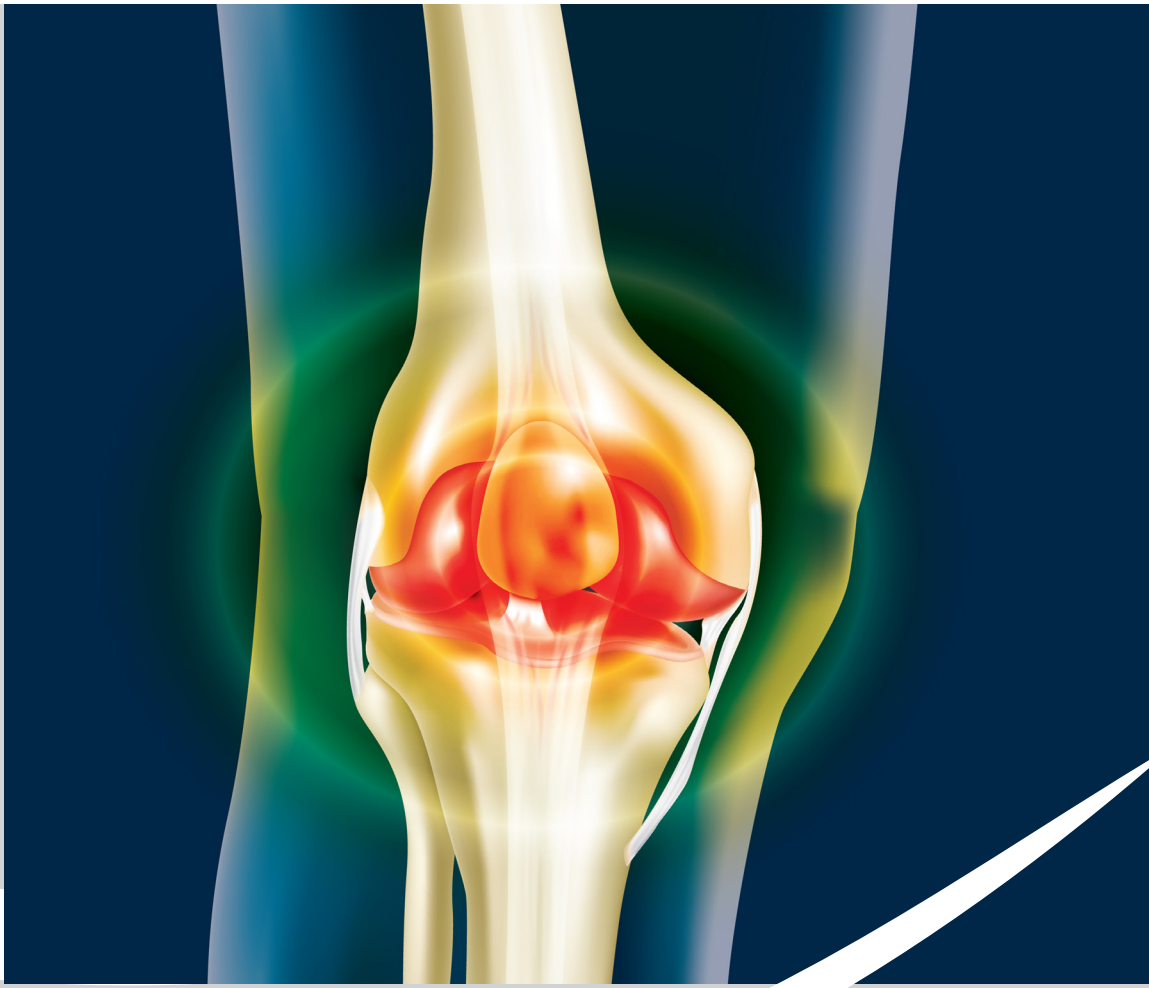
Joint Care?

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



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 10,000 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.

FOREWORD

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In an ideal world young people with juvenile idiopathic arthritis (JIA) would present soon after the onset of symptoms to a paediatric rheumatologist who would see them outside school hours alongside ophthalmology and psychology support, with a seamless transition to adult services when deemed developmentally appropriate. In practice the pathway is more complex, so healthcare providers need to think about how they can smooth the journey to minimise delays in starting treatment and detrimental effects on patients' education and mental health.

Young people with JIA present to a range of healthcare providers and fewer than half are currently seen by a rheumatologist within the recommended ten weeks. Training is essential to ensure that the symptoms are recognised and there should be processes in place for rapid direct referral to paediatric rheumatology services, reducing the number of steps and the time taken for referral. As there is no single recommended pathway, local services must work with patients and their carers to establish efficient local referral routes. Once a diagnosis has been made and treatment started, ongoing support from a range of healthcare services including ophthalmology, physiotherapy, occupational therapy and psychology should be in place and easily accessible.

Particular attention should be given to the transition from paediatric to adult care. As previous NCEPOD reports have demonstrated, embedding developmentally appropriate healthcare into all services, improving communication and co-ordination, involving patients and their parents or carers in transition planning, and providing strong leadership, are all essential to ensure that young people can transfer seamlessly to adult services without a break in care. And despite the term 'juvenile', defining when the disease was diagnosed, many do not stop having care for JIA as an adult.

This report highlights some excellent practice, which all providers should consider, such as evening appointments, combined rheumatology and ophthalmology clinics and combined paediatric and adult clinics for young people as they approach the age of 18. These, and the other recommendations in this report, provide a toolkit that providers can select from to improve services. National guidance and standards would be helpful and would enable further review and improvement in the quality of services provided for young people with JIA.

I'd like to finish by thanking everyone involved in the development of this report, including NCEPOD staff, the study advisory group, clinical co-ordinators, local reporters and clinicians, the authors who have worked so hard to produce the final report and the trustees for their support and guidance.

Dr Suzy Lishman CBE

NCEPOD Chair

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"

CHAPTER 1: 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.

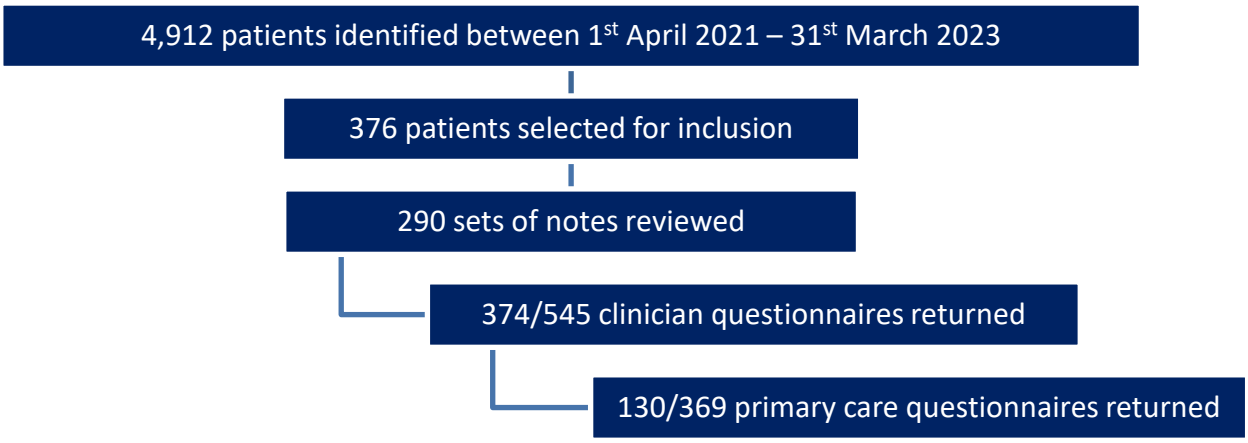

Figure 1.1 Data returned

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.

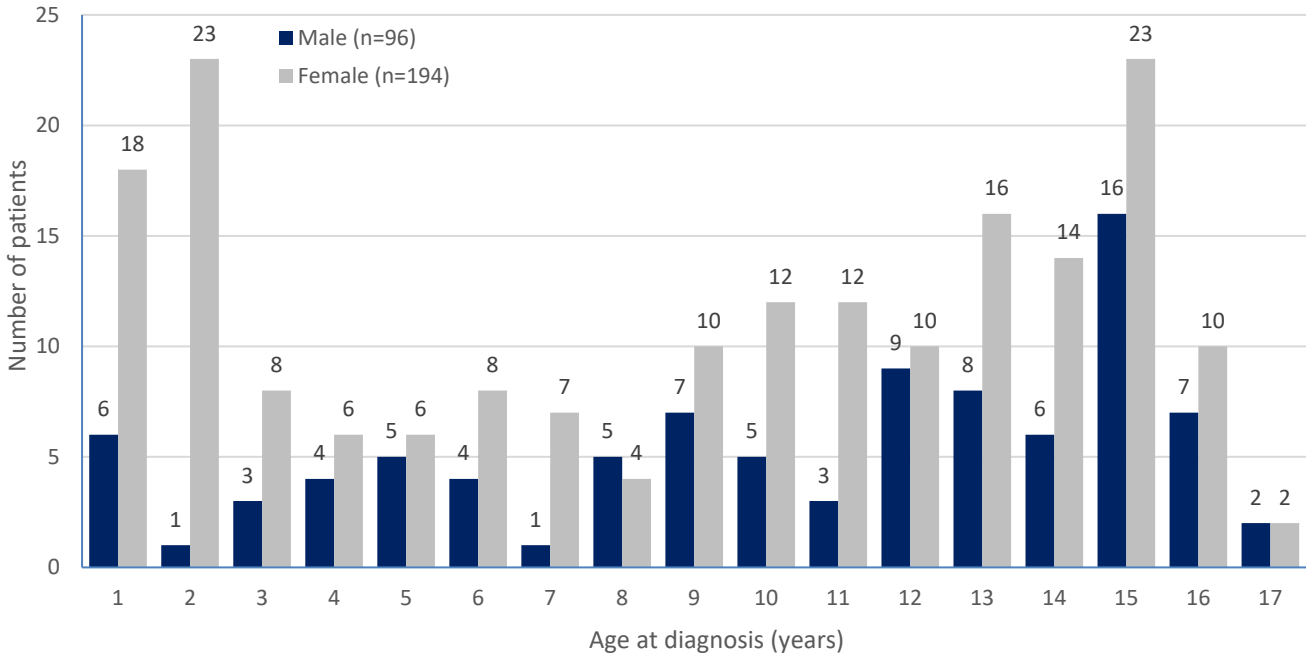

Figure 2.1 Age at diagnosis and sex (n=290)

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.

