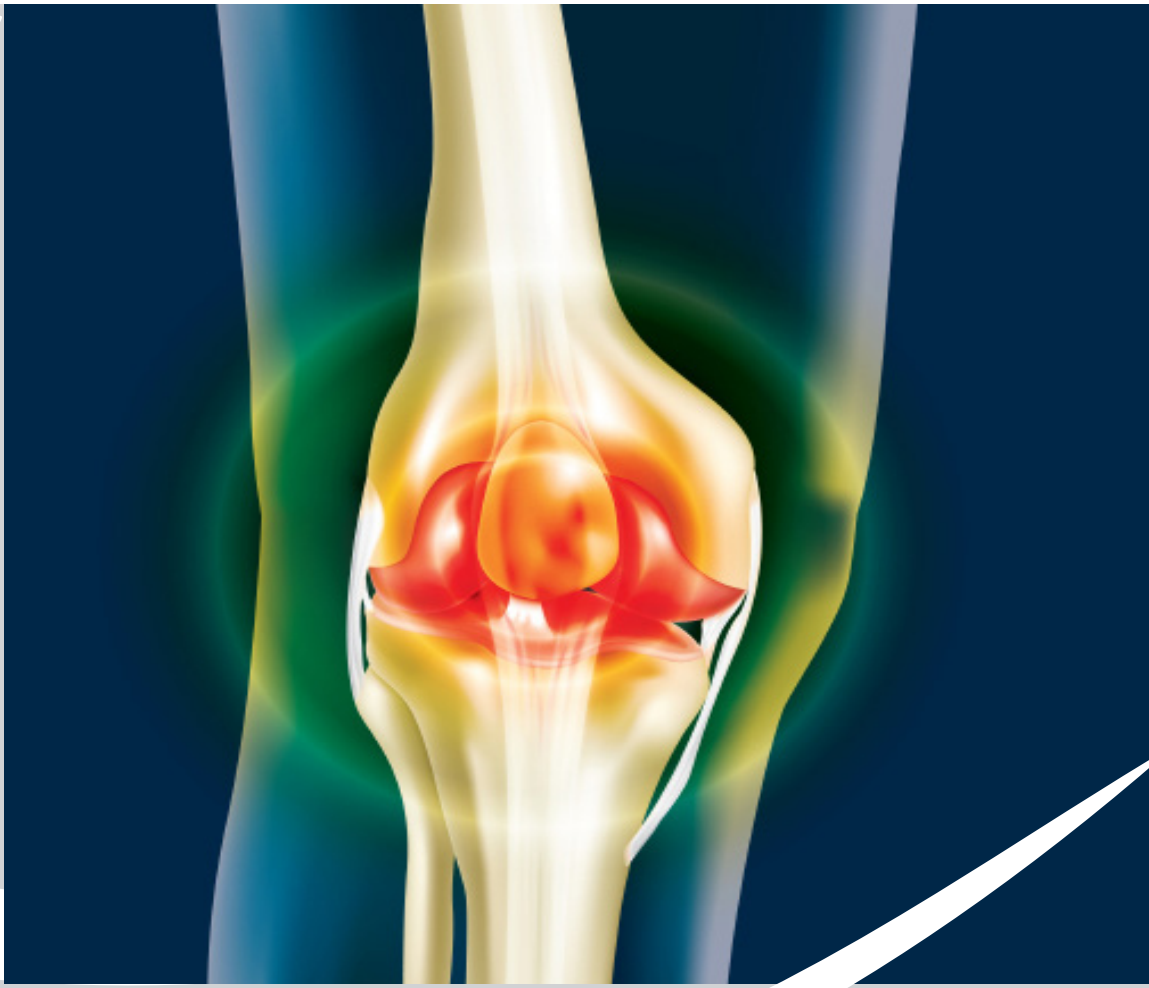
Joint Care?

A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis

SUMMARY



NCEPOD

Improving the quality of healthcare

JOINT CARE?

A review of the quality of care provided to children and young adults with juvenile idiopathic arthritis

A report published by the National Confidential Enquiry into Patient Outcome and Death (2025)

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Cohort: *All children and young adults aged 0-24 years, coded before their 16th birthday for a diagnosis of juvenile idiopathic arthritis between 1st April 2019 and 31st March 2023.*

The Child Health Clinical Outcome Review Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.
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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

RECOMMENDATIONS

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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.

