

What the report is looking at	Child Health Clinical Outcome Review Programme Joint Care? <i>A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis (JIA)</i>
What countries are covered	England, Wales and Northern Ireland
The date the data are related to	All children and young adults aged 0-24 years, coded for a diagnosis of JIA diagnosed between 1 st April 2019 and 31 st March 2023, and before their 16 th birthday.

No.	Recommendation	Evidence in the report which underpins the recommendation	Guidance available
1	<p>Raise awareness of juvenile idiopathic arthritis and its symptoms with the healthcare professionals who will see this group of patients.</p> <ul style="list-style-type: none"> Painful, swollen or stiff joint(s) Joint(s) that are warm to touch Increased tiredness A fever that keeps returning A limp but no injury. <p>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.</p> <p>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.</p>	<p>CHAPTER 3 PAGE 19</p> <p>A total of 10/13 young people and 58/68 parents/carers spoke to a GP prior to being referred for a diagnosis, and 4/8 young people and 20/54 parents/carers felt that they were not taken seriously by the GP during the consultation.</p> <p>CHAPTER 3 PAGE 20</p> <p>The GP is one of the first contacts with healthcare for a patient with presenting symptoms. Very few GP practices (23/101; 22.8%) reported having protocols for the investigation and care of patients with suspected JIA. Where they did exist, protocols were less likely to exist for adolescents (7/101; 6.9%) than for paediatric (11/101; 10.9%) and adult patients (19/101; 18.8%) (T3.2).</p> <p>CHAPTER 7 PAGE 44</p> <p>Table 7.10 shows that the access to continuing professional development (CPD) in JIA was more readily available to clinicians in paediatrics than in adolescent and adult practice. Data from the primary care questionnaire indicated that 21/89 practices or individuals within the practice participated in a rheumatology CPD programme.</p>	<p><u>Arthritis and Musculoskeletal Alliance (ARMA) and the British Society for Paediatric and Adolescent Rheumatology (BSPAR). 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis</u></p>
2	<p>Streamline and publicise local referral pathways with clear measurable timelines for patients with suspected juvenile idiopathic arthritis.</p> <p>Ensure that this includes:</p> <ul style="list-style-type: none"> The ability to refer patients with suspected JIA directly from primary care to a secondary/tertiary care rheumatology service 	<p>CHAPTER 2 PAGE 17</p> <p>Reviewers found evidence of at least one healthcare inequality which impacted on the care provided to 26/280 (9.3%) patients (T2.3). The most cited reasons were geographic deprivation (7/26) and travel time to hospital (6/26).</p>	<p><u>Arthritis and Musculoskeletal Alliance (ARMA) and the British Society for Paediatric and Adolescent Rheumatology (BSPAR). 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis</u></p>

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

CHAPTER 3 PAGE 19

Following assessment by the primary care clinician, only 12/58 patients were then referred directly to a rheumatologist.

CHAPTER 3 PAGE 20

General practitioners can be guided on the referral process for suspected early inflammatory JIA by the accepting rheumatology team, with protocols or criteria for a referral being set. Of the GPs asked, 34/64 were unaware of any such referral criteria, while 30/64 did have set criteria that patients must match before a referral could be made.

CHAPTER 3 PAGE 21

Patients should be seen by a rheumatologist within ten weeks of symptom onset.[9] However, only 31/70 patients were seen within this time frame and just 16/70 patients were seen by a rheumatologist within six weeks (F3.4).

CHAPTER 3 PAGE 22

Delay in assessment by the rheumatologist was evident in the responses to the clinician questionnaire (51/290; 17.6%) and the reviewer assessment form (71/266; 26.7%). Furthermore, the reviewers believed that diagnosis was delayed in 93/274 (33.9%) patients. The most common reason was that referrals were initially made to the wrong speciality, followed by a wait for investigations and/or results (T3.5).

CHAPTER 3 PAGE 23

The primary care questionnaire showed that only 31/64 patients were initially referred to general paediatrics. Not all rheumatology services would take primary care referrals, but it may be that the GP did not suspect inflammatory arthritis and so did not refer to rheumatology. Just 18/64 patients were referred to either paediatric or adult rheumatology services (T3.6).

CHAPTER 3 PAGE 24

The reviewers found that most referrals to rheumatology came from general paediatricians (113/274; 41.2%) and GPs (98/274; 35.8%), and there were 81/274 (29.6%) referrals from orthopaedic surgeons (T3.7).

