

RECOMMENDATIONS

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives. The results of which should be presented at quality or governance meetings, and action plans to improve care should be shared with executive boards. Suggested target audiences are listed under each recommendation.

ONE

Raise awareness of juvenile idiopathic arthritis and its symptoms with the healthcare professionals who will see this group of patients.

- Painful, swollen or stiff joint(s)
- A fever that keeps returning
- Joint(s) that are warm to touch
- A limp but no injury
- Increased tiredness

Target audiences: Royal College of General Practitioners, Royal College of Paediatrics and Child Health, Royal College of Physicians, 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

Supported by: Musculoskeletal leads with a responsibility for children and young people working with integrated care boards, commissioners, executive boards, NHS England, Welsh Government, Department of Health Northern Ireland, Government of Jersey

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: Patients were not being referred to rheumatology services early enough. There was an absence of standardised protocols for treating juvenile idiopathic arthritis (JIA). There was also a lack of opportunity for continuing professional development in this disease.

Implementation ideas:

- ✓ Information in JIA can be found at the following links and shared with colleagues
 - www.thinkjia.org, which includes checklists for GPs and video guidance
 - www.versusarthritis.org/about-arthritis/healthcare-professionals/
 - www.pmmonline.org/page-1617
 - [Getting it Right First Time](#) - paediatric rheumatology report should be reviewed and GIRFT should also be followed for guidance on pathways and waiting times in their [Further Faster handbook](#)
- ✓ Use a standard "when to think JIA" document that prompts clinicians to look at other joints and ask about prior joint symptoms if there is no fracture seen in a swollen joint
- ✓ Sample letters for referral from GPs with key red flag wording could be provided
- ✓ There should be improved education in JIA for undergraduate/postgraduate medical trainees, qualified doctors, nurses, pharmacists and allied health professionals in all specialties who see children and/or young people
- ✓ Support packs, webinars or face-to face sessions could be provided to teachers by local paediatric rheumatology teams
- ✓ Dissemination of information to the wider public by means of national/regional initiatives e.g. posters, social media, television campaigns.

TWO

Streamline and publicise local referral pathways with clear measurable timelines for patients with suspected juvenile idiopathic arthritis.

Ensure that this includes:

- The ability to refer patients with suspected JIA directly from primary care to a secondary/tertiary care rheumatology service where a diagnosis can be made and ongoing care provided
- Access to advice from rheumatology services regarding the need for/appropriateness of investigations at the time of referral
- Agreed referral pathways within secondary care from specialties such as orthopaedics and emergency medicine to age-appropriate rheumatology services
- Agreed referral pathways from rheumatology services to ophthalmology clinics (including same day/ combined clinics) with clear standards for referral and follow-up timeframes
- Direct access to age-appropriate services if the patient should have a disease flare or other urgent disease-related issue.

Target audience: Medical directors and healthcare professionals treating patients with JIA

Supported by: Integrated care boards, commissioners, executive boards, Getting it Right First Time

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: Clearer lines of referral are needed to ensure that treatment starts promptly and that all necessary multidisciplinary input is arranged. Discussion amongst the clinical groups involved in the study showed that getting referred to rheumatology quickly was often based on luck, with many clinicians reflecting on how parents had to advocate for their child based on their own research or after multiple visits to their GP.

This recommendation aims to reduce healthcare inequalities; consideration needs to be given to the populations accessing the services, distance travelled, and costs involved as well as seldom heard and 'at risk' groups.

Implementation ideas:

- ✓ Think about what your paediatric rheumatology service should look like and who should see patients referred to your service – as a minimum they should be able to make a diagnosis of JIA and start appropriate treatment – community diagnostic centres may aid this
- ✓ [Getting it Right First Time](#) - paediatric rheumatology report should be reviewed and GIRFT should also be followed for guidance on pathways and waiting times in their [Further Faster handbook](#)
- ✓ Integrated care boards, operational delivery networks and clinical commissioners should use the local pathways as a basis to commission services. NICE guidelines would support this, if developed.

THREE

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 audience: Medical directors and healthcare professionals treating patients with JIA

Supported by: Integrated care boards, commissioners, executive boards, Getting it Right First Time

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: There was a decline in access to these services as the young person moved to adulthood, however it should be noted that many patients have JIA as adults and so equivalent access to care needs to exist.

Implementation ideas:

- ✓ Identify gaps in your hospital's service for patients with JIA and develop metrics for optimal staffing
- ✓ Provide guidance on standardisation of the multidisciplinary team: who should be included and how often each patient should be discussed and assessed
- ✓ Utilise operational delivery networks to support this
- ✓ Define how the details of care provided by specialist services should be communicated to the patient's primary treating clinician.