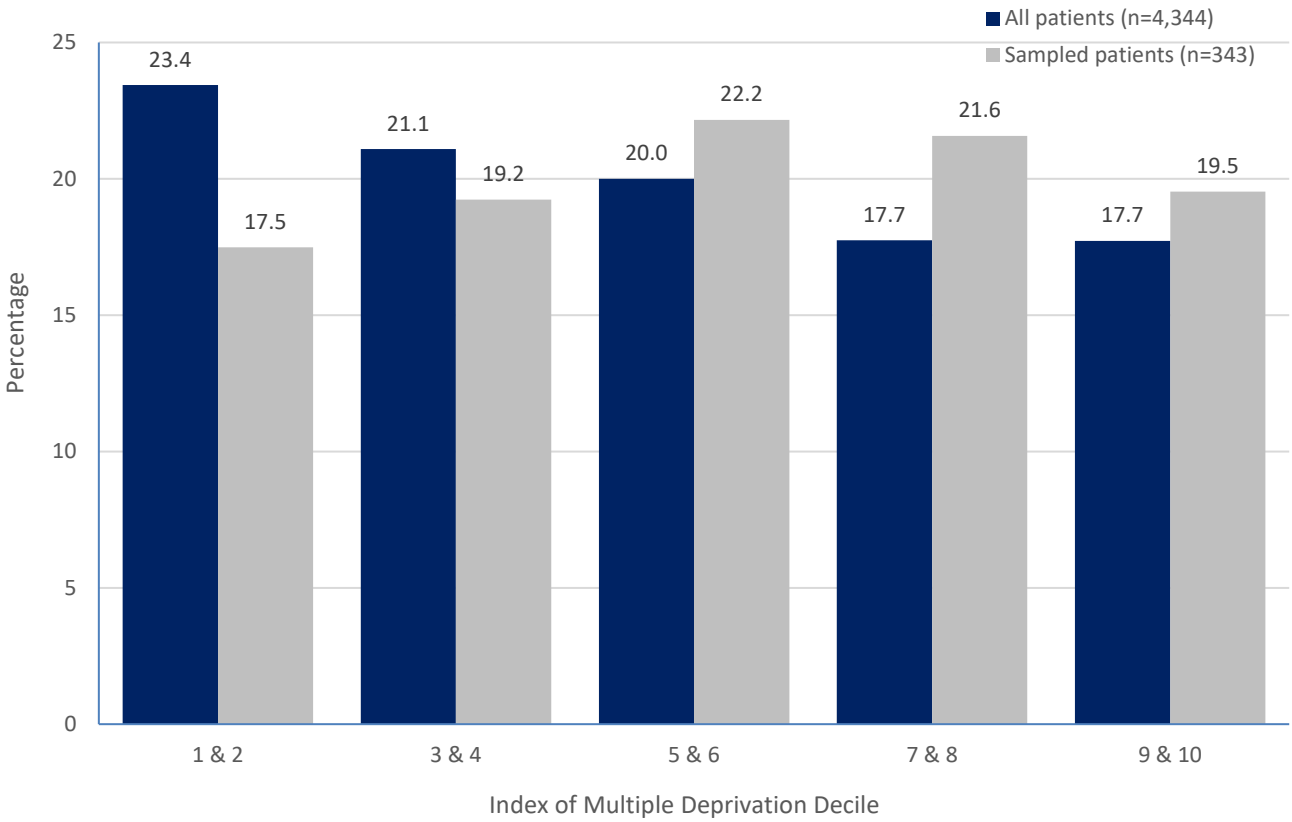

Figure 2.2 Index of multiple deprivation decile

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%).

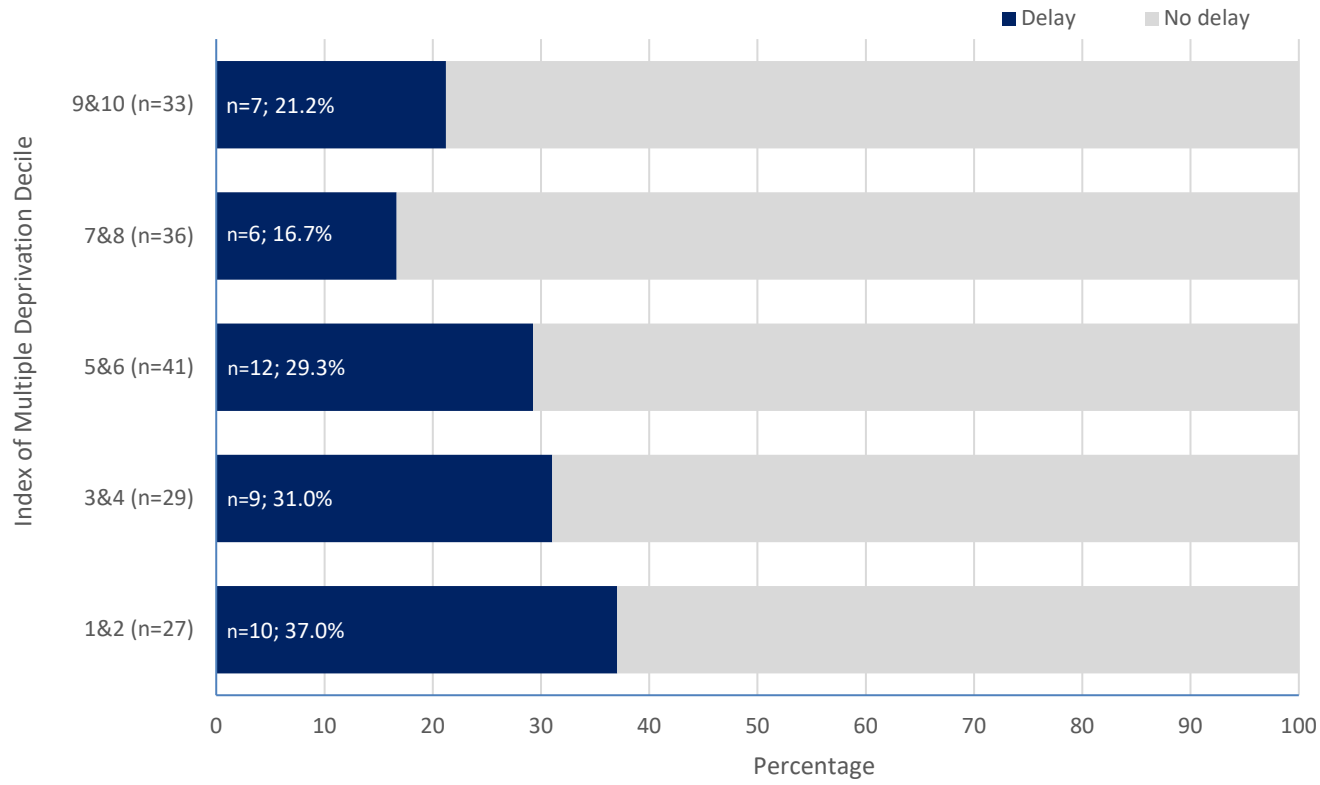

Figure 2.3 Index of multiple deprivation decile by delay in first assessment by a rheumatologist

CHAPTER 3: CARE PATHWAYS

(BACK TO CONTENTS)

Figure 3.1 demonstrates the many different routes of referral for patients with juvenile idiopathic arthritis (JIA). This chapter looks at how these variations may impact for better or worse on patient care.

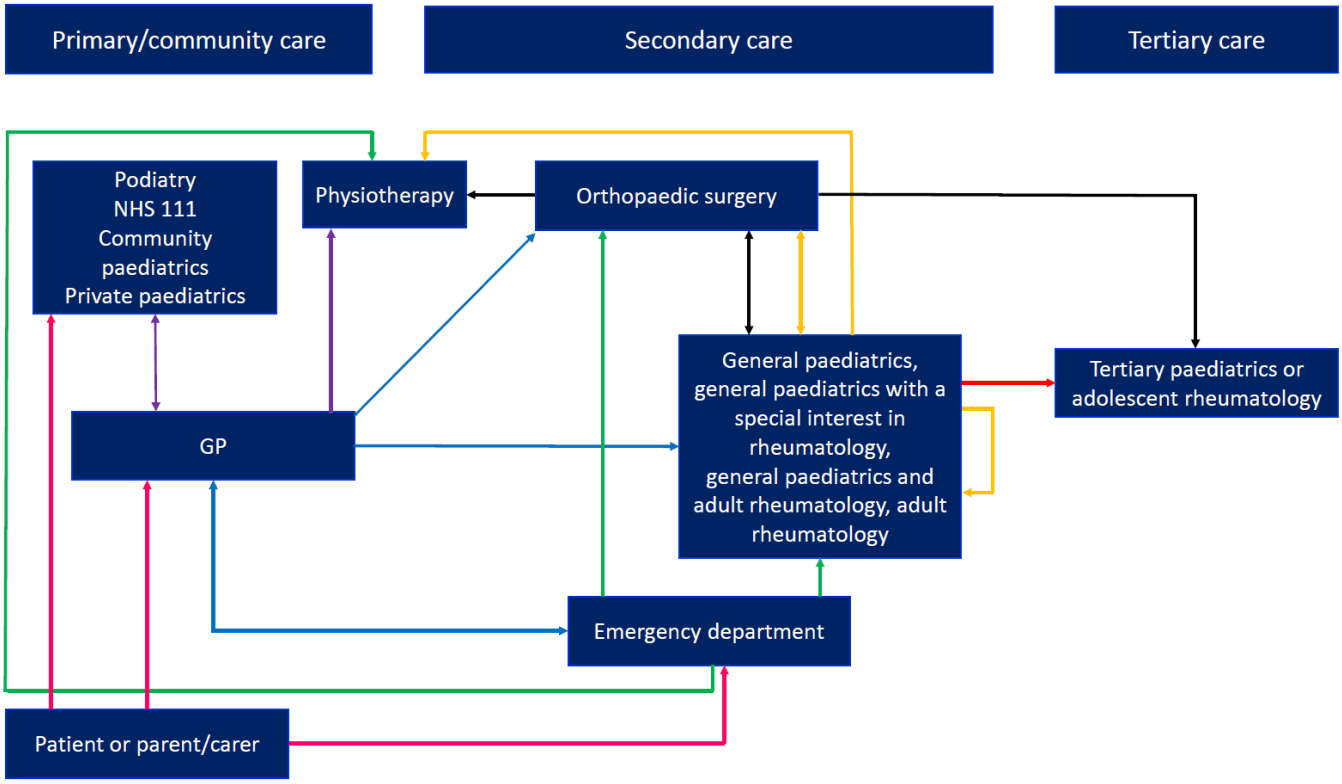

Figure 3.1 Example routes of referral to rheumatology

Regional variations not possible to capture

Initial presentation and referral to specialist services

The parent/carer surveys showed that many patients (41/68) were initially taken to either an urgent care facility or emergency department (T3.1). Other points of contact prior to the GP were NHS 111, podiatry or a community paediatrician. 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. Following assessment by the primary care clinician, only 12/58 patients were then referred directly to a rheumatologist.

Table 3.1 Specialties contacted by parents/carers before the diagnosis of juvenile idiopathic arthritis

Specialty	Number of patients
NHS hospital (urgent care or emergency department)	41
Physiotherapist	10
Private GP	6
Private hospital	5
Other	10
Not applicable - did not contact any of the above	11

Parent/carer survey data: answers may be multiple; n=68.

There were 8/13 young people, and 37/68 parents/carers who felt that there was a delay in the diagnosis of JIA being made.

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).

Table 3.2 The GP practice had a protocol for the investigation and care of JIA patients

GP protocol for JIA	Number of patients	%
Yes - for paediatrics	11	10.9
Yes - for adolescents	7	6.9
Yes - for adults	19	18.8
No	78	77.2

Primary care questionnaire data: answers may be multiple; n=101 (unknown for 23, not answered for 6)

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. Some of these criteria stated that investigations had to be done and results available prior to referral (9/21) but this was not thought to delay the referral process in many patients (14/22).

The reviewers found examples of situations where waiting for imaging to be undertaken or blood test results to be communicated did delay the referral process. Waiting for results before referral could cause unnecessary on-going pain and poor quality of life as well as potential joint damage in patients awaiting a diagnosis and appropriate treatment. Test results add evidence to support a diagnosis, although JIA cannot be diagnosed on blood tests or imaging alone. It should also be noted that not all rheumatology services would take primary care referrals.

CASE STUDY 1

A 13-year-old saw their GP with a three-month history of multiple joint pains. The GP organised blood tests and magnetic resonance imaging (MRI) and ultrasound scans (USS). Initial blood tests showed raised inflammatory markers and a positive antinuclear antibody (ANA) result. The patient was not seen by the paediatric rheumatology team until four months later, once the imaging had been undertaken, which confirmed joint inflammation.

Reviewers stated that the assessment and management was delayed by the GP following a local protocol and waiting for the results of investigations.

