

Juvenile idiopathic arthritis study: Clinician questionnaire

A. Introduction

What is this study about?

The aim of this study is to review the quality of care in children and young people (0-24 years) with Juvenile Idiopathic Arthritis (JIA).

Inclusions

- Data is being collected on young people aged 0-24 years with JIA.
- Questionnaires have been sent for young people where the arthritis diagnosis was made between the 1st April 2019 – 31st March 2023.

Who should complete this questionnaire?

- This questionnaire should be completed by a member of the clinical team responsible for providing rheumatology care to the young person. This may be in a acute, community or independent setting
- One questionnaire should be completed by each team providing rheumatology care to the young person. Where young people are seen in multiple organisations, the questionnaire has been sent to all organisations
- Please answer the questions in relation to the care provided up to the 31st March 2023

How to complete this questionnaire

This questionnaire has been split into sections based on the different parts of the pathway:

- The diagnosis of JIA
- The ongoing rheumatology care of the young person
- Treatment (medications)
- Therapy and community nursing services

Please complete the sections that are relevant to the rheumatology care this team has provided to this CYP (as indicated in your answer to question C2).

If you work in a community organisation or only provide therapy services, please tick 'therapy and community nursing services' and complete section L

In order to submit the questionnaire, all of the relevant questionnaires have to be answered. Questions that need to be completed are flagged up with an orange triangle down the right hand side of the screen.

Definitions

- Throughout this questionnaire, the child or young person will be referred to as the CYP

Questions or help

If you have any queries about this study or this questionnaire, please contact: arthritis@ncepod.org.uk or telephone 020 7251 9060.

CPD accreditation

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including:

Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) - 'An Acute Problem' (2005).
Appointment of a National Clinical Director for Trauma Care - 'Trauma: Who Cares?' (2007).
Development of NICE Clinical Guidelines for Acute Kidney Injury, published 2013 - 'Adding Insult to Injury' (2009).
Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 - 'On the right trach?' (2014).
Development of guidelines from the British Society of Gastroenterology: diagnosis and management of acute lower gastrointestinal bleeding, published 2019 - 'Time to Get Control' (2015).
Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' (2017).

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Child Health.

TO BE COMPLETED BY ALL TEAMS INVOLVED IN THE CARE OF THE CYP

1a. Are you part of a clinical team providing regular rheumatology care to this CYP?

- Yes No

1b. If answered "No" to [1a] then:

If NO, please provide the details of the organisations where the CYP's regular clinical team(s) are based. Please include the Trust/Health Board name(s) and the specialty of the team(s). This may be both within and outside of this organisation.

If NO to 1a, please hand this questionnaire back and notify the local reporter

1c. If answered "Yes" to [1a] then:

If YES to 1a, are there any other teams regularly involved in the rheumatology care of this CYP? (Please tick all that apply)

(This should include therapy teams)

- Yes - rheumatology care in another secondary/tertiary healthcare organisation
 Yes - rheumatology care in a community healthcare organisation
 Yes - rheumatology care in an independent healthcare organisation
 No
 Unknown

Please specify any additional options here...

1d. If answered "Yes" to [1a] and "Yes - rheumatology care in another secondary/tertiary healthcare organisation" to [1c] then:

If YES (rheumatology care in another secondary/tertiary healthcare organisation), please provide the details of other teams providing regular rheumatology care to this CYP (Trust/Health Board name and specialty of team):

1e. If answered "Yes" to [1a] and "Yes - rheumatology care in a community healthcare organisation" to [1c] then:

If YES (rheumatology care in a community healthcare organisation), please provide the details of other teams providing regular rheumatology care to this CYP (Trust/Health Board name and specialty of team):

1f. If answered "Yes" to [1a] and "Yes - rheumatology care in an independent healthcare organisation" to [1c] then:

If YES (Yes - rheumatology care in an independent healthcare organisation), please provide the details of other teams providing regular rheumatology care to this CYP (Trust/Health Board name and specialty of team):

2. If answered "Yes" to [1a] then:

Please provide the details of any organisations that have previously provided rheumatology care to the young person, but no longer do, e.g. care prior to transition to adult services. (Trust/Health Board name).