INTRODUCTION

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Juvenile idiopathic arthritis (JIA) is an autoimmune disease that affects around 12,000 children under 16 years of age in the United Kingdom.[1] It is a chronic disease and although symptoms or a diagnosis before a patient's 16th birthday defines the 'juvenile' aspect of the condition, many patients will continue to have JIA into adulthood. JIA causes inflammation, pain and stiffness in joints, and can be debilitating. JIA is an umbrella term for a diverse group of conditions characterised by chronic arthritis and categorised into subtypes. The most common of which affects a small number of joints, but other types exist which can affect multiple joints, which is more likely to extend into adulthood, or be associated with other systemic diseases.

The pathway for children and young people diagnosed with JIA varies depending on the initial presenting symptoms as well as the organisational and commissioning arrangements of the treating hospitals including clinical networks and geographical location. Differential diagnosis for a painful joint is wide and although the red flag symptoms for an inflammatory arthritis are clear, patients are frequently referred to other specialties prior to rheumatology, such as paediatric orthopaedics or emergency medicine, or parents seek advice from physiotherapy services. This leads to unnecessary delays in diagnosis and treatment resulting in pain and an increased risk of joint damage.

Medical treatment for JIA is focused on suppression of the inflammatory response. Single joints can be treated with intra-articular (IA) steroid injections. IA injections frequently require administration under general anaesthetic or conscious sedation, in an appropriate setting with access to radiological support if required. They can also be given with topical anaesthetic and Entonox if tolerated. Access to slots with appropriate anaesthetic support is essential if therapy is to be given in a timely fashion.

When multiple joints are affected, intravenous steroids and/or oral corticosteroids are used initially before progressing to methotrexate. There is an existing medication pathway for JIA,[2] but this pathway does not include all currently available treatments and varies considerably around the UK leading to inequalities of access to appropriate therapy. If the disease is resistant to these treatments, then biologic medications are becoming available, and the National Institute for Health and Care Excellence has published technology appraisal guidance on their use.[3]

Patients receive most of their treatment at home, it is therefore important for them and their parents/carers to understand the risks and benefits of the medications, particularly methotrexate and to be confident in administering it. Methotrexate frequently has side effects making it difficult to tolerate. It is most often given by the subcutaneous route which requires training for patients and parent/carers, the organisation of which can result in delays to treatment starting. The provision of training is variable and can lead to delays in starting therapy or increased risk.

Medications can also cause immunosuppression so there needs to be awareness of the signs and symptoms of sepsis and infections such as chickenpox. Additionally, methotrexate causes birth defects, so it is essential that sexual activity and birth control are discussed with the patient prior to treatment. These conversations need careful consideration as the development of the brain in adolescence can affect decision-making, including long-term planning and the appreciation of abstract concepts such as future health. All information given should be age-appropriate and should be a continuing conversation as the person matures and their needs change. This was highlighted by NCEPOD in 'The Inbetweeners' a review of the transition from child into adult healthcare services.[4]

WHAT YOUNG PEOPLE AND PARENTS/CARERS SAY

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WHAT ONE THING DO YOU THINK WOULD IMPROVE THE CARE OF PEOPLE WITH JUVENILE IDIOPATHIC ARTHRITIS?

DIAGNOSIS

"GPs taking it seriously and not dismissing it as growing pains"

"Listening to family more - they know their child best."

"Earlier diagnosis and for the GPs to consider that JIA might be what a child is suffering with. I know that not all doctors would have experience with JIA, but an early diagnosis will help in getting equipment and medication in place at an early stage to make their lives easier and less painful."

"The wait times between diagnosis and getting treatment"

COMMUNICATION

"Better communication, consistent amongst different professionals"

EDUCATION

"All teachers made aware of JIA and how to support the child in their education"

"I think schools need to be more understanding, but I cannot fault any of the medical specialists and nurses that have treated me, as they've always done as much as they can to help!"