		<p>CHAPTER 3 PAGE 24 The reviewers found a delay between first presentation with symptoms and referral to rheumatology in 108/251 (43.0%) patients, and this number was similar for clinicians completing the clinical questionnaire (129/278; 46.4%) (T3.8).</p> <p>CHAPTER 3 PAGE 25 The reviewer's assessment form revealed that delays in referral occurred less frequently if the patient had been seen by a general paediatrician (34/105; 32.4%) compared with orthopaedic surgeons (49/77; 63.6%).</p> <p>CHAPTER 3 PAGE 25 The organisational data showed that 68/101 (67.3%) hospitals held ophthalmology clinics for patients with JIA within the different age groups: paediatrics (65/101; 64.4%), 41/101 (40.6%) for adolescent and 23 for adults. Just 16/68 hospitals held combined rheumatology and ophthalmology clinics, with 12/65 held in paediatric rheumatology services and 8/41 in adolescent rheumatology services. Only 7/68 hospitals had the clinics on the same day, while the majority (53/68) had separate clinics on different days for rheumatology and ophthalmology (T3.9).</p> <p>CHAPTER 3 PAGE 26 There were 49/282 (17.4%) patients who were not referred to ophthalmology and of those referred, 56/233 (24.0%) were not seen in an appropriate timeframe, and a total of 105/282 (37.2%) patients were not seen or seen promptly.</p>	
3	<p>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.</p> <p><i>Target audience: Medical directors and healthcare professionals treating patients with JIA</i> <i>Supported by: Integrated care boards, commissioners, executive boards</i></p>	<p>CHAPTER 6 PAGE 36 Table 6.2 shows that there was a trend towards less involvement of physiotherapy, occupational therapy and psychology from paediatrics, through adolescents and into adulthood.</p> <p>CHAPTER 6 PAGE 36 The clinician survey demonstrated that 64/103 (62.1%) respondents always referred patients with a new diagnosis of JIA to physiotherapy at diagnosis and 34/105 (32.4%) referred them to occupational therapy services. The reviewers believed there was significant under-referral of patients at diagnosis of JIA to physiotherapy, occupational therapy and psychology (F6.2).</p>	<p><u>Arthritis and Musculoskeletal Alliance (ARMA) and the British Society for Paediatric and Adolescent Rheumatology (BSPAR). 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis</u></p>

		<p>CHAPTER 6 PAGE 37</p> <p>The clinicians reported that most patients saw a physiotherapist at follow-up (265/282; 94.0%), while 95/128 (74.2%) saw an occupational therapist and only 43/106 (40.6%) saw a psychologist (T6.3).</p> <p>CHAPTER 6 PAGE 37</p> <p>The reviewers found less evidence documented in the case notes that patients had been seen by a physiotherapist (193/290; 66.6%) or occupational therapist (62/290; 21.4%) than reported by the clinicians. They believed 54/86 patients who were not seen by a physiotherapist should have been and, similarly, that 67/212 patients should have been seen by occupational therapy.</p>	
4	<p>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.</p> <p><i>Target audience: Healthcare professionals treating patients with JIA</i></p>	<p>CHAPTER 7 PAGE 41</p> <p>A total of 86/102 (84.3%) hospitals reported that patients and carers were routinely provided with information about juvenile idiopathic arthritis (JIA) at diagnosis and 80/102 (78.4%) at the time the treatment started. However, 10/102 (9.8%) reported that there was no routine information given at these times (T7.1)</p> <p>CHAPTER 7 PAGE 41</p> <p>The reviewers found no evidence in the notes that patients had been given information about their therapy for 45/276 (16.3%) patients (T7.2).</p> <p>CHAPTER 7 PAGE 42</p> <p>170/270 (63.0%) clinicians thought that further appointments offering education on JIA were offered, reviewers only found evidence of this in the notes of 150/279 (53.8%) patients (T7.5).</p>	<p><u>Arthritis and Musculoskeletal Alliance (ARMA) and the British Society for Paediatric and Adolescent Rheumatology (BSPAR). 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis</u></p>
5	<p>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.</p> <p><i>Target audience: Healthcare professionals responsible for training on administration of medications for JIA</i></p>	<p>CHAPTER 5 PAGE 32</p> <p>Reviewers reported that inappropriate medications were given to 26/298 (8.7%) patients. Examples included oral methotrexate being given while patients and their carers waited for training on how to administer the subcutaneous injections, or oral steroids being given because admission of the patient for intravenous steroids was not possible.</p> <p>CHAPTER 7 PAGE 42</p> <p>In 80/110 (72.7%) hospitals it was the role of the clinical nurse specialists (CNSs) to train young people and their parents/carers on how to administer medication. It was not clear whether in the</p>	<p><u>Royal College of Nursing. Administering Subcutaneous Methotrexate for Inflammatory Arthritis</u></p>

