



Joint Care?

A review of the quality of care provided to children and young people with Juvenile Idiopathic Arthritis

NCEPOD Stakeholder Meeting

BACKGROUND

In 2025, NCEPOD's report "Joint Care?" identified five key areas, informed by eight recommendations that needed addressing to improve the quality of care provided to children and young people with Juvenile Idiopathic Arthritis (JIA). One year on from the release of the report, a stakeholder group met to discuss progress since the report, changes that have been made locally based on the recommendations, and to highlight areas that need further work to implement improvements.

KEY AREAS

1. RAISE AWARENESS OF JIA AND ITS SYMPTOMS WITH THOSE WHO MIGHT SEE PATIENTS

Awareness of JIA would improve recognition, encouraging earlier referral to rheumatology services which may prevent joint damage.

2. STREAMLINE LOCAL REFERRAL PATHWAYS, WITH CLEAR TIMELINES FOR PATIENTS WITH SUSPECTED JIA

Standardising pathways between hospitals would lead to referrals to the correct speciality.

3. PROVIDE PROMPT TRAINING TO PATIENTS/PARENTS/CARERS ON HOW TO INJECT MEDICATIONS FOR JIA

Methotrexate administration training would reduce delays in treatment starting.

4. ENSURE ONGOING ACCESS TO PHYSIOTHERAPY, OCCUPATIONAL THERAPY, PAIN, AND PSYCHOLOGY SERVICES

As many patients have JIA as adults, equivalent access to care should be available from diagnosis through to adulthood.

5. PROVIDE A HOLISTIC, DEVELOPMENTALLY APPROPRIATE RHEUMATOLOGY SERVICE FOR PATIENTS WITH JIA

As many patients are diagnosed with JIA at a young age, all aspects of wellbeing and education should be age appropriate.

IMPACT TO DATE

Guidelines and Articles

- Royal College of Ophthalmologists, 2026. [NCEPOD Report Summary for UK ophthalmologists \(and eye health and care professionals\)](#)
- GIRFT, 2025. [Paediatric Rheumatology: GIRFT Programme National Specialty Report](#)
- Freeth H, *et al.* 2025. Archives of Disease in Childhood. [A review of the quality of care in children and young people with juvenile idiopathic arthritis \(JIA\)](#)
- Bray L, *et al.* 2025 (updated guideline in prep). Rheumatology Advances in Practice. [Hot, swollen or stiff joints in children and young people: British Society for Rheumatology guideline scope](#)
- Arthritis UK, 2025. [Arthritis UK statement: our response to the NCEPOD report](#)
- The Royal College of Ophthalmologists, 2025. [Joint Care? Report on the care received by children & young people diagnosed with juvenile idiopathic arthritis \(JIA\)](#)
- National Rheumatoid Arthritis Society, 2025. [Key findings from the NCEPOD 'Joint Care?' Report, and the Path Forward](#)
- NCEPOD, 2025. [Juvenile Idiopathic Arthritis: A conversation between primary and secondary care](#)
- NCEPOD, 2025. [Joint Care? Webinar](#)
- Patient Safety Learning: The Hub, 2025. [NCEPOD: A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis](#)

Conference Presentations

- British Society of Rheumatology annual conference, 2025
- British Society of Rheumatology annual conference, 2026
- Royal College of Paediatrics and Child Health annual conference, 2025.
- British Society for Children's Orthopaedic Surgery annual conference, 2025
- Education Commissioning and Quality-Clinical Assessment Service (ECQ-CAS) meeting, 2025

PROGRESS

Recommendation

Raise awareness of Juvenile Idiopathic Arthritis and its symptoms with the healthcare professionals who will see this group of patients.

Target audience: Royal College of General Practitioners, Royal College of Paediatrics and Child Health, British Society for Children's Orthopaedic Surgery, British Orthopaedic Association, Royal College of Ophthalmologists and Royal College of Emergency Medicine, Getting It Right First Time.

National Examples of Practice

- MP Sharon Hodgson asked if the Secretary of State for Health and Social Care will take steps to implement the recommendations of NCEPOD's report.