THE ORGANISATION OF SERVICES AND ADOLESCENT CARE

"Possibly Saturday clinics to help children miss less school, particularly in high school"

"More support for children who go to the adult department when approaching the age of 18"

HOLISTIC CARE

"Awareness of the true severity for some children"

"Understanding why it happens and impact on the mental health of children with it"

"Access to longer term psychology support for anxiety, coming to terms with their disability and how to communicate their emotions"

"Meeting other young people with JIA"

METHOD AND DATA RETURNS

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Focus groups and interviews

Young person and parent/carer focus groups and interviews were conducted to inform the study advisory group (SAG) on the issues facing those with juvenile idiopathic arthritis (JIA).

Study Advisory Group

A multidisciplinary group of clinicians was convened to steer the study from design to completion, define the objectives of the study and advise on the key questions. The group comprised lay and parent/carer representatives along with healthcare professionals in rheumatology, paediatrics, pharmacy, nursing, physiotherapy, occupational therapy, general practice, and ophthalmology.

Study aims and objectives

To review the quality of care in children and young adults with juvenile idiopathic arthritis (JIA). The areas of focus were:

- Recognition of JIA and the referral process
- Timeliness of the first assessment by rheumatology and ophthalmology
- Protocols for the treatment of JIA
- Multidisciplinary team working and clinical nurse specialist involvement
- Transition from child to adult healthcare
- Availability of peer support, information and training

Hospital participation

All providers of healthcare across England, Wales and Northern Ireland, where children and young adults with JIA might be cared for including primary, acute, community and independent hospitals, were asked to participate.

Study population and case ascertainment

Inclusion criteria

All children and young adults aged 0-24 years, coded for a diagnosis of JIA*, who were being seen by the rheumatology department as an outpatient or who presented to hospital between 1st April 2021 and 31st March 2023, were identified. From this larger group, patients were randomly selected for the peer review 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. Due to this sampling method patients aged 20 years and older were not included in the peer review process.

**ICD10 codes: L40.54, M08.0 to M08.9, M09.0, M09.8 and SNOMED codes*

Exclusion criteria

Juvenile arthritis in Crohn's disease (regional enteritis) and juvenile arthritis in ulcerative colitis.

Information governance

All data collections complied with the General Data Protection Regulation 2016 (Z5442652) and Section 251 of the NHS Act 2006 (21/CAG/0085), App No 007.

Data collection - peer review

Questionnaires

Three questionnaires were used to collect data for this study:

- A clinician questionnaire was sent electronically to all teams responsible for providing the ongoing rheumatology care of each person sampled for inclusion
- A combined clinician and organisational questionnaire was sent to the GP of each person sampled for inclusion, where the GP could be identified
- An organisational questionnaire was electronically sent to all participating hospitals to collect data from paediatric, adolescent and young adult teams around the referral process, networks of care, the use of protocols for the management of JIA, treatments, multidisciplinary team working, access to equipment, job planning, transition to adult services, and audit.

Case notes

Case notes were requested from all participating organisations from diagnosis until 31st March 2023 including:

- All primary care notes relating to JIA and GP referral letters
- Consultation notes, outpatient correspondence and clinic letters
- Discharge summaries for inpatient stays and outpatient appointments
- Therapy notes and multidisciplinary team summaries.

Peer review of the case notes and questionnaire data

A multidisciplinary group of case reviewers comprising consultants, clinical nurse specialists and allied health professionals from: rheumatology (paediatric and adult), paediatrics, acute medicine, primary care, pharmacy and physiotherapy were recruited to peer review the case notes and questionnaires.

Using a semi-structured electronic questionnaire, each set of case notes was reviewed by at least one reviewer within a multidisciplinary meeting. A discussion, chaired by an NCEPOD clinical co-ordinator, took place at regular intervals, allowing each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for further discussion. In addition to assessing various aspects of care they were also asked to assign an overall quality of care grade:

- **Good practice:** A standard that you would accept from yourself, your trainees and your institution
- **Room for improvement:** Aspects of **clinical care** that could have been better
- **Room for improvement:** Aspects of **organisational care** that could have been better
- **Room for improvement:** Aspects of **both clinical and organisational care** that could have been better
- **Less than satisfactory:** Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution
- **Insufficient data:** Insufficient information submitted to assess the quality of care

Data collection – surveys

An anonymous online survey gathered the views of children, young adults and parents/carers on the services available to them. The patient survey was completed by 13 respondents, who were not necessarily the same people included in the case note review. The parent/carer survey was completed by 68 respondents. This low response might indicate that they were the subgroup least happy with their care and may not be representative of the whole study group.