3. If answered "Yes" to [1a] then:

Please provide the name of the CYP's GP practice.

Please do not provide any clinician names.

TO BE COMPLETED BY ALL TEAMS INVOLVED IN THE CARE OF THE CYP

1a. Specialty of the team providing care to the CYP:

1b. Which service does this team sit under?

- Paediatric service Adolescent service Adult service Unknown

If not listed above, please specify here...

1c. What type of organisation is this? (Please tick all that apply)

- Secondary care Tertiary care Community care Independent care
 Unknown

This question is repeated at the start of each section throughout the remainder of the questionnaire. It is acting as a filter to bring up the relevant questions in each section based on the rheumatology care this team provides to the young person. If you change the answer to this question at any point, your answers in the previous sections may be lost and you will need to go back and recomplete them before the questionnaire can be submitted.

2. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
 The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing care)
 Treatment (medications)
 Community therapy or community nursing services
 None of the above

If none of these aspects of care are provided by you or this team, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

3. Please use the box below to provide a brief summary of this case, adding any additional comments or information you feel relevant. You should be assured that this information is confidential. NCEPOD attaches great importance to this summary. Please give as much information as possible about the care of this CYP.

TO BE COMPLETED BY ALL TEAMS INVOLVED IN THE CARE OF THE CYP

Please answer the questions in relation to the care provided up to the 31st March 2023

1. Date of arthritis diagnosis:

Unknown

If diagnosed* before 1st April 2019, please return this questionnaire to your Local Reporter (hand your assignment back) who will notify NCEPOD

*Please see definitions

2. What was the age of the CYP on 31/03/2023

 years

Unknown

Value should be no more than 24

3. Sex

Male

Female

Unknown

4. Ethnicity

White British/White - other

Black/African/Caribbean/Black British

Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)

Mixed/Multiple ethnic groups

Unknown

If not listed above, please specify here...

5. What classification of Juvenile Idiopathic Arthritis (JIA) did/does the CYP have? (Please tick all that apply)

Systemic-onset JIA

RF-negative polyarthritis

Psoriatic JIA

Undifferentiated

Persistent or extended oligoarthritis

RF-positive polyarthritis

Enthesitis-related arthritis

Unknown

Please specify any additional options here...

6. Has this CYP been diagnosed with uveitis?

Yes

No

Unknown

7. Does the CYP have a learning or physical disability that impacts on their care?

Yes

No

Unknown

8. How far does the CYP have to travel to access rheumatology services at this organisation?

- 1 hr 2 hrs 3 hrs \geq 4 hours
 Unknown

If not listed above, please specify here...

TO BE COMPLETED BY A MEMBER OF THE TEAM WHO MADE THE JIA DIAGNOSIS

If you or a member of this team did not make the JIA diagnosis, please continue to section G

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the care)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2a. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

How was the CYP referred to rheumatology? (Please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Via GP | <input type="checkbox"/> Via ED |
| <input type="checkbox"/> Via general paediatrics | <input type="checkbox"/> Via orthopaedics |
| <input type="checkbox"/> Via physiotherapy | <input type="checkbox"/> Via ophthalmology |
| <input type="checkbox"/> Via oncology | <input type="checkbox"/> Via an independent organisation |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

2b. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Please give any further information regarding the referral pathway:

If referred via the GP

3. If answered "Via GP" to [2a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

How many times did the CYP present to the GP with the same problem? (i.e. similar symptoms which may have indicated JIA)

- Unknown

4. If answered "Via GP" to [2a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Which specialty did the GP refer the CYP to?

- General Paediatrician
- General paediatrician with an interest in rheumatology
- Paediatric rheumatologist
- Adolescent rheumatologist
- Adult rheumatologist
- Adult rheumatologist with an interest in CYP/JIA
- Orthopaedics
- Unknown

If not listed above, please specify here...

5a. If answered "Via GP" to [2a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Did the GP request any investigations?

- Yes No Unknown

5b. If answered "Via GP" to [2a] and "Yes" to [5a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

If YES, which of the following were requested? (Please tick all that apply)

- Blood tests Radiology Urine dip Unknown

Please specify any additional options here...