Assessment in secondary care

Organisational data indicated that 110/122 (90.2%) hospitals provided rheumatology care to children and young adults with JIA (T3.3). Despite services being available (T3.4), the data showed that not all of them were specially commissioned services. Adolescent rheumatology was less frequently commissioned, even though a diagnosis was often made during adolescent years (F2.1); this variation in commissioning may be due to adolescent patients being seen by paediatricians or adult specialists (paediatric 33/52; adolescent 16/41; adult 32/45) (T3.5). Commissioning will impact on the resource available for patients and the availability of medications to treat patients.

Table 3.3 The organisation provided rheumatology care to children and young adults with JIA

Rheumatology care provided	Number of hospitals	%
Yes - in paediatric services	89	73.0
Yes - in adolescent services	49	40.2
Yes - in adult services	68	55.7
No	12	9.8

Organisational questionnaire data: answers may be multiple; n=122

Table 3.4 The rheumatology service was commissioned

Commissioned rheumatology service	Paediatrics	Adolescents	Adults with JIA
	Number of hospitals	Number of hospitals	Number of hospitals
Yes	33	16	32
No	19	25	14
Subtotal	**52**	**41**	**46**
Unknown	28	12	22
Total	**80**	**53**	**68**

Organisational questionnaire data

According to NHS England specialist services quality dashboards,[8] patients should be seen within ten weeks of onset of symptoms and within four weeks of referral. However, the clinician survey revealed that only 42/101 (41.6%) clinicians saw patients within these specified time frames.

Reviewers found that the time from first presentation to GP to first assessment by a specialist in secondary care was variable. The longest a patient waited was 175 weeks, while 34/67 patients were seen within six weeks, and 45/67 within 10 weeks (F3.2).

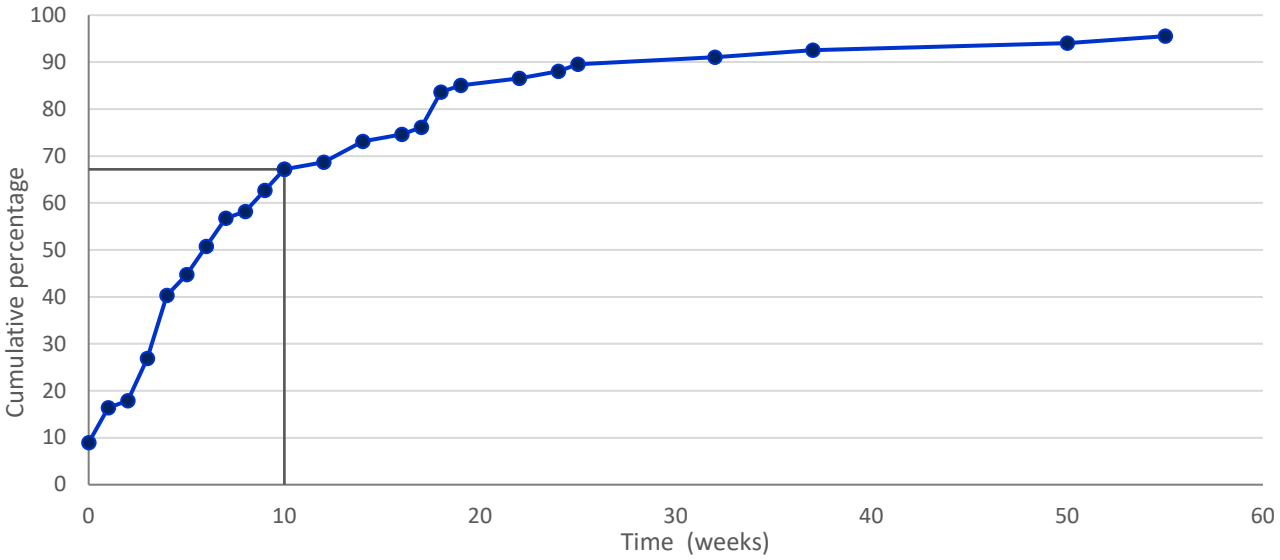

Figure 3.2 Time from first presentation to GP to first assessment following referral (weeks) (n=67) (data not shown for three patients) *Reviewer assessment form data: line at ten weeks*

Figure 3.3 shows the time from first presentation to GP to first assessment by a rheumatologist. 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).

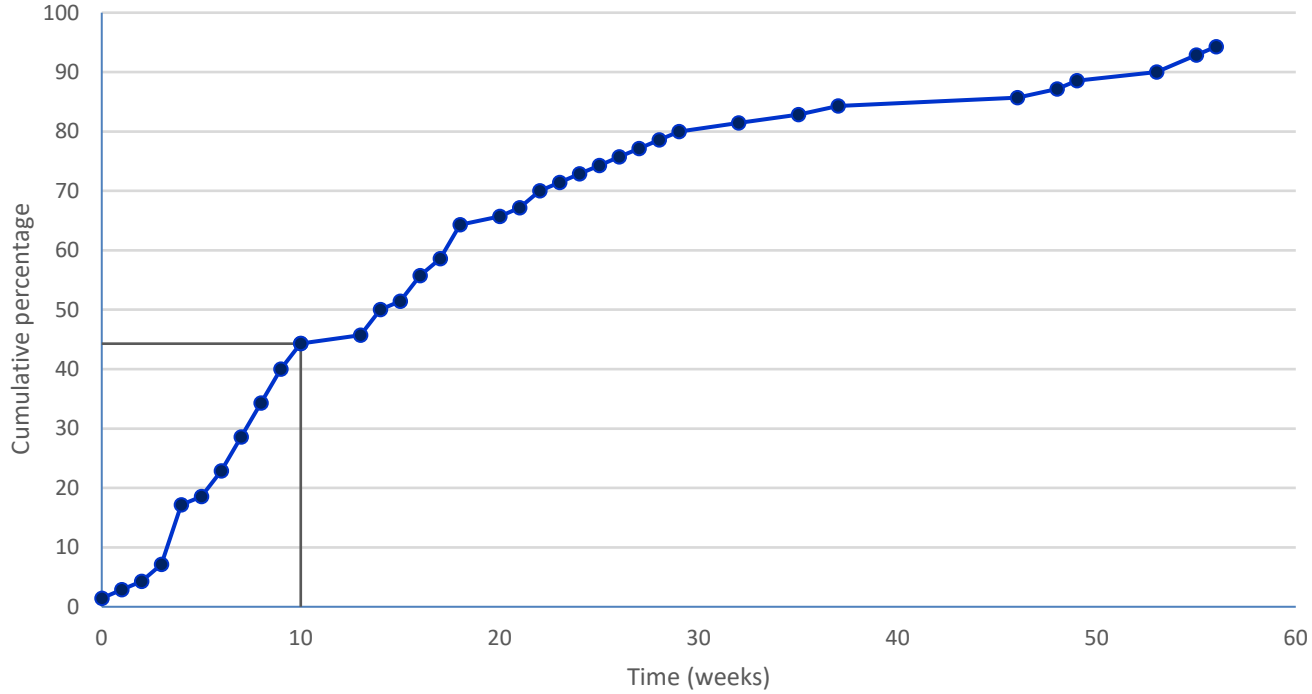

Figure 3.3 Time from first presentation to GP to date of first assessment by a rheumatologist (weeks) (n=70) (data not shown for four patients) *Reviewer assessment form data: line at ten weeks*

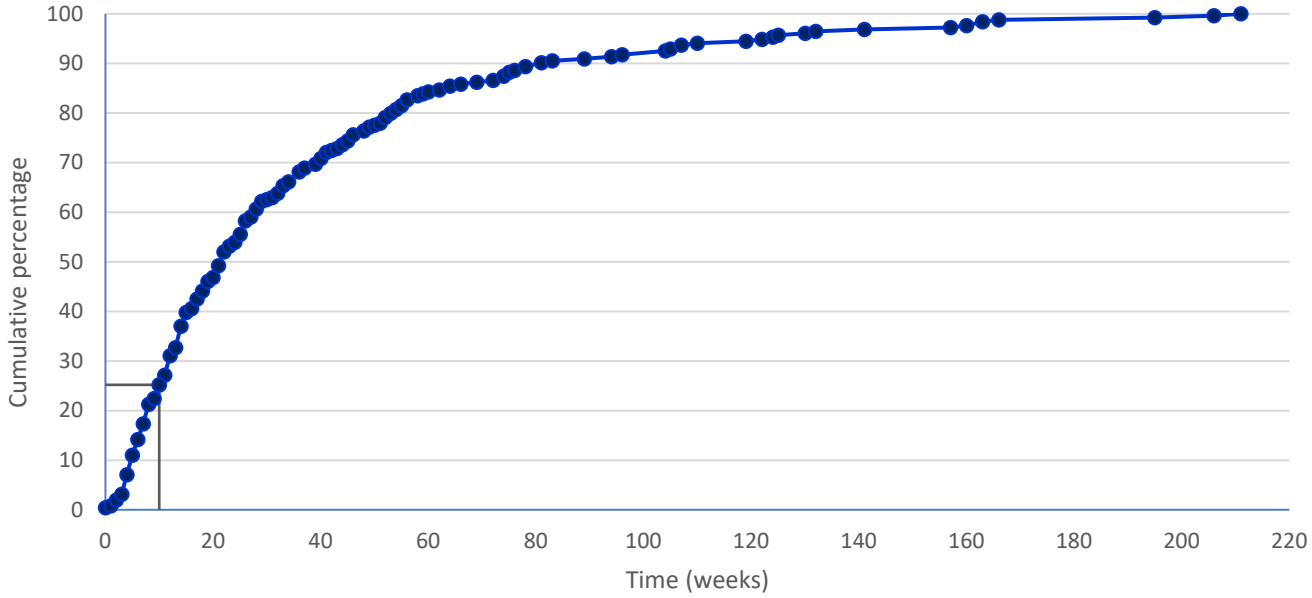

Figure 3.4 Time from symptoms starting to first assessment by a rheumatologist (weeks) (n=254)
Reviewer assessment form data: line at ten weeks

It was generally reported that the referral process caused delay in assessment and diagnosis. Patients were frequently seen to 'bounce' between primary care and various specialties, and then back to primary care before being seen by rheumatology services. 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).

Table 3.5 Reasons for delay in referral

Reason	Number of patients
Referral sent to the wrong specialty	37
Waiting for investigations	22
Patient or parent/carer factors (e.g. taking time to research the treatment; appointment cancelled by the patient or parent/carer)	12
Pathway error	11
Service capacity	8
Differential diagnosis	5
Administration error	4
Other	9

Reviewer assessment form data: answers may be multiple; n=77 (unable to answer for 16)

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).

Table 3.6 Specialty service the patient was initially referred to

Specialty	Number of patients
General paediatrics	31
Orthopaedics	11
Paediatric rheumatology	10
Rheumatology	8
Emergency department	3
Ophthalmology	1
Total	**64**

Primary care questionnaire data

Reviewers indicated that the specialty of the clinician undertaking the first review following referral was not appropriate for 45/280 (16.1%) patients. Within this group, reviewers found that referral to orthopaedic specialties was only appropriate in 18/40 (45.0%) patients. They also stated that patients were wrongly assessed initially by an adult rheumatologist in 6/25 (24.0%) cases and by a general paediatrician in 17/85 (20.0%) (F3.5). Initial assessment by the wrong specialist could potentially lead to a delay in diagnosis.