A second survey gathered data on the views of clinicians on the services available for them to provide. This survey was completed by 177 respondents (general paediatricians 20/177 (11.3%); general paediatricians with an interest in rheumatology 23/177 (13.0%); paediatric rheumatologists 57/177 (32.2%); adolescent rheumatologists 7/177 (4.0%); adult rheumatologists 57/177 (32.2%); general practitioners 9/177 (5.1%); other 4/177 (2.3%).

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced. Qualitative data collected from the case reviewers' opinions and free text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. As the methodology provides a snapshot of care over a set period, with data collected from several sources to build a national picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and anonymised case studies have been used throughout this report to illustrate themes. The sampling method of this enquiry means that data cannot be displayed at a granular level.

Data analysis rules

- Small numbers have been suppressed if they risk identifying an individual
- Any percentage under 1% has been presented as <1%
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings, unless used to allow comparison across different groups
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given

The findings of the report were reviewed prior to publication by the SAG, case reviewers and the NCEPOD Steering Group, which included clinical co-ordinators, trustees, and lay representatives.

Data returns

Clinical data

Figure 1.1 summarises the data included. There were 553 patients who were initially selected and subsequently excluded as they did not meet the study inclusion criteria when the case notes were reviewed locally, most commonly because the patient was diagnosed with JIA before 1st April 2019.

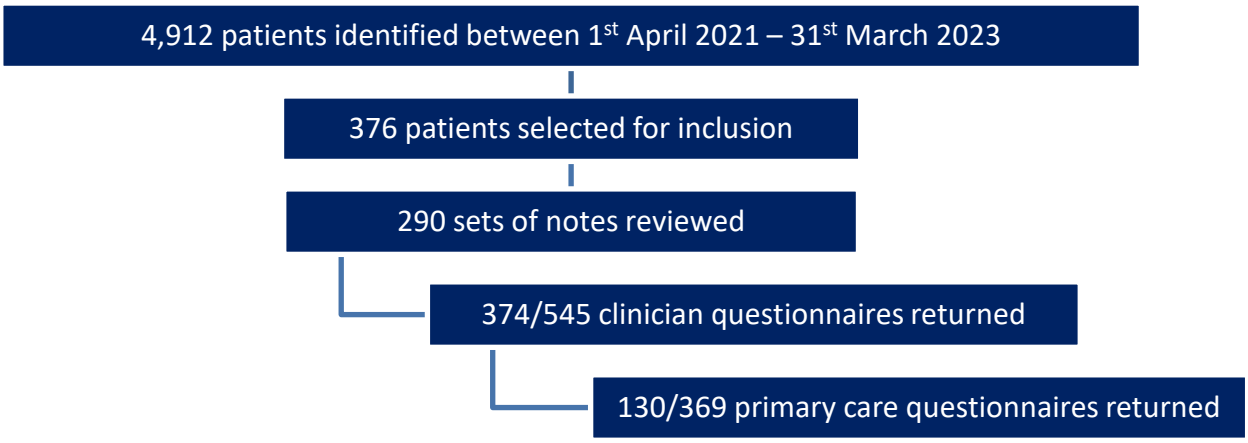

Figure 1.1 Data returned

Organisational data

Organisational questionnaires were returned from 122/145 (84.1%) trusts/health boards.

CHAPTER 2: SAMPLE POPULATION

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Previous research has shown JIA is slightly more common in females.[5,6] In this sample 194/290 (66.9%) patients were female and 96/290 (33.1%) patients were male. The age of patients at diagnosis sampled for inclusion ranged between 1 to 17 years (F2.1). The average age of females at diagnosis was 8.9 years and 10.4 years for males.