5c. If answered "Via GP" to [2a] and "Yes" to [5a] and "Blood tests" to [5b] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

If BLOOD TESTS; which tests were requested? (Please tick all that apply)

- | | | | |
|---------------------------------|-----------------------------------|---|--------------------------------------|
| <input type="checkbox"/> Hb | <input type="checkbox"/> WBC | <input type="checkbox"/> Platelet count | <input type="checkbox"/> ESR |
| <input type="checkbox"/> CRP | <input type="checkbox"/> Ferritin | <input type="checkbox"/> ANA | <input type="checkbox"/> anti ds-DNA |
| <input type="checkbox"/> RF | <input type="checkbox"/> anti-CCP | <input type="checkbox"/> ANCA | <input type="checkbox"/> LFT |
| <input type="checkbox"/> HLAB27 | <input type="checkbox"/> Unknown | | |

Please specify any additional options here...

All patients

6a. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Was there a delay between first presentation with symptoms and referral to rheumatology?

- Yes No Unknown

6b. If answered "Yes" to [6a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

If YES, please give further details:

7. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Specialty of clinician undertaking the first assessment following referral:

- General Paediatrician
- General paediatrician with an interest in rheumatology
- Paediatric rheumatologist
- Adolescent rheumatologist
- Adult rheumatologist
- Adult rheumatologist with an interest in CYP/JIA
- Orthopaedics
- Unknown

8a. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Was there a delay in assessment by a rheumatologist?

- Yes No Unknown

8b. If answered "Yes" to [8a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

If YES, what was the reason for this? (Please tick all that apply)

- CYP/parent or carer factor
- Referral sent to the wrong specialty
- Administration error
- Service capacity
- Pathway error (i.e. referral to multiple specialties prior to referral to rheumatology)
- Unknown

Please specify any additional options here...

TO BE COMPLETED BY A MEMBER OF THE TEAM WHO MADE THE JIA DIAGNOSIS

If you or a member of this team did not make the JIA diagnosis, please continue to section G

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the care)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

At initial assessment by the rheumatologist

2. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Did the initial assessment include: (Please tick all that apply)

- | | |
|--|--|
| <input type="checkbox"/> A past medical history | <input type="checkbox"/> Psychosocial needs |
| <input type="checkbox"/> Pain management needs | <input type="checkbox"/> Educational needs |
| <input type="checkbox"/> Active joint count | <input type="checkbox"/> Musculoskeletal examination |
| <input type="checkbox"/> Exclusion of an alternative diagnosis | <input type="checkbox"/> None of these |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

3a. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

What investigations were undertaken? (Please tick all that apply)

- | | | | |
|--------------------------------------|-------------------------------|--------------------------------|-------------------------------------|
| <input type="checkbox"/> Blood tests | <input type="checkbox"/> MRI | <input type="checkbox"/> X-ray | <input type="checkbox"/> Ultrasound |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> None | | |

Please specify any additional options here...

3b. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

Were any of these investigations repeat investigations?

- | | |
|-------------------------------|---|
| <input type="radio"/> Yes | <input type="radio"/> No |
| <input type="radio"/> Unknown | <input type="radio"/> Not applicable - no investigations undertaken |

3c. If answered "Yes" to [3b] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:

If YES, why were these repeated? (Please tick all that apply)

- The wrong type of test was requested
- The initial result was not within the right time frame
- Other additional tests needed for diagnostic reasons
- Unknown

Please specify any additional options here...

**4a. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
Was the CYP referred to ophthalmology at diagnosis?**

- Yes No Unknown

**4b. If answered "Yes" to [4a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
Date of referral to ophthalmology:**

Unknown

**4c. If answered "Yes" to [4a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
Date of first ophthalmology assessment:**

Unknown

**5. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
Was the CYP referred to any of the following services by the Rheumatology team at diagnosis? (Please tick all that apply)**

- | | | |
|---|---|-------------------------------------|
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Psychology |
| <input type="checkbox"/> CAMHs | <input type="checkbox"/> Adult mental health services | <input type="checkbox"/> Podiatry |
| <input type="checkbox"/> None of these services | <input type="checkbox"/> Unknown | |

Please specify any additional options here...