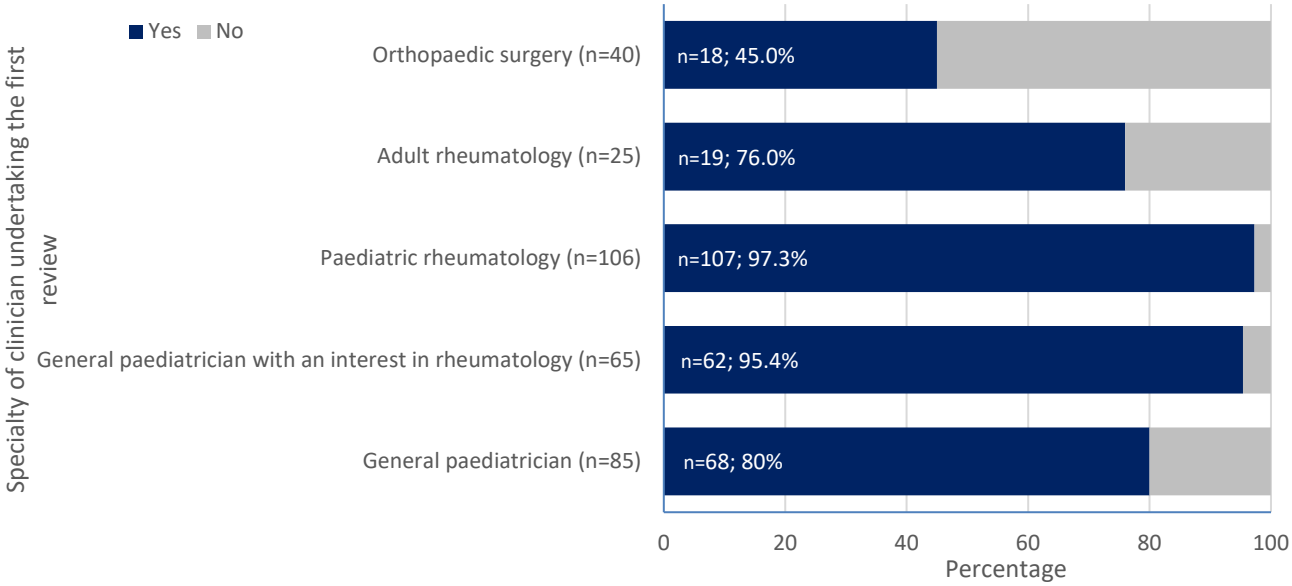

Figure 3.5 Specialty of the clinician undertaking the first review and whether the speciality was appropriate
Reviewer assessment form data

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).

Table 3.7 How the patient was referred to rheumatology

Referral process	Number of patients	%
Via general paediatrics	113	41.2
Via general practitioners	98	35.8
Via orthopaedic surgeons	81	29.6
Via the emergency department	26	9.5
Via physiotherapy	8	2.9
Via an independent organisation	7	2.6
Via ophthalmology	3	1.1
Other	10	3.6

Reviewer assessment form data: answers may be multiple; n=274 (unknown for 16)

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).

Table 3.8 Delay between first presentation with symptoms and referral to rheumatology

Delay	Clinical questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	129	46.4	108	43.0
No	149	53.6	143	57.0
Subtotal	**278**		**251**	
Unknown/Unable to answer	23		39	
Total	**301**		**290**	

Clinical questionnaire and reviewer assessment form data

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%). This may demonstrate that there was no clear pathway for referral, or poor training regarding inflammatory arthritis amongst paediatric and adult orthopaedic surgeons but may also be influenced by a less clear diagnosis.

CASE STUDY 2

An 11-year-old presented to primary care with swelling and pain in an ankle joint and was referred by the GP to the orthopaedic service, as the patient had a history of minor trauma thought to have precipitated the symptoms. An X-ray showed no fracture but an effusion. When seen by orthopaedics they had pain and swelling in their ankle and wrist. Further X-rays were requested, which showed no bone injury. The patient had ultrasound and magnetic resonance imaging scans of their left ankle and wrist. As the results showed inflammation they were referred to paediatric rheumatology, and treatment with oral prednisolone and methotrexate was initiated.

The reviewers stated that joint swelling and pain should prompt referral to rheumatology but that this was delayed by the initial referral to orthopaedics. There was a further delay by the orthopaedic team, which should have referred to rheumatology services sooner.

Assessment for uveitis

People with JIA can develop uveitis, a condition that causes inflammation inside part of the eye, which, if left untreated, can cause permanent vision loss. Therefore, all patients diagnosed with JIA should be referred to an ophthalmologist for an assessment for uveitis within six weeks of diagnosis.

Time to see an ophthalmologist will be influenced by the availability and convenience of ophthalmology clinics. 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).

Table 3.9 Ophthalmology clinics held for patients with JIA

Ophthalmology clinics	Paediatrics	Adolescents
	Number of hospitals	Number of hospitals
Yes - combined clinics	12	8
Yes - same day clinics	6	5
Yes - another clinic	1	2
No - separate clinic	46	26
Total	**65**	**41**

Organisational questionnaire data: adult data not shown; answers may be multiple

The prevalence of uveitis in patients with JIA is 11-38%[10] but can be 45-57% in young onset oligoarticular JIA.[11] In the study population, 34/357 (9.5%) patients had been diagnosed with uveitis. Uveitis in JIA is generally asymptomatic and so patients may not be aware that they have the disease or that they need an ophthalmology assessment. Despite this, the clinician's survey revealed that not

all clinicians referred patients directly to an ophthalmologist at the point of diagnosis of JIA (15/99). The main reason given was that the ophthalmologist only reviewed patients aged over 16 years, or who had transferred from the paediatric service (13/15). Similarly, the reviewers found that 233/282 (82.6%) patients were referred to ophthalmology at diagnosis. 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. There was evidence in the notes that 188/258 (72.9%) patients had on-going ophthalmology assessments. This may not be necessary for all patients as assessment is determined by age at diagnosis and the subtype of JIA.

CASE STUDY 3

A 15-year-old was referred to adolescent rheumatology with a history of right knee and right elbow pain and swelling. Inflammatory arthritis was diagnosed. The patient had to travel for two hours to attend a clinic in a tertiary centre. Additionally, as they were approaching exams in year eleven, they were reluctant to miss school for appointments. The hospital policy ensured that the patient was able to have their eyes screened for uveitis on the same day as the rheumatology clinic appointment.

The case reviewers thought this was an excellent example of having services configured to optimise patient engagement and attendance.

Arrangements between secondary and tertiary services

Shared care

The structure of shared care arrangement across clinical networks depends on many factors including historical structures and relationships, geographical locations, and commissioning arrangements. The most common arrangement was between secondary and tertiary centres, whereby the secondary care hospitals provide a review in a crisis, on-going assessment, education, prescription of medications and blood test monitoring. Patients also attend a tertiary centre for diagnosis or confirmation of diagnosis, treatment initiation, more specific management, and provision of biologics if the secondary centre is not commissioned. There were 59/94 hospitals in which shared care was provided in this format. There were 38/94 hospitals in which there was an arrangement whereby the tertiary care rheumatologist provided an outreach service within the secondary care hospital (T3.10).

Table 3.10 Hospital provided shared care for patients with JIA

Shared care	Secondary care	Tertiary care	Community care
	Number of hospitals		
Yes - with tertiary care (ongoing care at local hospital and paediatric rheumatologist in tertiary centre)	59	6	5
Yes - with tertiary care (tertiary care provides an outreach clinic at local hospital)	38	4	2
Yes - with secondary care (ongoing care at local hospital and paediatric rheumatologist in tertiary centre)	23	13	3
Yes - with secondary care (tertiary care provides an outreach clinic at local hospital)	21	13	0
No	16	4	0

Organisational questionnaire data: secondary care n=96; tertiary care n=22; community care n=7

Shared care benefits patients as it means fewer appointments. Additionally, having a shared care agreement so that the patient does not need to travel to the tertiary centre also reduces the time to travel. The clinical questionnaire data demonstrated that 34/167 (20.4%) patients travelled for two hours to a tertiary centre compared with 7/216 (3.2%) patients to a secondary care centre (T3.11).

Table 3.11 How long it took the patient to travel to access rheumatology services

Duration	Secondary care		Tertiary care		Community care
	Number of patients	%	Number of patients	%	Number of patients
<1 hour	50	23.1	21	12.6	0
1 hour	154	71.3	104	62.3	1
2 hours	7	3.2	34	20.4	0
3 hours	3	1.4	6	3.6	0
≥4 hours	0	0.0	2	1.2	0
Other	2	0.9	0	0.0	1
Subtotal	**216**		**167**		**2**
Unknown	13		11		0
Total	**229**		**178**		**2**

Clinical questionnaire data

Within the secondary care centres there was considerable variability in the role and skillset of the clinician who initially assessed the patient, according to the organisational data (T3.12). The level of training the clinicians have in paediatric and adolescent rheumatology is unclear and may impact on time to diagnosis and appropriate ongoing referral and treatment.

Table 3.12 First specialty review in secondary care – organisational policy

Specialty	Number of hospitals
Adult rheumatologist	54
General paediatrician with an interest in rheumatology	48
Paediatric rheumatologist	27
General paediatrician	22
Other	13

Organisational questionnaire data: answers may be multiple; n=96

These data contrasted with the reviewer data, in that most patients were seen by a paediatric rheumatologist (106/288; 36.8%), while general paediatricians saw 89/288 (30.9%) patients and 65/288 (22.6%) were seen by a general paediatrician with an interest in rheumatology (T3.13).

Table 3.13 First specialty review in secondary care as documented in the case notes

Specialty	Number of patients	%
Paediatric rheumatologist	106	36.8
General paediatrician	89	30.9
General paediatrician with an interest in rheumatology	65	22.6
Orthopaedic surgeon	43	14.9
Adult rheumatologist	18	6.3
Adolescent rheumatologist	2	<1
Other	11	3.8

Reviewer assessment form data: answers may be multiple; n=290

Considering different aspects of JIA care, most hospitals had a service involved with making the diagnosis of JIA (88/110; 80.0%), the ongoing rheumatology care (106/110; 96.4%) and treatment (99/110; 90.0%) (T3.14).

Table 3.14 Aspects of JIA care that the hospital has a service for

JIA service	Number of hospitals	%
Making the diagnosis of JIA	88	80.0
The ongoing rheumatology care of the young person	106	96.4
Treatment	99	90.0
Community therapy or community nursing services	39	35.5
Other	4	3.6

Organisational questionnaire data: answers may be multiple; n=110

Access to care

Access to care can be an ongoing issue and adds to delay in recognition of disease and appropriate treatment. Organisational data demonstrated that all (80/80) hospitals held paediatric clinics during conventional office hours of Monday to Friday 8am to 6pm, and 48/51 for adolescent clinics. Three hospitals running rheumatology clinics for adolescents held an evening clinic (T3.15).

Table 3.15 When rheumatology clinics were held

Availability of rheumatology clinics	Paediatric	Adolescent
	Number of hospitals	Number of hospitals
Normal working hours (Monday to Friday, 8am to 6pm)	80	48
Evenings	0	3
Saturdays	1	1
Sundays	0	0
Other	0	0

Organisational questionnaire data: answers may be multiple; paediatric n=80; adolescent n=51; adult data not shown

Access to acute care

When patients experience a flare of symptoms it is crucial for them to be able to access a clinician for urgent assessment. There were 76/110 (69.1%) hospitals in which there was no dedicated urgent access for patients with JIA (T3.16). It was not possible to determine from the data whether some of these hospitals had dedicated additional clinic slots for urgent review, but this may be a possibility. Most patients (310/349; 88.8%) had a named rheumatologist documented in the case notes.

Table 3.16 The hospital had a dedicated urgent access clinic for patients with JIA

Urgent access clinic	Number of hospitals	%
No	76	69.1
Yes - for paediatrics	18	16.4
Yes - for adolescents	17	15.5
Yes - for adults with JIA	14	12.7

Organisational questionnaire data: answers may be multiple; n=110

CHAPTER 4: ADOLESCENT SERVICES AND TRANSITION

(BACK TO CONTENTS)

Adolescence is a key stage in a young person's development. Young people are adapting to physical changes as they go through puberty and accepting their own body shape and image is often a challenge, which may also be affected by inflammatory disease caused by JIA. Mental ill health and risk-taking, including non-adherence to medications is common among adolescents, therefore keeping young people well informed and involved in their care is key to ensuring that their treatment continues effectively as they transition from child to adult healthcare.