- BSR launched its Paediatric and Adolescent QI Network (PQuIN) and are planning to meet virtually every 3-4 months to integrate quality improvement throughout routine JIA care.
- Health Conditions in School Alliance (HCSA)'s new policy for the Department of Education advocates that every child with a health condition will need an Individual Healthcare Plan (IHP) in place and includes a section on JIA.
- Using NCEPOD's data to shape recommendations, Arthritis UK, in collaboration with children and young people with JIA, launched a Welsh manifesto and shared it with Welsh MPs in the Senedd.
- JAR have introduced *Juvenile Arthritis Awareness Month* (JAM-JAR), which will take place every March.
- JAR shared their *Think JIA Campaign* to raise awareness that children and young people get arthritis.

Local Examples of Practice

- GIRFT and Arthritis UK are using the NCEPOD report locally to raise awareness of JIA.

Other Updates

- JAR appointed Daniella Sutton (a 17-year-old F4 driver) as an ambassador for JIA to increase awareness and media coverage.
- JAR's *Joint Voices* hosted a webinar with Daniella Sutton to share their experiences.
- JAR has expanded its local in-person engagement events, with its largest event (*Racing for a Cure*) at the F1 Arcade in London bringing ~100 children and young people with JIA, families, researchers, and clinicians together.
- JAR's *A Little Box of Hope* has continued its success.
- BBC News Tees shared that Dean and Becky Ranyard raised more than £1,500 for JAR by walking and running two miles every day for 30 days.
- BBC News West Yorkshire shared Samantha and Ella's JIA diagnosis, increasing awareness that children and young people get arthritis.
- More than 1500 people have attended Arthritis UK's 2026 local in-person events, online sessions, and workshops.
- For *World Young Rheumatic Disease (WORD) Day*, Arthritis UK hosted an awareness event in Northern Ireland.
- Arthritis UK are currently supporting ~40 quality improvement projects across the UK.

Recommendation

Streamline and publicise local referral pathways with clear measurable timelines for patients with suspected Juvenile Idiopathic Arthritis.

Target audiences: Medical directions and healthcare professionals treating patients with JIA.

National Examples of Practice

- GIRFT's *Further Faster* programme has updated its modernised JIA pathway in collaboration with the British Society of Rheumatology, which includes pre-referral guidance.
- Alongside its traditional analogue JIA pathway, GIRFT is developing and piloting a digital pathway (JIA is one of three paediatric topics to be selected to pilot a digital pathway).

Local Examples of Practice

- GIRFT's *Further Faster Programme* for paediatric rheumatology is being used locally to support service improvement, access to treatment, and outcomes of care.

Challenges

- GIRFT anticipate funding and implementation challenges post-pilot.
- GPs continue to experience pushback and declined referrals across both paediatric and adult rheumatology services.

Recommendation

Provide timely access to appropriately trained physiotherapy, occupational therapy, pain and psychology services at the diagnosis of Juvenile Idiopathic Arthritis, and then as needed through adolescence and adulthood.

Target audiences: *Medical directors and healthcare professionals treating patients with JIA.*

National Examples of Practice

- Arthritis UK's *Musculoskeletal Diagnosis Toolkit* is available for primary, secondary, specialist, and community care.
- Arthritis UK host online training courses for healthcare professionals.

Local Examples of Practice

- A Trust/ Health Board are planning to create a JIA transition clinic to support adolescents transitioning into adult rheumatology services.
- A Trust/ Health Board are expanding current outreach clinics to include ophthalmology, allowing children and young people with JIA to be reviewed by both rheumatology and ophthalmology teams on the same day.
- JAR delivers quarterly peer-support Zoom sessions with specialist input from healthcare professionals to parents and carers of children and young people with JIA.
- JAR's *Joint Voices* peer-support group is a supportive, virtual space for young adults (aged 18-30) with JIA to share experiences and receive specialist input from healthcare professionals.

Challenges

- As there is currently no training required to be a paediatric physiotherapist, rheumatology care for children and young people with JIA is not standardised.

- The NHS is increasingly relying on charities to support children and young people with JIA due to limited funding for embedded psychological support within paediatric services.
- Even when paediatric rheumatology services provide psychological support, waiting lists are long.
- Although some Trusts/ Health Boards have a transition process in place for adolescents with JIA, many rely on an unstandardised checklist, leaving patients feeling unprepared as they transition into adult services.