**6. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
Was a further appointment to offer JIA education booked following the initial assessment?**

- Yes No Unknown

**7a. If answered "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
Was the CYP or parent/carer given information regarding the diagnosis?**

- Yes No Unknown

**7b. If answered "Yes" to [7a] and "Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)" to [1] then:
If YES, what format was this in? (Please tick all that apply)**

- | | |
|---|--|
| <input type="checkbox"/> Information leaflet | <input type="checkbox"/> Signposted to a website |
| <input type="checkbox"/> Signposted to a video | <input type="checkbox"/> Signposted to charity support |
| <input type="checkbox"/> Offered access to peer support | <input type="checkbox"/> Unknown |

Please specify any additional options here...

TO BE COMPLETED BY A MEMBER OF THE TEAM INVOLVED IN THE ONGOING RHEUMATOLOGY CARE OF THE CYP

If you or a member of this team are not involved in the ongoing rheumatology care of the CYP, please continue to section I

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2a. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Was the CYP under the care of an MDT?

- Yes No Unknown

2b. If answered "No" to [2a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

If NO, why not?

2c. If answered "Yes" to [2a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

If YES, which specialties were members of this team? (Please tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Paediatric rheumatology | <input type="checkbox"/> Adolescent rheumatology |
| <input type="checkbox"/> Rheumatology | <input type="checkbox"/> General paediatrics |
| <input type="checkbox"/> Rheumatology clinical nurse specialist | <input type="checkbox"/> Rheumatology physiotherapy |
| <input type="checkbox"/> Pharmacy | <input type="checkbox"/> Psychology |
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Podiatry |
| <input type="checkbox"/> Social worker | <input type="checkbox"/> SENCO/School nurse/School liaison |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

3. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Did the CYP have a named rheumatologist?

- Yes No Unknown

4. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Did/Does this CYP have a key worker?

Yes

No

Unknown

5. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Is there access to the rheumatology team via: (please tick all that apply)

Email

Direct phone line

App

Website

Unknown

Please specify any additional options here...

TO BE COMPLETED BY A MEMBER OF THE TEAM INVOLVED IN THE ONGOING RHEUMATOLOGY CARE OF THE CYP

If you or a member of this team are not involved in the ongoing rheumatology care of the CYP, please continue to section I

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

At each rheumatology appointment, is inflammation assessed clinically?

- Yes No Unknown

3a. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

If not referred at diagnosis, was the CYP referred to ophthalmology?

- Yes No
 Unknown NA - referred at initial assessment

3b. If answered "Yes" to [3a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Date of referral to ophthalmology:

- Unknown

3c. If answered "Yes" to [3a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Date of first ophthalmology assessment:

- Unknown

TO BE COMPLETED BY A MEMBER OF THE TEAM INVOLVED IN THE TREATMENT OF THE CYP

If you or a member of this team are not involved in the medication management of the CYP, please continue to section J

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the care)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2. If answered "Treatment (medications)" to [1] then: What treatment has this CYP received (up to the 31st March 2023)? (Please tick all that apply)

- | | | |
|--|---|--|
| <input type="checkbox"/> NSAIDS | <input type="checkbox"/> IA steroid joint injection | <input type="checkbox"/> PO steroids |
| <input type="checkbox"/> IV steroids | <input type="checkbox"/> IM steroids | <input type="checkbox"/> Methotrexate SC |
| <input type="checkbox"/> Methotrexate PO | <input type="checkbox"/> Other DMARDs | <input type="checkbox"/> Biologics |
| <input type="checkbox"/> Unknown | | |

Please specify any additional options here...

NSAIDS

3. If answered "NSAIDS" to [2] and "Treatment (medications)" to [1] then: If NSAIDS, where were these initiated?

- Primary care
 Secondary care
 Tertiary care
 Unknown

If not listed above, please specify here...

IA steroid joint injection

4a. If answered "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then: If IA joint injection, where was this initiated?