Data from the organisational questionnaire showed that written protocols, pathways or guidelines were less common in hospitals for adolescents than younger children (30/109; 27.5% vs 54/109; 49.5%) and used even less common for adults (27/109; 24.8%) (T4.1). The age at which the adolescent protocol, pathway or guidance was initiated was not uniform, starting at 12, 13 or 16 years old and finishing at 18, 20 or 24 years.

Table 4.1 A written protocol, pathway or guideline for the investigation and treatment of patients with JIA

JIA protocol	Number of hospitals	%
Yes - for paediatrics	54	49.5
Yes - for adolescents	30	27.5
Yes - for adults	27	24.8
No	42	38.5

Organisational questionnaire data: answers may be multiple; n=109 (unable to answer for 13)

The environment in which adolescents are seen can impact on how well they engage in their care. Adolescents were rarely seen in age-appropriate environments. Just 48/101 (47.5%) clinics for adolescents occurred in an age-appropriate environment. Online platforms to communicate and remote consultations can be a good option for engagement. However, 18/104 (17.3%) hospitals offered no option for this for any patients.

The clinician questionnaire showed that adolescents were slightly more likely to miss appointments than children under 13 years of age (39/134; 29.1% vs 40/179; 22.3%) (T4.2).

Table 4.2 Missed rheumatology appointments by age on 31st March 2023

Missed appointments	≤12 years		≥13 years	
	Number of patients	%	Number of patients	%
Yes	40	22.3	39	29.1
No	139	77.7	95	70.9
Subtotal	**179**		**134**	
Unknown	19		17	
Total	**198**		**151**	

Clinical questionnaire data

Transition

Transition describes the continuum of service planning, delivery and patient engagement as young people move to adult health services. It is important that they understand their disease and become

empowered in managing it, taking away the responsibility from parents or carers. Transition is dependent on developmentally appropriate healthcare, which means adapting services to optimise patient engagement and adherence. A previous NCEPOD report 'The Inbetweeners' looked at the facilitators and barriers to a good transition in young people with chronic health conditions.[4]

A dedicated transition process was present in 76/103 (73.8%) hospitals with 51/60 hospitals following NICE guidance for transition.[12] Transition clinics with staff from both paediatric and adult services were held in 59/104 (56.7%) hospitals. Despite transition processes being in place, the evidence of developmentally appropriate healthcare was lacking. 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. This is relevant as many young people with JIA are on medications that can cause birth defects so a discussion about birth control is vitally important. 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.

Table 4.3 Evidence of developmentally appropriate healthcare in the case notes for patients aged ≥13 years

Evidence	Number of patients	%
There had been a discussion of transfer to adult services	42	36.8
Clinic letters were addressed to the young person	28	24.6
A combined appointment with paediatric and adult rheumatology	25	21.9
Wider psychosocial aspects had been addressed	23	20.2
The patient was given the opportunity to be seen alone	22	19.3
'Ready Steady Go' or equivalent documentation had been used	16	14.0
A key worker was named	9	7.9
A transition co-ordinator was in place	8	7.0
There were opportunities to attend clinics out of school hours	2	1.8
None of the above	36	31.6

Reviewer assessment form data: answers may be multiple; n=114 (unable to answer for 3)

According to the GP questionnaire, despite 61/101 (60.4%) patients being over 13 years old, the GP was only involved in transition planning for just one patient.

CASE STUDY 4

A 14-year-old with finger pain was referred from orthopaedic services to the general paediatric service. They were found to have inflammation in the finger so were referred to tertiary paediatric rheumatology. They were seen within three weeks by which time they had right knee pain and swelling as well as back pain. They were diagnosed with enthesitis-related JIA and treatment was initiated. At the tertiary centre they were seen in the adolescent clinic where transition was discussed from the initial appointment, and then moved into young adult care at the same hospital where they had met the adult team during previous visits.

The reviewers felt that this was an excellent example of a good transition.

CHAPTER 5: ACCESS TO MEDICATIONS

(BACK TO CONTENTS)

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).

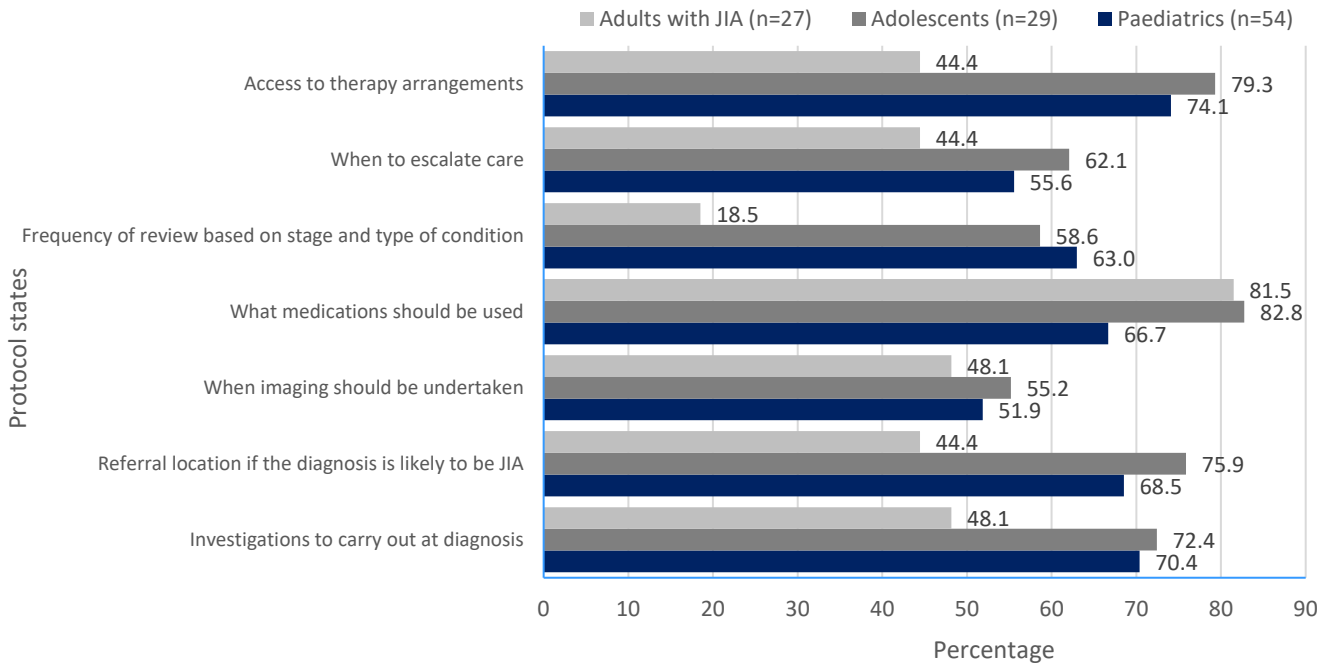

Figure 5.1 What hospital JIA protocols were stated

Organisational questionnaire data: answers may be multiple; paediatrics n=54; adolescents n=29; adults n=27

Treatment for JIA was reasonably standard, with non-steroidal anti-inflammatory drugs (NSAIDs) being the most widely used and most initiated within primary care, followed by intra-articular steroid joint injections administered in secondary or tertiary centres (F5.2 and F5.3).

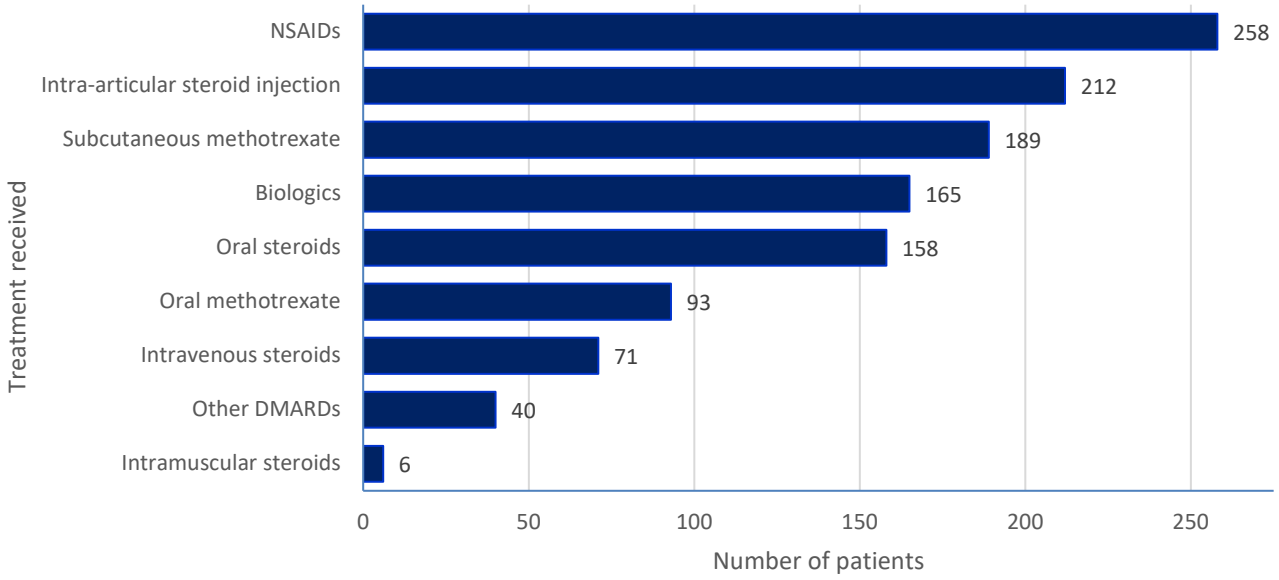

Figure 5.2 Treatment received (up to 31st March 2023)

Clinical questionnaire data: answers may be multiple; n=337

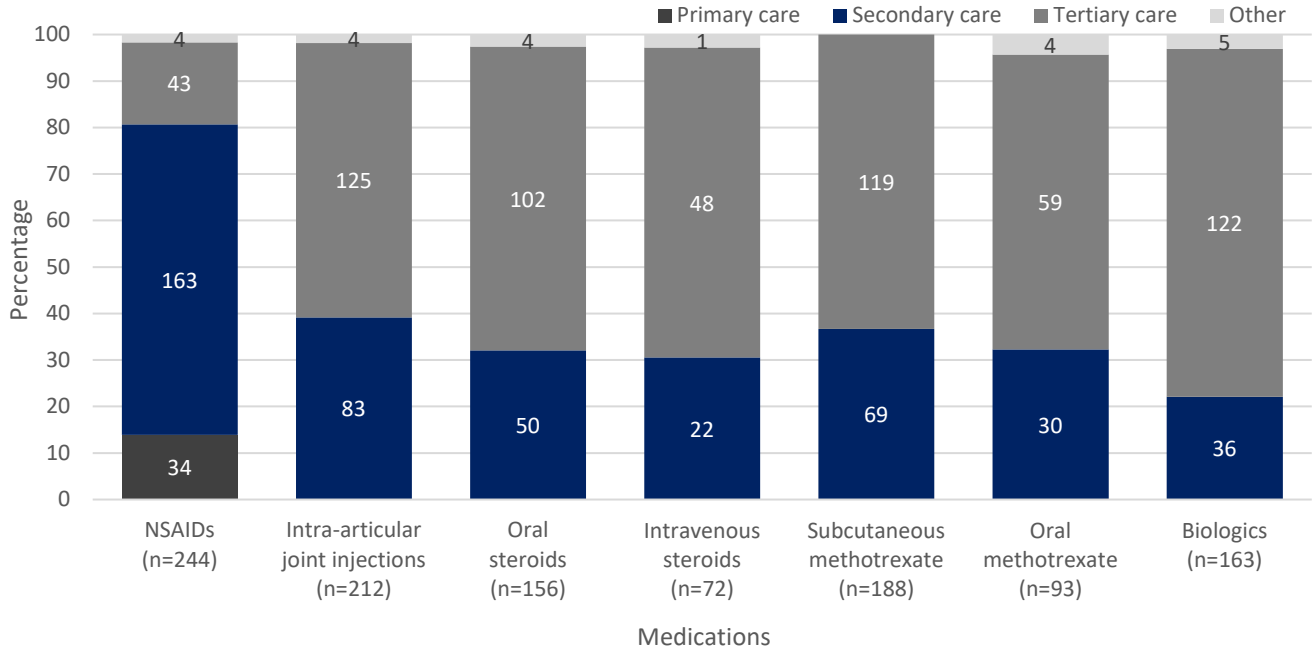

Figure 5.3 Medications received by location of initiation

Clinical questionnaire data

Biologics were most frequently commissioned in tertiary centres for all age groups (T5.1).

