

INFOGRAPHIC SUMMARY

Juvenile idiopathic arthritis (JIA) is an autoimmune disease that affects around 12,000 children under 16 years of age in the United Kingdom. It is a chronic disease, and many patients will continue to have JIA into adulthood. JIA causes inflammation, pain and stiffness in joints, and can be debilitating. For more information on JIA see:

[VERSUS ARTHRITIS](#) [NATIONAL RHEUMATOID ARTHRITIS SOCIETY](#)

[JUVENILE ARTHRITIS RESEARCH](#) [CHILDREN'S CHRONIC ARTHRITIS ASSOCIATION](#)

In this study, the quality of care provided to patients diagnosed with JIA was reviewed. Patients were randomly selected for inclusion in the peer review process if their diagnosis had been made between 1st April 2019 and 31st March 2023, and they were diagnosed or experienced symptoms before their 16th birthday. Data included 374 clinician questionnaires and the assessment of 290 sets of case notes. In addition, 122 organisational questionnaires were returned along with 130 primary care questionnaires, survey responses from 68 parents/carers and 117 healthcare professionals.

★ Raise awareness of JIA and its symptoms with those who might see patients

Better recognition would encourage faster referral to rheumatology which may prevent joint damage.



23/101 (22.8%) GP practices reported having protocols for the investigation and care of patients with suspected JIA

20/54 (37.0%) parents/carers felt that they were not taken seriously by the GP during the consultation

★ Streamline your local referral pathway, with clear timelines for patients with suspected JIA

Pathways exist but vary between hospitals. It is not always clear who is involved, leading to incorrect referrals.



The most common reason for delay in being seen by a rheumatologist was initial referral to the wrong speciality

71/266 (26.7%) patients had a delay in assessment by a rheumatologist

Only 12/58 (20.7%) patients were referred directly to a rheumatologist

★ Provide prompt training to patients/parents/carers on how to inject medications for JIA

Patients/parents/carers do not always get trained to administer methotrexate, which can lead to a delay to treatment starting.



22/118 (18.6%) patients and parents/carers had no evidence of being trained in how to give methotrexate injections

26/298 (8.7%) patients had inappropriate medications given while patients and parents/carers waited for training on how to give injections

★ Ensure ongoing access to physiotherapy, occupational therapy, pain and psychology services

Many patients have JIA as adults and so equivalent access to care needs to exist from diagnosis through to adulthood.



193/290 (66.6%) patients saw a physiotherapist - 54 not seen should have

62/290 (21.4%) patients saw an occupational therapist - 67 not seen should have

There was a trend towards less involvement of physiotherapy, occupational therapy and psychology from paediatrics into adulthood

★ Provide a holistic, developmentally appropriate rheumatology service for patients with JIA

Being diagnosed with JIA at a young age, impacts all aspects of wellbeing and education, which is not always addressed.



Only 48/101 (47.5%) adolescent clinics were in an age-appropriate environment

Being seen out of school hours was reported for 2/114 (1.8%) patients

Only 114/262 (43.5%) patients had their holistic health supported

Signposting to peer support decreased with age