Recommendation

Offer age-appropriate information about Juvenile Idiopathic Arthritis and medication risks and benefits to patients and their parents/carers at diagnosis and on an ongoing basis.

Target audiences: *Healthcare professionals treating patients with JIA.*

National Examples of Practice

- Paediatric Rheumatology European Association (PReS) and GIRFT are developing age-appropriate information for children and young people with JIA, which will be available via NHS's *Healthier Together* website.
- JAR relaunched their *Juvenile Arthritis at School* kit, giving schools and teachers across the UK the resources they need to support students with JIA.
- Arthritis UK are working with NRAS, CCAA, and Lupus UK to develop JIA-specific resources for schools across the UK.
- Arthritis UK's *The School Series* on YouTube shares top tips and support for children and young people living with JIA.

Local Examples of Practice

- Arthritis UK's *Young People and Families Service* (YPFS) provide one-to-one support and hold local events for children and young people (aged 0-25) with JIA, whilst also supporting them as they transition into adult rheumatology services.

Recommendation

Provide training to the patient, if age-appropriate, and/or their parents/carers on how to administer subcutaneous injections for Juvenile Idiopathic Arthritis at the point treatment is initiated.

Target audiences: *Healthcare professionals responsible for training an administration of medications for JIA.*

Challenges

- Variation in subcutaneous injection administration training across settings.

Recommendation

Ensure timely access to intra-articular steroid injections by staff who have been trained to deliver age-appropriate care in units where local or general anaesthesia can be delivered.

Target audiences: *Integrated care boards, commissioners, medical directors and healthcare professionals treating patients with JIA.*

Local Examples of Practice

- A Trust/ Health Board has reduced delays in access to intra-articular steroid injections by holding regular meetings to monitor timeliness across hospitals in their network.

Challenges

- A reduction in delays is not yet widespread across the NHS due to reduced theatre capacity.

Recommendation

Provide a holistic, developmentally appropriate rheumatology service for patients with Juvenile Idiopathic Arthritis.

Target audiences: *Medical directors and healthcare professionals treating patients with JIA.*

Challenges

- Limited standardisation across paediatric rheumatology services and variation in who reviews the patient; some children and young people may be seen by adult rheumatologists.
- Specialist commissioning capacity within Integrated Care Boards (ICBs) for children are expected to reduce and merge with adult services.
- Some clinicians would like to provide out-of-hours services for children and young people with JIA, but there is insufficient infrastructure to support delivery.

Recommendation

Develop NICE guidelines for the management of Juvenile Idiopathic Arthritis.

Target audiences: *National Institute for Health and Care Excellence*

National Examples of Practice

- BSR's pain in inflammatory arthritis guideline is under peer review and is due to be published in 2026.
- BSR's hot, swollen joints guideline is due to be updated and published in 2027.
- BSR's holistic JIA guideline is due to be published in 2027.
- PReS are developing European-wide guidance for the treatment of non-systemic JIA, with the aim of standardising care across Europe.

Challenges

- Although GIRFT have tried to develop NICE guidelines for the management of JIA, they do not have the evidence (e.g., randomised controlled trials) required for NICE's guideline development processes.

Additional Resources

General

- MP Sharon Hodgson's statement: <https://questions-statements.parliament.uk/written-questions/detail/2025-03-06/36055/>
- Department for Education statutory guidance draft for supporting children and young people with medical conditions: https://consult.education.gov.uk/medical-conditions-at-school/medical-conditions-at-school-statutory-guidance/supporting_documents/supporting-children-and-young-people-with-medical-conditions-and-allergypdf
- BBC News West Yorkshire article: <https://www.bbc.co.uk/news/articles/cy03ez7yk93o>
- BBC News Tees article: <https://www.bbc.co.uk/news/articles/cq6v26prlzyo>
- Children's Chronic Arthritis Association (CCAA)'s support groups in England and Wales: <https://www.ccaa.org.uk/how-we-help/local-groups-2/find-your-local-area-group/>
- National Voice's *Ask Me How I Am*: <https://www.nationalvoices.org.uk/project/ask-how-i-am/>
- The Lucy Project: <https://www.sheffieldchildrens.nhs.uk/news/lets-talk-about-the-lucy-project/>