- Secondary care
 Tertiary care
 Unknown

If not listed above, please specify here...

4b. If answered "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then: If IA joint injection, how many joints were injected?

- 1
 2
 3
 4
 5+
 Unknown

4c. If answered "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then: If IA joint injection, was this undertaken (Please tick all that apply):

- Under general anaesthetic
 Under local anaesthetic
 Unknown

Please specify any additional options here...

**4d. If answered "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then:
If IA joint injection, was any other analgesia given? (ie entonox)**

- Yes No Unknown

**4e. If answered "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then:
If IA joint injection, on how many occasions was the CYP injected?**

Unknown

**4f. If answered "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then:
If IA joint injection, in your opinion was there any delay in giving any of the injections?**

- Yes No Unknown

**4g. If answered "Yes" to [4f] and "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then:
If IA joint injection and YES to delay, what were the reasons for this delay? (Please tick all that apply)**

- CYP/parent or carer factors (e.g. taking time to research the treatment, CYP/parent or carer getting a s
 Organisational factors (e.g. availability of theatre space)
 Unavailability of a trained healthcare professional to administer the injection
 Unknown

Please specify any additional options here...

**4h. If answered "Yes" to [4f] and "IA steroid joint injection" to [2] and "Treatment (medications)" to [1] then:
If IA joint injection and YES to delay, please give further details**

PO steroids

**5a. If answered "PO steroids" to [2] and "Treatment (medications)" to [1] then:
If PO steroids, where were these initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

**5b. If answered "Treatment (medications)" to [1] and "PO steroids" to [2] then:
If PO steroids, in your opinion was there any delay in giving any of the injections?**

- Yes No Unknown

5c. If answered "PO steroids" to [2] and "Yes" to [5b] and "Treatment (medications)" to [1] then:

If PO steroids and YES to delay, what were the reasons for this delay? (Please tick all that apply)

- CYP/parent or carer factors (e.g. taking time to research the treatment, CYP/parent or carer getting a s
- Organisational factors
- Unavailability of a trained healthcare professional to administer the injection
- Unknown

Please specify any additional options here...

5d. If answered "Treatment (medications)" to [1] and "PO steroids" to [2] and "Yes" to [5b] then:

If PO steroids and YES to delay, please give further details

IV steroids

**6a. If answered "Treatment (medications)" to [1] and "IV steroids" to [2] then:
If IV steroids, where were these initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

**6b. If answered "Treatment (medications)" to [1] and "IV steroids" to [2] then:
If IV steroids, in your opinion was there any delay in giving any of the injections?**

- Yes No Unknown

6c. If answered "Treatment (medications)" to [1] and "IV steroids" to [2] and "Yes" to [6b] then:

If IV steroids and YES to delay, what were the reasons for this delay? (Please tick all that apply)

- CYP/parent or carer factors (e.g. taking time to research the treatment, CYP/parent or carer getting a s
- Organisational factors
- Unavailability of a trained healthcare professional to administer the injection
- Unknown

If not listed above, please specify here...

**6d. If answered "Treatment (medications)" to [1] and "IV steroids" to [2] and "Yes" to [6b] then:
If IV steroids and YES to delay, please give further details**

IM steroids

**7a. If answered "Treatment (medications)" to [1] and "IM steroids" to [2] then:
If IM steroids, where were these initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

**7b. If answered "Treatment (medications)" to [1] and "IM steroids" to [2] then:
If IM steroids, in your opinion was there any delay in giving any of the injections?**

- Yes No Unknown

**7c. If answered "Treatment (medications)" to [1] and "IM steroids" to [2] and "Yes" to [7b] then:
If IM steroids and YES to delay, what were the reasons for this delay? (Please tick all that apply)**

- CYP/parent or carer factors (e.g. taking time to research the treatment, CYP/parent or carer getting a s
 Organisational factors
 Unavailability of a trained healthcare professional to administer the injection
 Unknown

If not listed above, please specify here...