Table 5.1 Hospital was commissioned to prescribe biological treatments for patients with JIA

Biologics prescribed	Secondary care Number of hospitals	Tertiary care Number of hospitals	Community care Number of hospitals
Yes - for paediatrics	24	16	2
Yes - for adolescents	25	17	1
Yes - for adults with JIA	57	16	3
No	23	1	3

Organisational questionnaire data: answers may be multiple; secondary care n=89 (unknown for 7); tertiary care n=22; community care n=7

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.

Table 5.2 Number of medication delays

Number	Number of patients	%
0	192	68.3
1	58	20.6
2	24	8.5
3 or more	7	2.5
Subtotal	**281**	
Unable to answer	9	
Total	**290**	

Reviewer assessment form data

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). In addition, 58/106 (54.7%) respondents to the clinician survey indicated that they thought there were delays in the initiation of treatments. 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).

The most delayed medications were intra-articular steroid injections (46/185; 24.9%), subcutaneous methotrexate (32/158; 20.3%) and subcutaneous biologics (23/124; 18.5%) (F5.4). Reasons included co-ordination of appointments, and availability of medications, e.g. liquid methotrexate is often not stocked, particularly in district general hospitals. It is important to note that any delay in medication can result in a flare of inflammation ultimately leading to joint destruction.

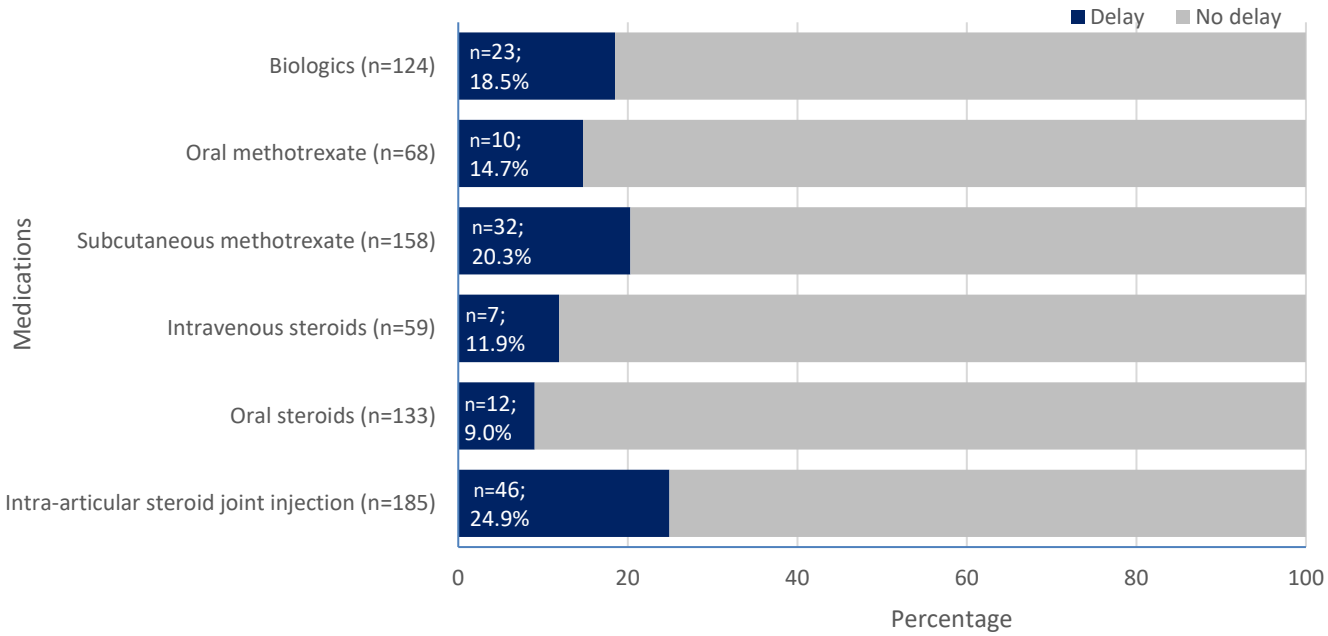

Figure 5.4 Evidence in the case notes of delays in treatment

Reviewer assessment form data

CASE STUDY 5

A 15-year-old with right knee pain and swelling was referred by the GP to a general paediatric clinic. The paediatrician organised magnetic resonance imaging (MRI) of the knee, requested blood tests for an autoimmune screen, initiated treatment with naproxen and made a referral to the adolescent rheumatology service in the same secondary care hospital. The paediatrician with a special interest in rheumatology and the adult rheumatologist saw the patient two weeks later with the MRI result showing inflammation. A diagnosis of oligoarticular JIA was made. They performed an intra-articular steroid injection to the right knee on the same day with Entonox.

The reviewers thought this was an example of excellent care. However, it must be recognised that a patient needs to be accurately assessed to determine the appropriateness of Entonox use. It should only be used in older children as there is a risk of the patient being traumatised and then averse to future injections. Support from psychologists or play therapists/youth workers should be considered as well as other distraction techniques.

The frequency of blood tests for disease-modifying antirheumatic drugs (DMARDs) and biologics is determined by when the treatment was initiated, changes in dose and any abnormalities in results detected. Blood tests were most frequently undertaken in secondary care (T5.3).

Table 5.3 Where blood test monitoring occurred

Location	Subcutaneous methotrexate		Oral methotrexate		Other DMARDs		Biologics	
	n	%	n	%	n	%	n	%
Secondary care	103	76.9	37	64.9	7	58.3	72	75.8
Primary care (GP)	28	20.9	16	28.1	1	8.3	16	16.8
Tertiary care	23	17.2	10	17.5	0	0.0	27	28.4
Community nurses	19	14.2	4	7.0	2	16.7	8	8.4
Other	3	2.2	3	5.3	2	16.7	2	2.1

Reviewer assessment form data; n=number of patients

Answers may be multiple; subcutaneous methotrexate n=134 (unable to answer for 14); oral methotrexate n=57 (unable to answer for 6); other DMARDs n=12 (unable to answer for 1); biologics n=95 (unable to answer for 8)

General practitioners were less likely to carry out blood tests in children than adults (for methotrexate monitoring the reviewer data demonstrated 11/81 children ≤12 years old had blood tests carried out by the GP vs 17/53 ≥13 years). Furthermore, children's community nurses (CCNs) were more likely to perform blood tests on children than adolescents (T5.4).

Table X. Who is carrying out the monitoring (subcutaneous methotrexate) by age of patient on 31/03/2023

Service	≤12 years	≥13 years
	Number of patients	Number of patients
Secondary care	63	40
Primary care (GP)	11	17
Tertiary care	18	5
Community nurses	15	4
Other	1	1

Reviewer assessment form data: answers may be multiple; ≤12 years n=81 (unable to answer for 5); ≥ n=53 (unable to answer for 8)

Medication delays may be impacted by the type of centre in which blood tests are performed as it depends upon the speed with which test results are communicated to the prescribing centre. Blood test monitoring can be an area of significant anxiety for parents/carers as they often become the main co-ordinator for organising and chasing tests and results.

CASE STUDY 6

A 6-year-old patient presented to the emergency department (ED) with a swollen knee. They were referred to a fracture clinic, then back to the GP for investigations which resulted in a second referral to the ED. At this point, the patient was referred appropriately to the paediatric rheumatology service. However, the intra-articular steroid injection was delayed due to the family not being able to travel to the tertiary centre, and the local hospital having a long waiting list for a general anaesthetic.

The reviewers stated that the patient's treatment was significantly delayed due to geographical location of appropriate services.

CHAPTER 6: HOLISTIC CARE

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Elements of the initial assessment

Figure 6.1 shows that the initial assessment of the patient followed a largely medical model with assessment of educational and psychological needs taking place less frequently.

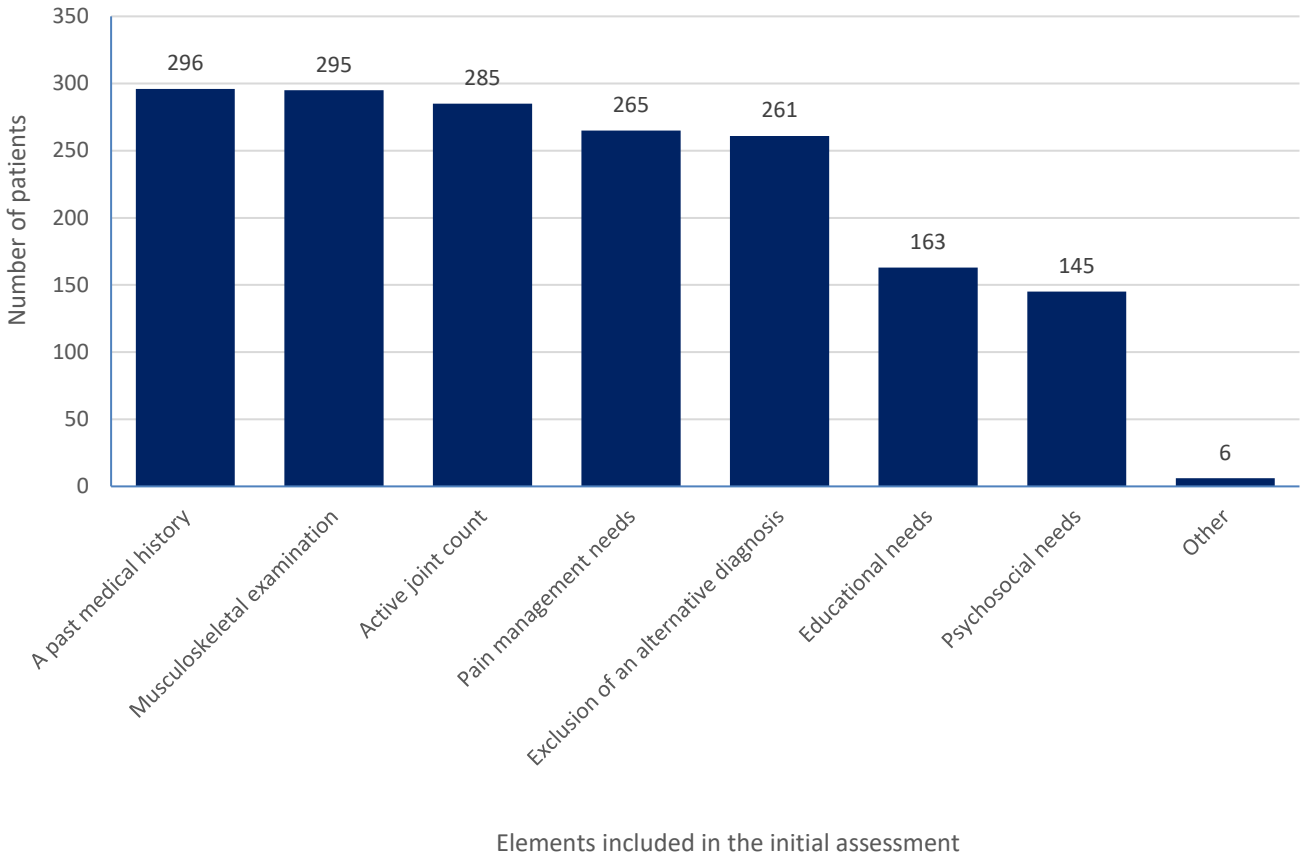

Figure 6.1 Elements included in the initial assessment

Clinical questionnaire data: answers may be multiple; n=298 (unknown for 3)

Multidisciplinary care

In some specialties, such as oncology, the multidisciplinary team (MDT) is central to all key decisions on a patient's care being decided. However, only 38/110 (34.5%) paediatric JIA units used a similar model (T6.1). British Society for Paediatric and Adolescent Rheumatology guidelines recommend that all children with a diagnosis of JIA should have access to a robust MDT.[9]

Table 6.1 Scheduled multidisciplinary meetings were held to discuss patients with JIA

Multidisciplinary meetings	Number of hospitals	%
Yes - for paediatrics	38	34.5
Yes - for adolescents	26	23.6
Yes - for adults with JIA	17	15.5
No	56	50.9
Total	**110**	

Organisational questionnaire data: answers may be multiple; n=110

The configuration of an MDT meeting is critical: staff who are central to the decisions being taken should attend, but it is not a good use of time for other staff to be present unless needed for the individual patient. There needs to be ongoing communication with other professionals such as social workers, youth workers and play therapists. These could be outside of the main MDT meeting so the multidisciplinary team involved in a patient's care will be bigger than the attendees at the meeting. 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.