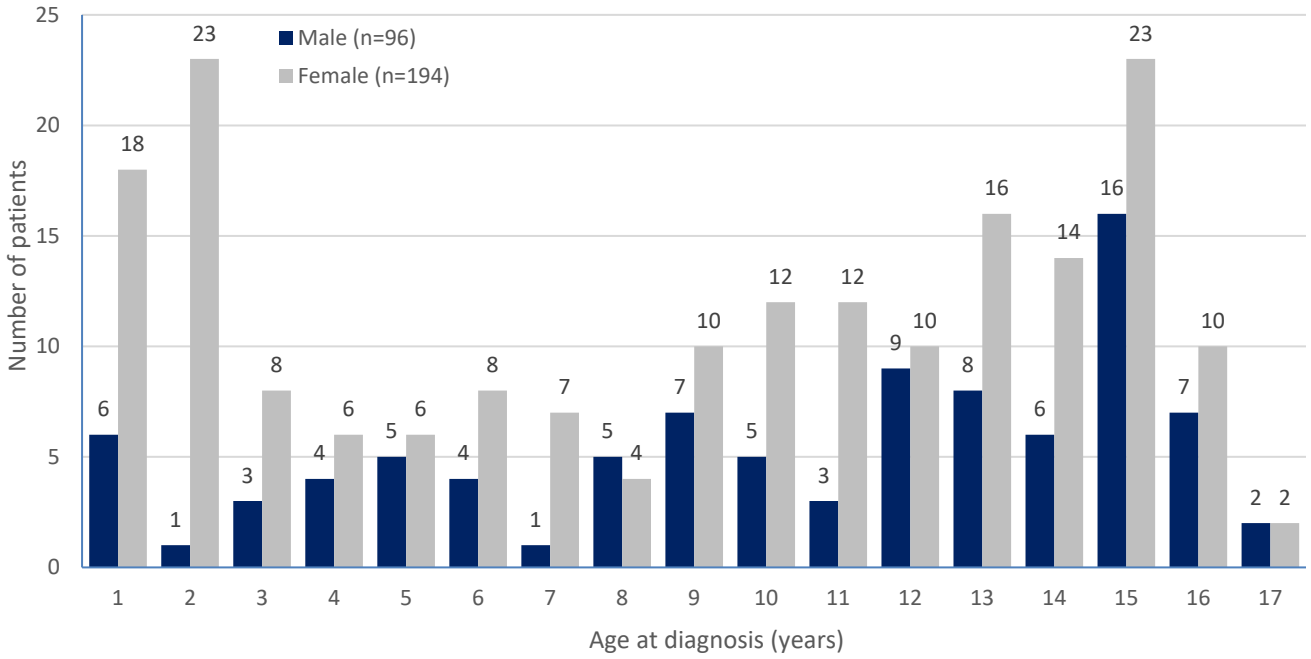

Figure 2.1 Age at diagnosis and sex (n=290)

Reviewer assessment form data

Table 2.1 shows the classification of JIA of patients sampled for inclusion in the study, showing that most patients had oligoarthritis (101/287; 35.2%). Of these, 81/101 had persistent oligoarthritis and 20/101 had extended oligoarthritis (unknown for 13).

Table 2.1 The classification of juvenile idiopathic arthritis of the included sample of patients

Classification of JIA	Number of patients	%
Persistent or extended oligoarthritis	101	35.2
Rheumatoid factor-negative polyarthritis	76	26.2
Psoriatic JIA	28	9.7
Enthesitis-related arthritis	25	8.6
Rheumatoid factor positive polyarthritis	22	7.6
Systemic-onset JIA	19	6.6
Other	14	4.8
Undifferentiated	5	1.7
Subtotal	**287**	
Unable to answer	3	
Total	**290**	

Reviewer assessment form data: answers may be multiple; n=287 (unknown for 3)

Table 2.2 shows the ethnicity of the study population. Previous research has shown the incidence of diagnosed JIA to be higher among children and young people of White ethnic group compared with Asian, Black and Mixed ethnic groups.[7]

Table 2.2 Ethnicity of the included sample of patients

Ethnicity	Number of patients	%
White British/White other	175	78.8
Asian/Asian British	33	14.9
Black/African/Caribbean/Black British	6	2.7
Mixed/Multiple ethnic groups	6	2.7
Other	2	<1
Subtotal	**222**	
Unknown	68	
Total	**290**	

Reviewer assessment form data

Healthcare inequalities

Reviewers found evidence of at least one characteristic associated with 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).