**7d. If answered "Treatment (medications)" to [1] and "IM steroids" to [2] and "Yes" to [7b] then:
If IM steroids and YES to delay, please give further details**

SC Methotrexate

**8a. If answered "Methotrexate SC" to [2] and "Treatment (medications)" to [1] then:
If SC Methotrexate, where was this initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

**8b. If answered "Methotrexate SC" to [2] and "Treatment (medications)" to [1] then:
If SC Methotrexate, in your opinion was there any delay in initiating treatment?**

- Yes No Unknown

**8c. If answered "Methotrexate SC" to [2] and "Yes" to [8b] and "Treatment (medications)" to [1] then:
If SC Methotrexate and YES to delay, what were the reasons for this delay? (Please tick all that apply)**

- CYP/parent or carer factors (e.g. taking time to research the treatment, CYP/parent or carer getting a s
 Organisational factors under the control of the treating team (e.g. delays to drug education)
 Organisational factors not within the control of the treating team (e.g. organising the community nurse
 Unavailability of a trained healthcare professional to administer the injection
 Unknown

Please specify any additional options here...

**8d. If answered "Methotrexate SC" to [2] and "Yes" to [8b] and "Treatment (medications)" to [1] then:
If SC Methotrexate and YES to delay, please give further details:**

**8e. If answered "Methotrexate SC" to [2] and "Treatment (medications)" to [1] then:
If SC Methotrexate, did the CYP receive training in how to give the injection?**

- Yes No Unknown NA - CYP too young

**8f. If answered "Methotrexate SC" to [2] and "Yes" to [8e] and "Treatment (medications)" to [1] then:
If YES, who delivered this training? (Please tick all that apply)**

- Rheumatologist (any) Rheumatology clinical nurse specialist
 Pharmacist Community children's nurse
 Unknown

Please specify any additional options here...

**8g. If answered "Methotrexate SC" to [2] and "Treatment (medications)" to [1] then:
If SC Methotrexate, did the parent/carer receive training in how to give the injection?**

- Yes No Unknown NA

8h. If answered "Methotrexate SC" to [2] and "Yes" to [8g] and "Treatment (medications)" to [1] then:

If YES, who delivered this training?

- | | |
|---|---|
| <input type="checkbox"/> Rheumatologist (any) | <input type="checkbox"/> Rheumatology clinical nurse specialist |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Community children's nurse |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

Methotrexate PO

**9. If answered "Methotrexate PO" to [2] and "Treatment (medications)" to [1] then:
If Methotrexate PO; where was this initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

Other DMARDs

**10. If answered "Other DMARDs" to [2] and "Treatment (medications)" to [1] then:
If other DMARDs; where was this initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

Biologics

**11a. If answered "Biologics" to [2] and "Treatment (medications)" to [1] then:
If Biologics, where was this initiated?**

- Secondary care Tertiary care Unknown

If not listed above, please specify here...

**11b. If answered "Biologics" to [2] and "Treatment (medications)" to [1] then:
If Biologics, in your opinion was there any delay in initiating treatment?**

- Yes No Unknown

**11c. If answered "Biologics" to [2] and "Yes" to [11b] and "Treatment (medications)" to [1] then:
If Biologics and YES to delay, what were the reasons for this delay? (Please tick all that apply)**

- CYP/parent or carer factors (e.g. taking time to research the treatment, CYP/parent or carer getting a s
- Organisational factors under the control of the treating team (e.g. delays to drug education)
- Organisational factors not within the control of the treating team (e.g. home care delivery service dela
- Unavailability of a trained healthcare professional to administer the injection
- Unknown

Please specify any additional options here...

**11d.If answered "Biologics" to [2] and "Yes" to [11b] and "Treatment (medications)" to [1] then:
If Biologics and YES to delay, please give further details:**

**12a.If answered "Treatment (medications)" to [1] then:
Are there any barriers to the continuation of medication on transfer to adult services?**

- Yes
- No
- Unknown
- Not applicable - patient too young to transfer to adult services

**12b.If answered "Treatment (medications)" to [1] and "Yes" to [12a] then:
If YES, please give further details**

**13a.If answered "Treatment (medications)" to [1] then:
Was the CYP or parent/carer given information regarding treatment?**

- Yes
- No
- Unknown

**13b.If answered "Yes" to [13a] and "Treatment (medications)" to [1] then:
If YES, how was this information given? (Please tick all that apply)**

- Leaflet
- Signposted to a website
- Signposted to a video
- Unknown

Please specify any additional options here...