		<p>remaining 30/110 (27.3%) hospitals the training was done by another specialist (e.g. community nurse) or not done at all.</p> <p>CHAPTER 7 PAGE 42</p> <p>The reviewers found no evidence in the case notes that 22/118 (18.6%) patients and parents/carers had been trained in how to give injections for biologics and 19/159 (11.9%) for methotrexate (T7.4).</p>	
6	<p>Ensure timely access to intra-articular steroid injections by staff who have been trained to deliver age-appropriate care in units that can deliver local or general anaesthesia.</p> <p><i>Target audience: Medical directors and healthcare professionals treating patients with JIA</i></p> <p><i>Supported by: Orthopaedic surgeons, anaesthetists, theatre booking staff</i></p>	<p>CHAPTER 5 PAGE 33</p> <p>Delays in medication were common with reviewers finding evidence of medication delays in 89/281 (31.7%) patients (T5.2). There were 255/290 (87.9%) patients on multiple medications, and data from the reviewers showed that medication delay occurred with more than one type of medication per patient (131 delays across 89 patients).</p> <p>CHAPTER 5 PAGE 33</p> <p>The most common delay was due to waiting for another treatment to work (n=14), noting that this delay may be reasonable. This was followed by a lack of theatre space for IA steroid injections (n=11), delay in referral to rheumatology services (n=12) and the patient/parent/carer declining treatment (n=8).</p>	<p><u>NHS: Steroid injections</u></p>
7	<p>Provide a holistic, developmentally appropriate rheumatology service for patients with juvenile idiopathic arthritis.</p> <p><i>Target audience: Medical directors and healthcare professionals treating patients with JIA</i></p> <p><i>Supported by: Integrated care boards, commissioners, executive boards, Getting it Right First Time</i></p>	<p>CHAPTER 4 PAGE 29</p> <p>Just 48/101 (47.5%) clinics for adolescents occurred in an age-appropriate environment.</p> <p>CHAPTER 4 PAGE 30</p> <p>The opportunity for the young person to be seen alone was evidenced in only 22/114 (19.3%) cases reviewed, and the opportunity to be seen out of school hours in only 2/114 (1.8%) cases.</p> <p>CHAPTER 4 PAGE 30</p> <p>A dedicated transition process was present in 76/103 (73.8%) hospitals with 51/60 hospitals following NICE guidance for transition.[12]</p> <p>CHAPTER 4 PAGE 30</p> <p>Transition clinics with staff from both paediatric and adult services were held in 59/104 (56.7%) hospitals.</p> <p>CHAPTER 4 PAGE 30</p> <p>Table 4.3 shows that wider psychosocial aspects of the young person's health had been addressed in just 23/114 (20.2%) cases reviewed.</p>	<p><u>Arthritis and Musculoskeletal Alliance (ARMA) and the British Society for Paediatric and Adolescent Rheumatology (BSPAR). 2010. Standards of care for children and young people with Juvenile Idiopathic Arthritis</u></p> <p><u>NCEPOD. 2023. The Inbetweeners</u></p>

		<p>CHAPTER 6 PAGE 38 The reviewers found that 141/198 (71.2%) patients had had counselling regarding treatment but only a minority had had formal mental health follow-up (T6.4). For those patients who did not have mental health follow-up the reviewers believed that 35/185 (18.9%) patients would have benefitted from it.</p> <p>CHAPTER 6 PAGE 39 There was evidence in the case notes that only 114/262 (43.5%) patients had advice and information to support their holistic health (T6.5).</p> <p>CHAPTER 7 PAGE 42-43 Providing information for parents and carers to review at home is useful. Evidence that information leaflets were given was found in 173/255 (67.8%) sets of case notes but signposting to other educational material was less frequent (T7.6).</p> <p>CHAPTER 7 PAGE 43 From the organisational data, it appeared that signposting to access to peer support decreased with age (T7.7).</p>	
8	<p>Develop NICE guidance for the management of juvenile idiopathic arthritis.</p> <p><i>Target audience: National Institute for Health and Care Excellence</i></p>	<p>CHAPTER 5 PAGE 31 Juvenile idiopathic arthritis (JIA) protocols specifying which medications should be used for paediatric patients were available in 36/54 hospitals, for adolescent patients in 24/29 hospitals and for adult patients in 22/27 hospitals (F5.1).</p> <p>CHAPTER 5 PAGE 32 Biologics were most frequently commissioned in tertiary centres for all age groups (T5.1).</p> <p>CHAPTER 5 PAGE 33 Delays in medication were common with reviewers finding evidence of medication delays in 89/281 (31.7%) patients (T5.2). There were 255/290 (87.9%) patients on multiple medications, and data from the reviewers showed that medication delay occurred with more than one type of medication per patient (131 delays across 89 patients).</p> <p>CHAPTER 5 PAGE 33 The most delayed medications were intra-articular steroid injections (45/185; 24.3%), subcutaneous methotrexate (32/158; 20.3%) and subcutaneous biologics (23/124; 18.5%) (F5.4).</p>	