Table 2.3 Evidence in the notes of at least one characteristic of healthcare inequality or bias that impacted on the care provided

Health inequality that impacted on care	Number of patients	%
Yes	26	9.3
No	254	90.7
Subtotal	**280**	
Unable to answer	10	
Total	**290**	

Reviewer assessment form data

Deprivation

Figure 2.2 shows the index of multiple deprivation decile (IMDD) for all patients reported to NCEPOD and those subsequently sampled for inclusion in the clinical peer review process. People living in the most deprived areas (1 and 2) were slightly under-represented in the sample of patients included in the study, and those in the least deprived areas were slightly over-represented. Geographical organisation of services should consider that having inflammatory arthritis can be a significant financial burden with the cost of travel to multiple appointments for medical review, blood test monitoring and therapies. Additionally, appointments require a parent/carer to take time off work, which is not always sustainable.

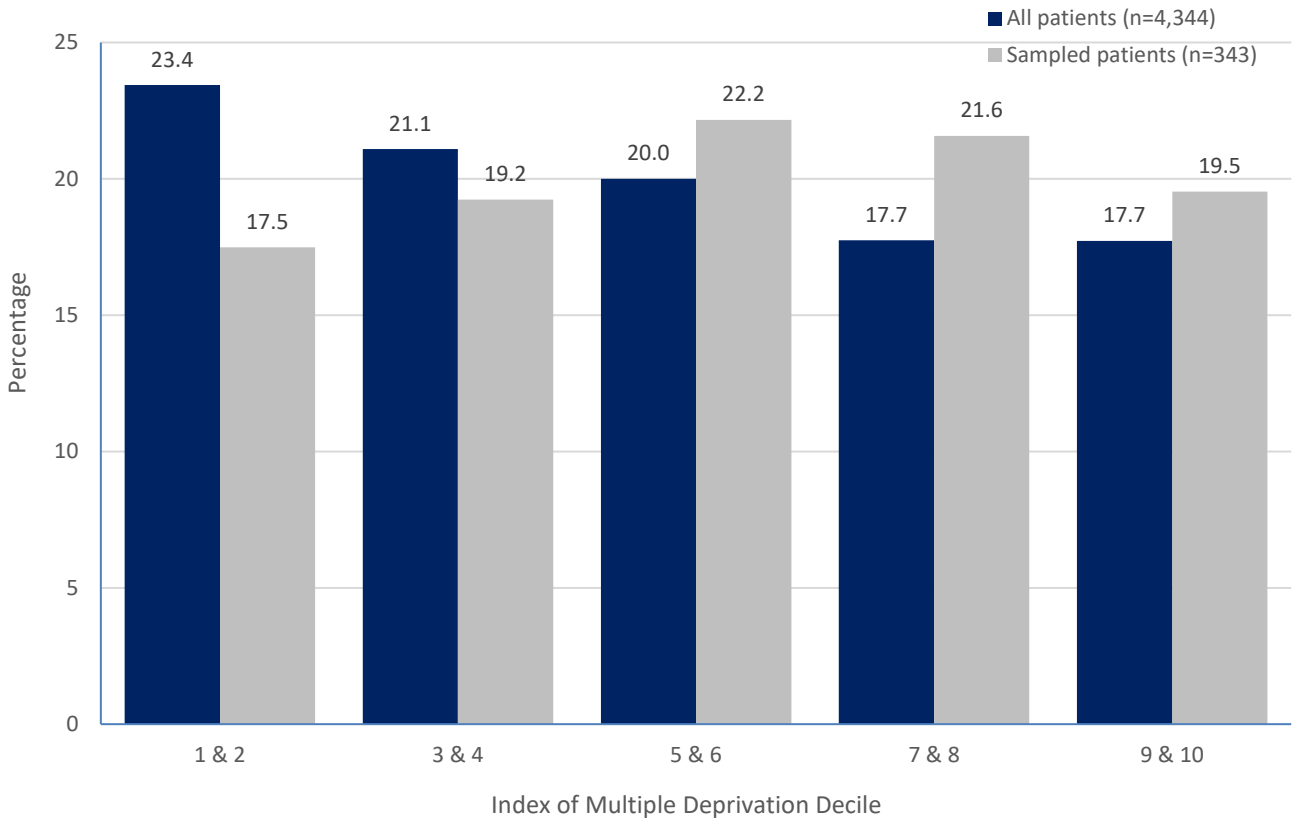

Figure 2.2 Index of multiple deprivation decile

Figure 2.3 shows that those patients in the lowest IMDD groups (1 and 2) were more likely to experience a delay in their first assessment by a rheumatologist than those in the highest groups (9 and 10) (IMDD 1 and 2 10/27; 37.0% vs. IMDD 9 and 10 7/33; 21.2%).