**14a.If answered "Treatment (medications)" to [1] then:
Did the CYP have counselling regarding treatment?**

- Yes
- No - not offered counselling
- No - counselling offered but CYP/parent or carer refused counselling
- Unknown
- NA - CYP too young

**14b.If answered "Yes" to [14a] and "Treatment (medications)" to [1] then:
If YES, who gave this counselling? (Please tick all that apply)**

- | | |
|---|--|
| <input type="checkbox"/> Rheumatologist (any) | <input type="checkbox"/> Other clinician |
| <input type="checkbox"/> Rheumatology clinical nurse specialist | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

**15a.If answered "Treatment (medications)" to [1] then:
Did the parent/carer have counselling regarding treatment?**

- Yes No Unknown

**15b.If answered "Yes" to [15a] and "Treatment (medications)" to [1] then:
If YES, who gave this counselling? (Please tick all that apply)**

- | | |
|---|--|
| <input type="checkbox"/> Rheumatologist (any) | <input type="checkbox"/> Other clinician |
| <input type="checkbox"/> Rheumatology clinical nurse specialist | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

TO BE COMPLETED BY A MEMBER OF THE TEAM INVOLVED IN THE ONGOING RHEUMATOLOGY CARE OF THE CYP

If you or a member of this team are not involved in the ongoing rheumatology care of the CYP, please continue to section L

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

What is the follow-up arrangement? (Please tick all that apply)

- Specialist paediatric rheumatology clinic in a designated specialist centre
- Adolescent paediatric rheumatology clinic with paediatric rheumatologist
- Adolescent paediatric rheumatology clinic with adult rheumatologist
- Dedicated paediatric rheumatology clinic in 2° Care/network centre – clinical lead paediatric rheumatologist
- Dedicated paediatric rheumatology clinic in 2° Care/network centre – clinical lead adult rheumatologist
- Dedicated paediatric rheumatology clinic in 2° Care/network centre – clinical lead paediatrician with special interest
- General paediatric clinic (with other non-rheumatological patients)
- Adult rheumatology clinic (with mixed non-JIA patients)
- Unknown

Please specify any additional options here...

3a. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

How frequently does the CYP have follow-up appointments with the rheumatologist?

- 3-monthly 6-monthly Annually Unknown

If not listed above, please specify here...

3b. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Please give any further details:

4a. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Has the CYP had follow up with physiotherapy?

- Yes No Unknown

4b. If answered "No" to [4a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Why not? (Please tick all that apply)

- Physiotherapy not needed CYP/parent or carer factors Organisational factors
 Unknown

Please specify any additional options here...

4c. If answered "No" to [4a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Please give any further details:

4d. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Has the CYP had follow up with occupational therapy?

- Yes No Unknown

4e. If answered "No" to [4d] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Why not? (Please tick all that apply)

- Occupational therapy not needed CYP/parent or carer factors
 Organisational factors Unknown

Please specify any additional options here...

**4f. If answered "No" to [4d] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:
Please give any further details:**

**4g. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:
Has the CYP had follow up with psychology?**

Yes No Unknown

**4h. If answered "No" to [4g] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:
Why not? (Please tick all that apply)**

Psychology not needed CYP/parent or carer factors Organisational factors
 Unknown

Please specify any additional options here...

**4i. If answered "No" to [4g] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:
Please give any further details:**

**4j. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:
Has the CYP had follow up with ophthalmology?**

Yes No Unknown

**4k. If answered "No" to [4j] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:
Why not? (Please tick all that apply)**

Ophthalmology not needed CYP/parent or carer factors Organisational factors
 Unknown

Please specify any additional options here...

4l. If answered "No" to [4j] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Please give any further details:

5. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Has the CYP missed any rheumatology appointments?