Table 6.2 Specialties attending the multidisciplinary meetings

	Paediatrics	Adolescents	Adults with JIA
Specialty	Number of hospitals	Number of hospitals	Number of hospitals
Rheumatology	35	26	14
Clinical nurse specialists	29	21	12
Physiotherapy	27	18	8
Occupational therapy	16	13	6
Radiology	9	5	4
Psychology	9	6	0
Ophthalmology	5	4	1
Other clinicians involved in JIA care within the same hospital	5	1	2
Other clinicians involved in JIA care from another organisation	3	2	0
Podiatry/orthotics	2	1	3
Other	6	3	2

Organisational questionnaire data: answers may be multiple; paediatrics n=38; adolescents n=26; adults n=17

Patients with JIA will have their other medical needs met by their GP, who also may be involved in the monitoring or prescribing for their JIA. None of the GPs who completed the primary care questionnaire said that they had attended an MDT about a JIA patient under their care, although 84/95 GPs who provided data said that they felt well informed about their patient's care.

Specialties involved in the care of patients with JIA patients outside of an MDT setting

The reviewers found that most patients (231/273; 84.6%) had a named rheumatologist and had been seen by a clinical nurse specialist (223/282; 79.1%) but in only 31/273 (11.4%) was there evidence of a key worker. This might be an issue with role descriptions, as the clinical nurse specialist may be working as a key worker without being defined as such.

Many patients will benefit from physiotherapy and/or occupational therapy following diagnosis. 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). Under-referral was not an issue of poor documentation as the clinical questionnaire also showed a correspondingly small number of patients referred to physiotherapy, occupational therapy and psychology.

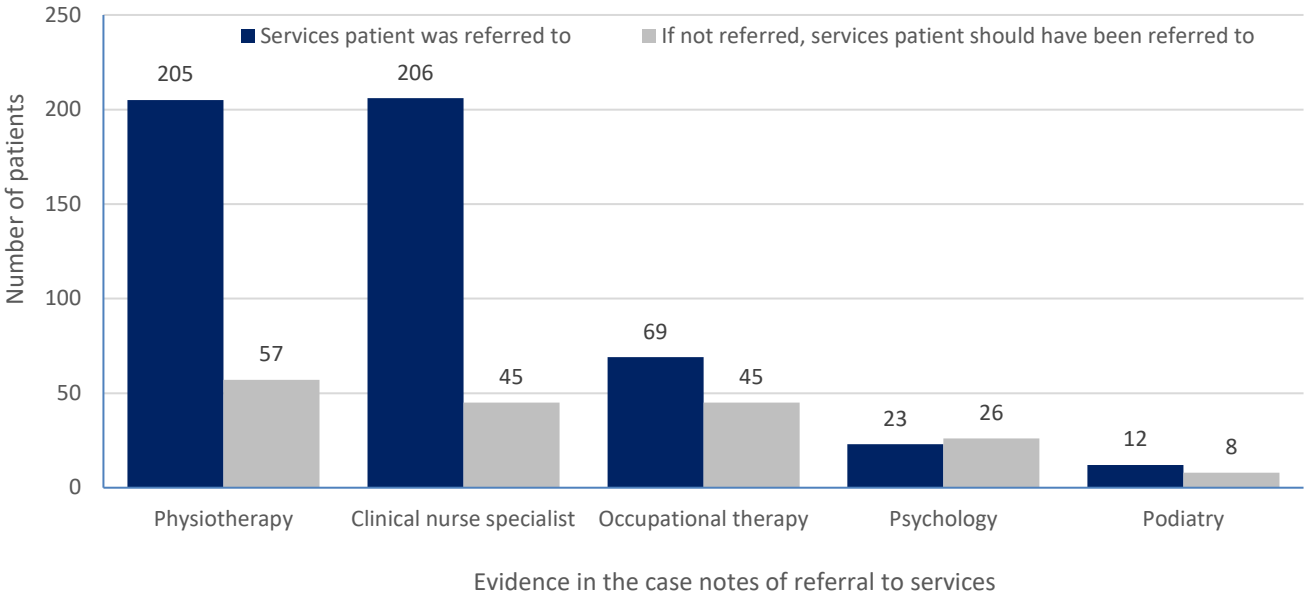

Figure 6.2 Services the patient was referred to by the rheumatology team at diagnosis

Reviewer assessment form data: answers may be multiple; services patient was referred to n=252 (not referred to any services for 33; unable to answer for 5); services should have been referred to n=112 (unable to answer for 2)

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).

Table 6.3 Specialties the patient had a follow-up appointment with

	Physiotherapy		Occupational therapy		Psychology	
Specialty	**Number of patients**	**%**	**Number of patients**	**%**	**Number of patients**	**%**
Yes	265	94.0	95	74.2	43	40.6
No	17	6.0	33	25.8	63	59.4
Subtotal	**282**		**128**		**106**	
Unknown	21		56		43	
No - referral not needed	47		166		201	
Total	**350**		**350**		**350**	

Clinical questionnaire data

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.

Pain

Pain is a major symptom of JIA and can be debilitating, interfering with school attendance throughout childhood, including at the critical time of examinations. Control of inflammation should relieve such symptoms over time and reduce the risk of joint damage but ensuring adequate pain relief at all stages of JIA is important. Overall, the management of pain across paediatric and adult rheumatology services was well provided.

Initial assessment of pain management needs was only seen in 195/277 (70.4%) cases reviewed. Furthermore, the organisational data showed that the availability of an acute pain team for

adolescents was less likely than for younger children (8/111; 7.2% vs 24/111; 21.6%). Adult services appeared to be better resourced with 64/111 (57.7%) hospitals having an acute pain service; however, these services are often centred around surgical/postoperative care and mainly for inpatients.

Hospitals also lacked services for adolescents with chronic pain (10/111; 9.0%), while there was marginally better provision for children (18/111; 16.2%) and considerably better provision for adults (65/111; 58.6%) (F6.3). Chronic pain networks are being developed in some areas, but discussion within the case reviewer group indicated that these are not fully developed or funded. Pain management could be improved by training of those working in rheumatology services on effective multidisciplinary pain management and involving patients and parents/carers.

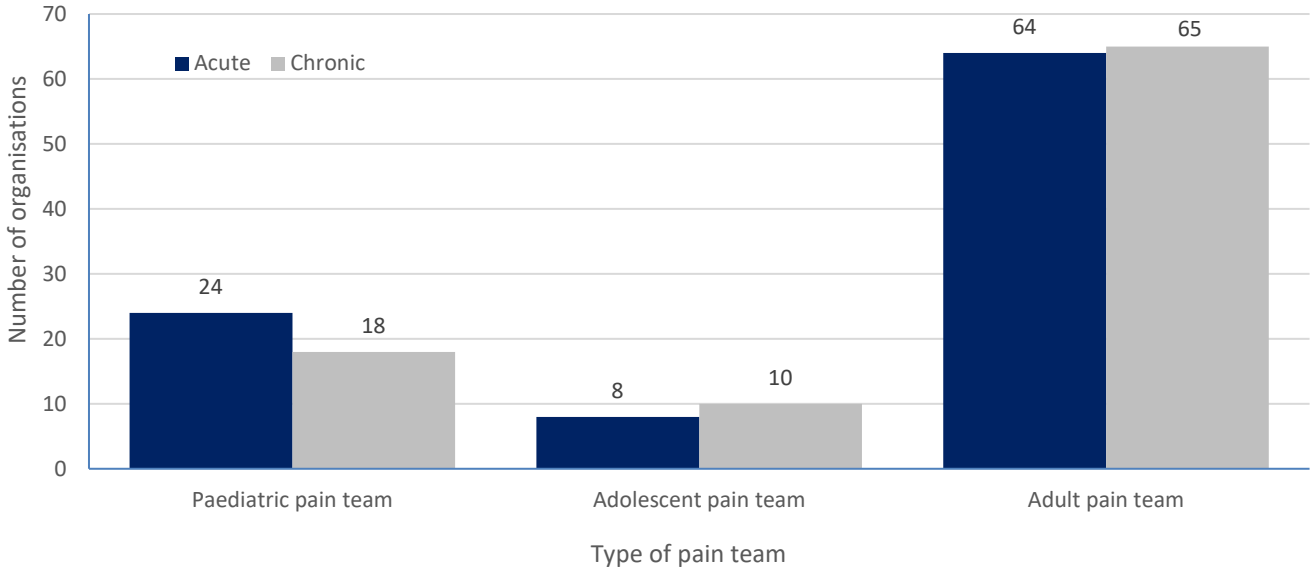

Figure 6.3 Availability of pain teams

Organisational questionnaire data: answers may be multiple; n=111 (unable to answer for 11)

There is published evidence on the psychological impact of JIA on patients.[13] 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.[14,15]

Table 6.4 Evidence that the patient had a mental health follow-up

Evidence	Number of patients	%
Psychology	34	12.7
Child and adolescent mental health services	12	4.5
Adult mental health services	0	0.0
Other (e.g. school counsellor, private therapy, art or music therapy)	7	2.6
No follow-up	221	82.8
Subtotal	**267**	
Unable to answer	23	
Total	**290**	

Reviewer assessment form data

JIA and its therapy can have far-reaching effects on general health and wellbeing. 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).

Table 6.5 Type of support offered to the patient during their follow-up appointments

Support offered	Number of patients	%
Information regarding treatment options	189	72.1
Information regarding general health issues (physical, psychosocial and emotional development with their family and community)	114	43.5
None of the above	50	19.1
Other	17	6.5

Reviewer assessment form data: answers may be multiple; n=262 (unknown for 28)

Impact on education and work

Younger patients with JIA will miss education (school or university) and older patients may have to take time off work. Table 6.6 shows that 117/255 (45.9%) patients had evidence in their notes of this occurring. The parent and carer survey also showed that during the previous calendar year an average of 15 days had been missed from education or work (range 0-100 days, median 10, mode 3).

Table 6.6 Evidence in the case notes that JIA was having an impact on the patient's education or work

JIA impact on education/work	Number of patients	%
Yes	117	45.9
No	138	54.1
Subtotal	**255**	
Unable to answer	35	
Total	**290**	

Reviewer assessment form data

Data from the young person and parent/carer surveys indicated that some schools, colleges and universities were understanding of the fact that patients needed to miss days due to their illness (8/10 young people and 44/54 parents/carer) and that most of these institutions put together plans to mitigate the effects of the time lost (7/11 young people and 35/59 parents/carer). However, this approach was not universal and all children and young people with JIA should have plans in place.