NHS England

- GIRFT's *Further Faster* Programme: https://gettingitrightfirsttime.co.uk/cross_cutting_theme/further-faster-programme/
- GIRFT's *Further Faster* Rheumatology Handbook: <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2026/03/FF-Handbook-Rheumatology-Master-March-2026.pdf>
- NHS *Healthier Together*: <https://www.healthiertogether.nhs.uk/young-person/rheumatology---muscle-and-joint-pain>

British Society of Rheumatology

- Paediatric and Adolescent QI Network (PQuIN): <https://www.rheumatology.org.uk/improving-care/quality-improvement/jia-learning-collaborative>
- BSR pain management guidance (2024): https://academic.oup.com/rheumap/article/8/4/rkae128/7903098?login=false#google_vignette

Juvenile Arthritis Research

- Juvenile Arthritis Month (JAM-JAR): <https://www.jarproject.org/jamjar>
- *Think JIA* resources: <https://www.thinkjia.org/>
- *Think JIA's* GP/ Primary Care resource pack: <https://www.thinkjia.org/i-am-a-health-professional>
- JIA ambassador announcement: <https://www.jarproject.org/news/2025/daniella-sutton-announcement>

- *Joint Voices* webinar with Daniella Sutton: <https://www.jarproject.org/hope/videos>
- A Little Box of Hope: <https://www.jarproject.org/alittleboxofhope>
- JAR's upcoming events: <https://www.jarproject.org/event>
- *Racing for a Cure* event: <https://www.jarproject.org/news/2025/racingforacure2025>
- JAR's parent carer Zoom sessions: <https://www.jarproject.org/join>
- JAR's *Joint Voices* peer-support group: <https://www.jarproject.org/jointvoices>
- *Juvenile Arthritis at School Kit*: <https://www.jarproject.org/toolkit>
- Information about Still's disease and systemic JIA: <https://www.stillsdisease.uk/>
- JAR's *JIA VIP Research Panel*: <https://www.jarproject.org/vip>
- Supporting mental health: <https://www.jarproject.org/hope/wellbeing>
- Arthritis isn't just for adults: <https://www.youtube.com/watch?v=-A1ZYQN90Zg>

Arthritis UK

- Senedd Election 2026, Arthritis UK's Welsh manifesto: <https://www.arthritis-uk.org/get-involved/campaigning/our-campaigns/senedd-election-2026/>
- Scottish Parliament Election 2026, Arthritis UK's Scottish manifesto: <https://www.arthritis-uk.org/get-involved/campaigning/our-campaigns/scottish-parliament-election-2026/>
- *World Young Rheumatic Diseases (WORD) Day* event: <https://www.arthritis-uk.org/about-us/contact-us/press-centre/press-releases/arthritis-uk-demands-change-for-young-people-with-arthritis-on-international-word-day/>
- *Musculoskeletal Diagnosis Toolkit*: <https://www.arthritis-uk.org/health-and-care-professionals/musculoskeletal-clinical-assessment/msk-diagnosis-toolkit/>
- Online training courses for healthcare professionals: <https://www.arthritis-uk.org/health-and-care-professionals/training-and-professional-development/>
- *The School Series* on YouTube: <https://youtube.com/playlist?list=PLXKNfcIcSzgUxkWSHoXDIBVOeqjNB0Bcb&si=yNH1mWgsxMloK2xO>
- Information for Schools: <https://www.arthritis-uk.org/information-and-support/understanding-arthritis/young-people-and-families/information-for-schools/>
- *Young People and Families Service*: <https://www.arthritis-uk.org/information-and-support/understanding-arthritis/young-people-and-families/>
- Arthritis UK Northern Ireland's report: <https://www.arthritis-uk.org/news/from-breaking-point-to-recovery-prioritising-musculoskeletal-healthcare-in-northern-ireland/>
- *Wellbeing Webinar*: <https://www.youtube.com/watch?v=3WwlaYPTPlg&t=2s>
- Tips for Parents and Carers: <https://www.arthritis-uk.org/news/2023/october/tips-for-parents-and-carers-how-to-support-a-child-living-with-arthritis-or-a-musculoskeletal-condition/>



For the full report and supporting documentation, please visit [NCEPOD Joint Care?](#)