Yes

No

Unknown

TO BE COMPLETED BY A MEMBER OF THE TEAM INVOLVED IN THE ONGOING RHEUMATOLOGY CARE OF THE CYP

If you or a member of this team are not involved in the ongoing rheumatology care of the CYP, please continue to section L

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2a. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

Was the CYP aged over 13yr on the 31/03/2023?

- Yes No Unknown

2b. If answered "Yes" to [2a] and "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] then:

If YES, which of the following have been offered to the CYP: (Please tick all that apply)

- The opportunity to attend clinics out of school, college or work hours
- The opportunity for the CYP to be seen alone
- Correspondence addressed to the CYP
- Correspondence copied to the CYP
- The completion of 'Ready Steady Go' or equivalent
- Discussion of transfer to adult services
- A joint appointment with paediatric and adult rheumatology
- A key worker for transition
- A transition coordinator
- None of the above
- Unknown

2c. If answered "The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the ongoing clinical rheumatology care of the young person)" to [1] and "Yes" to [2a] then:

Please give any further details regarding the transition process for this CYP (i.e. transition into adolescent or young adult service).

TO BE COMPLETED BY A MEMBER OF THE TEAM INVOLVED IN THE COMMUNITY THERAPY OR COMMUNITY NURSING SERVICES

Please answer the questions in relation to the care provided up to the 31/03/2023

1. What aspects of this CYP's rheumatology care has this team been involved with? (Please tick all that apply)

- Making the diagnosis of JIA (to be completed by a member of the team who made the JIA diagnosis)
- The ongoing rheumatology care of the young person (to be completed by a member of the team responsible for the care)
- Treatment (medications)
- Community therapy or community nursing services
- None of the above

2. If answered "Community therapy or community nursing services" to [1] then: What is provided by this service? (Please tick all that apply)

- Physiotherapy
- Occupational therapy
- Community nursing support
- Orthotics
- Unknown

Please specify any additional options here...

3. If answered "Community therapy or community nursing services" to [1] then: How was the CYP referred to this service? (Please tick all that apply)

- Via the GP
- Via paediatric rheumatology
- Via adolescent rheumatology
- Via rheumatology
- Via orthopaedics
- Unknown

Please specify any additional options here...

4. If answered "Community therapy or community nursing services" to [1] then: How frequently does the CYP have follow-up appointments with this service?

- One-off appointment
- A block of appointments
- Regular ongoing appointments
- Unknown

If not listed above, please specify here...

5a. If answered "Community therapy or community nursing services" to [1] then: Are these appointments: (Please tick all that apply)

- Face to face
- Virtual
- Telephone
- Unknown

Please specify any additional options here...

5b. If answered "Community therapy or community nursing services" to [1] then: If YES to face to face, does this team see the CYP at the same site as the current rheumatology team providing ongoing rheumatology care?

- Yes
- No
- Unknown

**6. If answered "Community therapy or community nursing services" to [1] then:
Is the patient seen:**

- During the same appointment as the rheumatology team
- On the same day but at a separate time to the rheumatology team
- On a different day to the rheumatology team
- Unknown

If not listed above, please specify here...

**7. If answered "Community therapy or community nursing services" to [1] then:
Has the CYP missed any appointments with this service?**

- Yes No Unknown

**8a. If answered "Community therapy or community nursing services" to [1] then:
Is the CYP aged over 13yr on the 31/03/2023??**

- Yes No Unknown

8b. If answered "Yes" to [8a] and "Community therapy or community nursing services" to [1] then:

If YES, which of the following have been offered to the CYP: (Please tick all that apply)

- The opportunity to attend clinics out of school hours
- The opportunity for the CYP to be seen alone
- Correspondence addressed to the CYP
- The completion of 'Ready Steady Go' or equivalent
- Discussion of transfer to adult services
- A joint appointment with paediatric and adult rheumatology
- None of the above
- Unknown

8c. If answered "Yes" to [8a] and "Community therapy or community nursing services" to [1] then:

If YES, is there a process for transfer to adult therapy services?

- Yes No Unknown

**9. If answered "Community therapy or community nursing services" to [1] then:
Please give any further information regarding the support this service provides to the CYP**

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

By doing so you have contributed to the dataset that will form the report and recommendations due for release in late 2024