointment, thereby saving both patient and health professional time.

- xxxii A legible, comprehensive discharge letter/note should be sent to the person's GP within 24 hours of discharge from hospital.
- xxxiii Commissioners of services for children and young people should reference the relevant sections of the Royal College of Paediatrics and Child Health - Commissioning Tertiary and Specialised Services for Children and Young People.^[32]
- xxxiv When planning services for people with arthritis and musculoskeletal conditions, commissioners should consider the requirements of relevant specialised services national definitions^[33]:
 - specialised services for children
 - specialised rheumatology services (adult)
 - specialised orthopaedic services (adult)
 - specialised pain services
 - specialised spinal services

Specialised services are those that may not be provided in all local hospitals. They cover the needs of patients with rare conditions and those who need specialised investigation or management that is not available in a local hospital setting. The services include:

- tertiary referral (ie: referral to a specialist centre that can deal with complex requirements) for complex connective tissue disease, complex needs, metabolic bone disease, rare conditions
- obstetric services, management of pregnancy in the context of connective tissue disease
- the management of rheumatoid cervical myelopathy (disease involving the spinal cord).

- xxxv People should have access to services to support them in returning to work or education. These could include post-operative physical rehabilitation, vocational rehabilitation and/or occupational health services, Disability Employment Advisors and Employment Medical Advisory Services, who are able to work in liaison with employers and individuals.

i For further information and resources, including details of ARMA's member organisations and other examples of good practice and information on implementation, visit www.arma.net.uk

25 British Society for Rheumatology (2004)

26 British Society for Paediatric and Adolescent Rheumatology (2000); British Society for Rheumatology (2004)

27 Korpela M et al (2004)

28 British Society for Rheumatology (2002, 2004); National Institute for Clinical Excellence (NICE) (2001, 2002, 2003)

29 British Society of Rehabilitation Medicine (2003)

30 Scottish Intercollegiate Guidelines Network (2000)

31 NICE guidance (2001, 2002, 2003); British Society for Rheumatology (2004)

32 Royal College of Paediatrics and Child Health (2004)

33 Department of Health (2002)

Allied Health Practitioner (AHP)

a member of the care team who is not a medical doctor. For example a nurse, physiotherapist, occupational therapist, podiatrist, dietician, pharmacist.

Nurses are registered with the Nursing & Midwifery Council.

Health professionals are registered with the HPC (Health Professions Council) who regulate arts therapists, orthoptists, biomedical scientists, prosthetists, orthotists, chiropodists/podiatrists, paramedics, clinical scientists, physiotherapists, dietitians, radiographers, occupational therapists, speech and language therapists.

Pharmacists are registered and regulated by the Royal Pharmaceutical Society

analgesics

drugs that relieve pain

anti-inflammatories

drugs that reduce inflammation

biologic therapies or 'biologics'

therapies used in the treatment of rheumatoid and other forms of inflammatory arthritis

care pathway

a person's route or journey through care, which can include a range of different treatments and services

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

co-morbidities

other conditions or diseases present as well as inflammatory arthritis

DMARDs

disease-modifying anti-rheumatic drugs; drugs that slow the progression of disease

multi-disciplinary team

a healthcare team that includes professionals from different disciplines, working together to care for people with inflammatory arthritis.

The team may include: GP, consultant rheumatologist, consultant orthopaedic surgeon, consultants in other disciplines, doctors in training (both hospital and GPs), nurse specialist, physiotherapist, occupational therapist, dietician, podiatrist, orthotist, psychologist, pharmacist and social worker

providers

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

specialist in rheumatology

rheumatologist, GP with special interest (GPwSI) or allied health professional with a specialism in rheumatology

rehabilitation

enabling and supporting a person to return to normal daily activity, including employment; a core rehabilitation team should include a rheumatologist, specialist nurse, physiotherapist, occupational therapist with ready access to podiatry, dietetics and clinical psychology

Appendix: Developing the Standards

The working group met five times between Sept 2003 – June 2004, and consulted widely and publicly on these standards during May and June 2004.

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