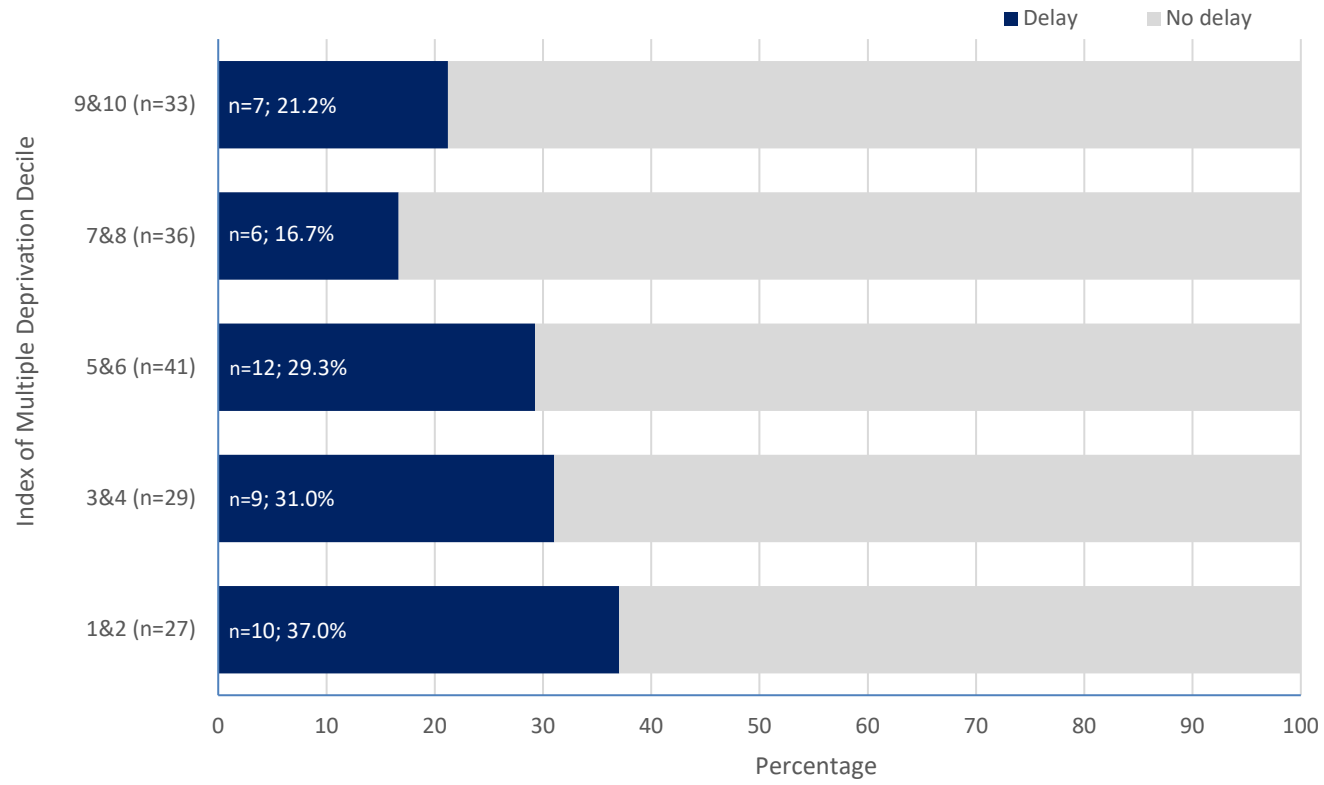

Figure 2.3 Index of multiple deprivation decile by delay in first assessment by a rheumatologist