CASE STUDY 7

A 13-year-old patient was diagnosed with polyarticular JIA affecting her knees, hips, shoulders and hands and was treated with etanercept and intra-articular steroid injections. The patient had regular comprehensive reviews by occupational therapy which were shared with the family and the school. The school integrated the recommendations into their support plan giving them laptop access, touch typing support, rest breaks during writing tasks and adapting the time they arrived at and left class so that they could avoid crowds when negotiating stairs. These measures allowed the patient to maximise their attendance in mainstream school.

Reviewers felt that this was an example of excellent practice with joined-up care between the hospital and education services.

Reasons for the gaps in provision of services for patients with JIA

There were 134/154 (87.0%) clinicians who identified gaps in staffing. The most common gaps were in the provision of clinical nurse specialists, psychology, physiotherapy and occupational therapy (T6.7).

Table 6.7 Gaps in staffing identified by the clinician survey

Staffing gaps	Number of responses	%
Clinical nurse specialist/nursing	60	45.8
Psychologist	47	35.9
Physiotherapist	42	32.1
Occupational therapist	38	29.0
Rheumatology consultant	27	20.6

Clinician survey data: answers may be multiple; n=131 (unknown for 3)

The gaps in service were identified across all types of healthcare organisations where care for patients with JIA was delivered (secondary care 87/101; 86.1%; tertiary care 52/57; 91.2%) as well as across the different age groups (paediatric services 24/36; adolescent services 26/53 and adult services 23/37), indicating that this is a broader issue

CASE STUDY 8

A 13-year-old patient with nephrotic syndrome who was on intermittent steroids had a five-month delay in referral for joint pain and diagnosis of JIA, and a further eight-month delay before starting treatment. No referrals were made to ophthalmology, physiotherapy or occupational therapy due to the 'service just starting and not organised yet'.

Reviewers stated that starting a service that was not adequately configured was putting patients at risk.

The reviewers rated the overall quality of care across the whole service for patients with JIA as good practice for 113/285 (39.6%) patients (F6.4), demonstrating that when the service is organised with appropriate resource and clear pathways, care can be extremely effective. However, delays throughout the pathway commonly led to less-than-optimal care for many patients.

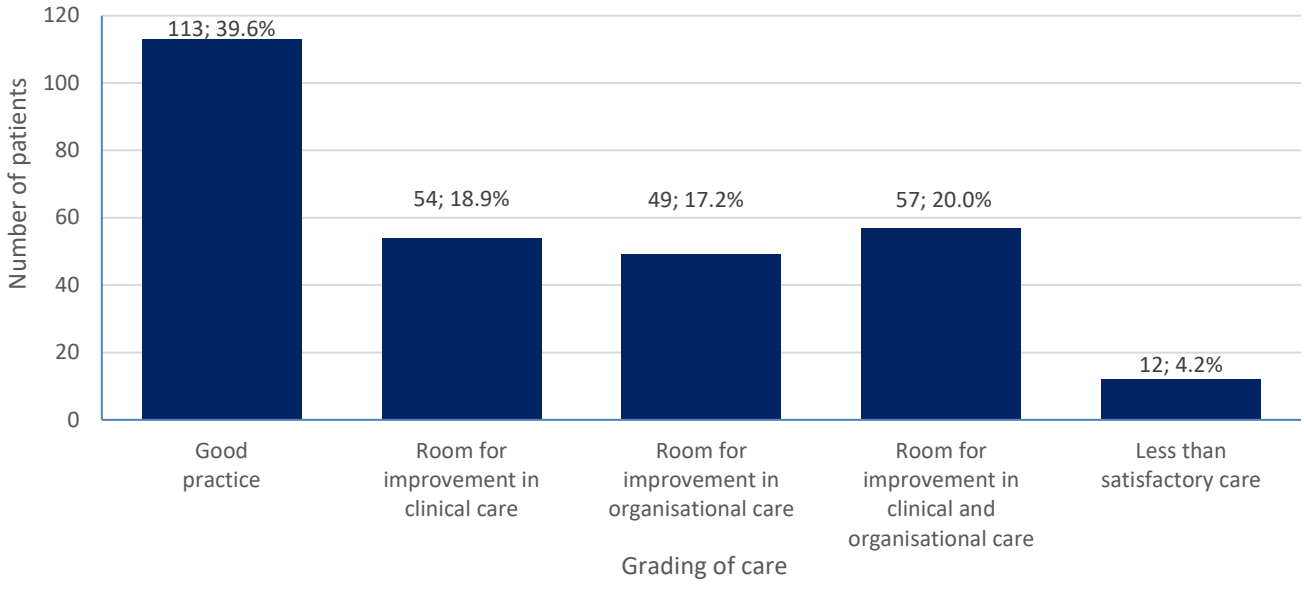

Figure 6.4 The overall quality of care

Reviewer assessment form data

CHAPTER 7: INFORMATION AND TRAINING

(BACK TO CONTENTS)

Information provided to patients and parents/carers at diagnosis

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). A formal process of informed consent for medical therapies such as chemotherapy is routine, and it may be that a similar strategy should be applied to the initiation of therapy for JIA.

Table 7.1 Patients and carers routinely given information on JIA at diagnosis

Information provided	Number of hospitals	%
Yes - at the time of diagnosis	86	84.3
Yes - at treatment initiation	80	78.4
Yes - at transition from child to adult services	46	45.1
No	10	9.8

Organisational questionnaire data: answers may be multiple; n=102 (unknown for 8)

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). This might have been because there was no process to document that information had been provided. However, given how important it is for patients and their carers to have adequate understanding of the therapy they are about to receive, there should be a more standardised approach to patient education.

Table 7.2 Evidence that the patient or parent/carer was given information regarding treatment

Evidence that information was provided	Number of patients	%
Yes - for all treatments	184	66.7
Yes - for some treatments	47	17.0
No	45	16.3
Subtotal	**276**	
Unable to answer	14	
Total	**290**	

Reviewer assessment form data

The information provided should enable patients and their carers to make informed decisions about the suitability of the treatment for them. It could come from a variety of sources (T7.3). The charity sector has a wealth of patient-centred information but only 60/93 hospitals from which a response was received directed patients to this.

Table 7.3 Information provided to patients

Information	Number of hospitals
Information on the disease	91
Information on who to contact and how if there are any problems	88
Information on the side effects of medicine	86
Information on how to access charities and other third sector information	60

Organisational questionnaire data: answers may be multiple; n=93

Training provided to patients and parents/carers at diagnosis

As well as providing patient information on medication, training on how to administer it correctly is also vital. Some of the key therapies for JIA are given by injection at home. 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 remaining 30/110 (27.3%) hospitals the training was done by another specialist (e.g. community nurse) or not done at all. It is important as training sessions on injection technique often act as a stimulus to discuss wider aspects of the disease and its therapy.

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).

Table 7.4 Evidence in the case notes the patient or parent/carer received training in how to give an injection

Evidence in the notes	Subcutaneous methotrexate		Biologics	
	Number of patients	%	Number of patients	%
Yes	140	88.1	96	81.4
No	19	11.9	22	18.6
Subtotal	**159**		**118**	
Unable to answer	4		13	
Total	**163**		**131**	

Reviewer assessment form data

CASE STUDY 9

A 6-year-old patient was diagnosed with psoriatic JIA. Their carer was a single mother with four other children and found it difficult to travel to appointments. The patient was seen in a tertiary centre where methotrexate was prescribed and dispensed. However, no teaching about medication administration was given so there was a six-week delay before treatment could be started.

Reviewers commented that the absence of training had interfered with the timely care for this patient.

Ongoing education, training and support for patients, parents/carers

Patient education should be an ongoing process rather than a single event. While 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).

Table 7.5 Evidence in the case notes that a further appointment to offer JIA education was booked

Evidence in the notes	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	170	63.0	150	53.8
No	100	37.0	129	46.2
Subtotal	**270**		**279**	
Unable to answer	31		11	
Total	**301**		**290**	

Clinical questionnaire and reviewer assessment form data

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). Signposting to resources that are already available is quick and inexpensive. There are many charities with a wealth of available resources (USEFUL RESOURCES).

Table 7.6 Evidence in the case notes that the patient was offered information

Evidence in the notes	Number of patients	%
Information leaflets	173	67.8
Signposted to a website	106	41.6
Signposted to charity support	38	14.9
Signposted to videos	18	7.1
Offered access to peer support	12	4.7
Other	24	9.4
Was not offered any signposting	51	20.0

Reviewer assessment form data: answers may be multiple; n=255 (unknown for 35)

Access to peer support, so often helpful, was found in only 12/255 (4.7%) sets of case notes. However, 5/10 young people and 32/65 parents/carers who responded to the surveys indicated that their child had been offered the opportunity to talk to other children or young people with JIA. The difference between the two figures is likely due to poor recording of this information. From the organisational data, it appeared that signposting to access to peer support decreased with age (T7.7).

Table 7.7 Patients with JIA were signposted to access peer support

Signposting	Number of hospitals	%
Yes - for paediatrics	60	60.0
Yes - for adolescents	46	46.0
Yes - for adults with JIA	31	31.0
No	25	25.0

Organisational questionnaire data: answers may be multiple; n=100 (unable to answer for 10)

As JIA is a chronic disease issues with care will likely arise at times when there is not an appointment scheduled. Being able to access the rheumatology team to discuss issues is an important form of support. Clinicians reported that their units had access arrangements by phone (303/348; 87.1%) or by e-mail (266/348; 76.4%) for most patients and their parents/carers, while the use of other electronic methods such as apps or websites was much less frequent (T7.8).

Table 7.8 Access to the rheumatology team

Mode of access	Number of patients	%
Direct phone line	303	87.1
Email	266	76.4
App	34	9.8
Website	31	8.9
Secretary	18	5.2
Text	4	1.1
Community nursing team phoneline	3	<1

Clinician questionnaire data: answers may be multiple; n=348 (unknown for 2)

The surveys revealed that there were 9/12 young people and 47/58 parents/carers who said that there was a health or social care professional they could contact directly about their child's care. A total of 82/101 (81.2%) paediatric teams had patient information on how to contact them, whereas just over half of the adolescent and young adult teams (62/101; 61.4%) provided it (T7.9).

Table 7.9 The hospital had information for patients on how to contact their rheumatology team

Contact information available	Number of hospitals	%
Yes - for paediatrics	82	81.2
Yes - for adolescents	62	61.4
Yes - for adults with JIA	63	62.4
No	1	1.0

Organisational questionnaire data: answers may be multiple; n=101 (unknown for 4)

Education and training for staff

JIA is not a common disease, and it is important that staff involved in caring for patients are appropriately trained. 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.

Table 7.10 Clinicians were able to access a rheumatology CPD programme about patients with JIA

CPD programme	Number of hospitals	%
Yes - for paediatrics	75	75.0
Yes - for adolescents	60	60.0
Yes - for adults with JIA	45	45.0
No	6	6.0

Organisational questionnaire data: answers may be multiple; n=100 (unknown for 10)

Clinicians will only know how well they are caring for patients if aspects of care are reviewed locally. Clinical audit was more likely to take place in hospitals providing tertiary care services (17/21) compared with those providing secondary care services (43/81). Table 7.11 shows the elements that were audited locally.

Table 7.11 Elements of care that were audited

Audited care	Paediatrics	Adolescents	Adults with JIA
	Number of hospitals	Number of hospitals	Number of hospitals
Time from referral to being seen	29	23	7
Patient satisfaction surveys	16	16	10
Other quality outcome measures	24	21	11
Other	5	2	3

Organisational questionnaire data: answers may be multiple; paediatrics n=36; adolescents n=29; adults with JIA n=17 (unknown for 5)