FOUR**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 audience: Healthcare professionals treating patients with JIA

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: Improving understanding and empowering patients and their carers to be involved in making informed decisions about their management will reduce unnecessary delays in starting a treatment due to patient/carer concerns and improve subsequent adherence and ensure treatment starts promptly and continues effectively. Ongoing education and training should be accessible to all patients and carers, and provided in developmentally appropriate formats, and departments. Both online and physical resources are still very important to patients and families.

Implementation ideas:

- ✓ A model for informed consent for JIA treatment could be developed to achieve this recommendation in addition to clear documentation of discussions around medication
- ✓ Departments could signpost patients and carers to appropriate online resources, the latest research findings, and JIA support groups to ensure that they are visible to patients and their parents/carers
- ✓ Provide support to parents/carers, for example, telling them who they can call if they need help with anything, such as administering medications
- ✓ Developmentally appropriate resources for the young person could be made available around disease therapy, peer support and self-management ([USEFUL RESOURCES](#)). Regular re-education could be given as the young person gets older and reaches different life points.

FIVE**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 audience: Healthcare professionals responsible for training on administration of medications for JIA

Supported by: Integrated care boards, commissioners, executive boards, Getting it Right First Time

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: There were delays to treatment starting as a lack of training meant the medication could not be administered.

Implementation ideas:

- ✓ Undertake the training at the time of prescribing

- ✓ Community diagnostic centres would be an appropriate place for trained nurses to deliver Methotrexate training for children and their families
- ✓ See if other similar models exist, such as WellChild's [Better at Home](#) training suites.
- ✓ Create training videos/instruction sheets in English and other languages relevant to your population, as well as in British Sign Language or easy read versions.

SIX

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

***Supported by:** Orthopaedic surgeons, anaesthetists, theatre booking staff*

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: Access to medical treatments and home care service should be equitable and not subject to social determinants of health or distance to travel to appointments. Patients needing intra-articular joint injections required a general anaesthetic but could often not access theatre lists.

Implementation ideas:

- ✓ This could work well when a relationship is formed between rheumatology/surgery/anaesthesia to allow a slot to be made available on a regular list, recognising the ad hoc nature of this patient group needing a 'medically' invasive procedure. It may be difficult to fill a traditional list on a regular basis with joint injections, so flexibility is required - possibly bookable semi-urgent slots.

SEVEN

Provide a holistic, developmentally appropriate rheumatology service for patients with juvenile idiopathic arthritis.

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

***Supported by:** Integrated care boards, commissioners, executive boards, Getting it Right First Time*

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Implementation ideas:

- ✓ High quality youth work, self-management opportunities and family support can make a significant difference to many young people and their families, especially at diagnosis, during flare ups, and at the time of transition to adult care. Allocate sufficient time* for JIA review appointments to:
 - ask patients (or their parents/carers if age-appropriate) about their physical health, mental health (moods, feelings, worries, concerns), educational/social/work-related concerns and signpost them to support services. Consider using a [HEADSSS](#) assessment to guide this discussion
 - signpost to educational resources/support for parents/carers as well as developmentally appropriate resources for children, young people and young adults covering range of topics including life skills
 - use 'apps' and text messaging to inform patients about JIA, to allow them to monitor their symptoms
 - incorporate discussions about the transition between child and adult services, see ['The Inbetweeners'](#) report

**NB: In line with current [guidance](#) at least 30 minutes will be required in the clinic schedule for face-to-face contact, with additional time for multidisciplinary team discussion, letter dictation and other necessary administration following the appointment.*

- ✓ Consider co-production of the service with young people and parents/carers
- ✓ Run combined clinics with the paediatric and adult rheumatology teams; members of both should be present for at least one visit before transfer. Involve members of the wider MDT who understand or are trained in the needs of adolescents (not just paediatrics or adult healthcare) and follow adolescent best practice such as those outlined by [BANNAR Network Adolescent Care Top Tips](#)
- ✓ Hold clinics outside of school/college hours - the young person's education should not be affected by hospital appointments
- ✓ Offer online appointments and patient/parent/carer access to electronic medical records
- ✓ Provide opportunities for adolescent patients to be seen alone
- ✓ Community diagnostic centres would be an ideal place for paediatric rheumatology teams to deliver health education and potentially peer support opportunities for patients and for parents/carers.

EIGHT

Develop NICE guidance for the management of juvenile idiopathic arthritis.

Target audience: National Institute for Health and Care Excellence

RATIONALE AND IMPLEMENTATION SUGGESTIONS

Rationale: There are no standard national guidelines for juvenile idiopathic arthritis. Many hospitals have their own pathway but there is no overarching standardisation.

Implementation idea:

- ✓ If this is not adopted by NICE there is a standard pathway of care, published in 2015 'draft' NHS guidance that could be updated and become a 'living' document which could be updated rapidly as new evidence is published.

[Getting it Right First Time](#) (GIRFT) are due to publish a report on paediatric rheumatology. The reports and their recommendations should be considered together, once the GIRFT report is published.