

# Juvenile idiopathic arthritis study: Reviewer assessment form

## A. Study inclusions and reviewer details

### 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.

The timeframe from which data will be sampled will be patients under the care of the rheumatology service between the 1st April 2021 – 31st March 2023.

Clinician questionnaires have been sent for young people where the arthritis diagnosis was made between the 1st April 2019 – 31st March 2023.

### Unable to answer

Please use the 'unable to answer' box if there is not enough information available in the notes to answer the question, or the part of the notes needed to answer the question have not been returned, or if there is not enough detail to form an opinion.

#### 1. NCEPOD number

*6 digit number beginning with 1*

*Value should be between 100,000 and 199,999*

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#### 2. Pseudo hospital number

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#### 3. Name of reviewer

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#### 4. Date of meeting

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#### 5. Site ID(s)

*6 digit number beginning with 3*

*Value should be between 300,000 and 399,999*

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#### 6. Trust ID(s)

*6 digit number beginning with 2*

*Value should be between 200,000 and 299,999*

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#### 7. Matching NCEPOD numbers (where applicable)

B. Child or Young Persons details

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

1a. What was the age of the CYP on 31/03/2023

 years

*Value should be no more than 24*

Unknown

1b. What was the age of the CYP at diagnosis?

 Years

*Value should be no more than 24*

Unknown

1c. If diagnosed after 16 years of age, did the patient have JIA symptoms before their 16th birthday?

Yes

No

Unable to answer

NA - diagnosed before 16 years

If the patient did not have any JIA symptoms before their 16th birthday, please let the NCEPOD staff know

2. Sex

Male

Female

Other

Unknown

3. Ethnicity

White British/White - other

Black/African/Caribbean/Black British

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

Mixed/Multiple ethnic groups

Unable to answer

If not listed above, please specify here...

4a. What classification of Juvenile Idiopathic Arthritis (JIA) did/does the CYP have? (Answers may be multiple)

Systemic-onset JIA

Persistent or extended oligoarthritis

RF-negative polyarthritis

RF-positive polyarthritis

Psoriatic JIA

Enthesitis-related arthritis

Undifferentiated

Unable to answer

Please specify any additional options here...

4b. If answered "Persistent or extended oligoarthritis" to [4a] then:  
If persistent or extended oligoarthritis, please specify which type.

Persistent oligoarthritis

Extended oligoarthritis

Unable to answer

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

Yes

No

Unable to answer

C. Summary of key dates and times

Please take a few minutes to read through the notes and familiarise yourself with the information available to you. As you go through the notes please record the following dates and times:

1. Date the symptoms started (approximately):

Unknown

2. Date CYP first presented to the GP with symptoms of JIA?

Not Applicable  Unknown

3. Date of referral from primary care to specialist services?

Not Applicable  Unknown

4. Date of first assessment following referral:

Unknown

5. Date of first assessment by a rheumatologist:

Unknown

6. Date of arthritis diagnosis:

Unknown

If diagnosed\* before 1st April 2019, please let the NCEPOD staff know

7a. Was the patient referred to ophthalmology?

Yes

No

Unable to answer

7b. If answered "Yes" to [7a] then:  
Date of referral to ophthalmology:

Unknown

7c. If answered "Yes" to [7a] then:  
Date of first ophthalmology assessment:

Unknown

8. Date JIA treatment started:

Unknown

D. Pathway of care

**1. 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"/> Unable to answer        |  |

Please specify any additional options here...

**If VIA GP**

**2a. If answered "Via GP" to [1] then:**

**In your opinion, did the GP refer to the right organisation(s)?**

- Yes                       No                       Unable to answer

**2b. If answered "Via GP" to [1] and "No" to [2a] then:**

**If NO, please expand on your answer:**

**3a. If answered "Via GP" to [1] then:**

**Which specialty(ies) was CYP referred to? (Please tick all that apply)**

- General Paediatrician  
 General paediatrician with an interest in rheumatology  
 Paediatric rheumatologist  
 Orthopaedics  
 Unable to answer

Please specify any additional options here...

**3b. If answered "Via GP" to [1] then:**

**In your opinion, did the GP refer to the right specialty(ies)?**

- Yes                       No                       Unable to answer

**3c. If answered "Via GP" to [1] and "No" to [3b] then:  
If NO, please expand on your answer:**

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**4a. If answered "Via GP" to [1] then:  
Did the GP request any investigations?**

Yes                       No                       Unable to answer

**4b. If answered "Via GP" to [1] and "Yes" to [4a] then:  
If YES, in your opinion, were these appropriate?**

Yes                       No                       Unable to answer

**4c. If answered "Via GP" to [1] and "Yes" to [4a] then:  
If YES, In your opinion, were any investigations not requested that should have been?**

Yes                       No                       Unable to answer

**4d. If answered "Via GP" to [1] and "Yes" to [4a] and "Yes" to [4c] then:  
If YES to 6c, please expand on your answer:**

**4e. If answered "Via GP" to [1] and "No" to [4a] then:  
If NO to investigations, in your opinion, should the GP have undertaken investigations  
prior to referral?**

Yes                       No                       Unable to answer

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**5a. If answered "Via GP" to [1] then:  
In your opinion, was there a delay in the GP referring to specialist services?**

Yes                       No                       Unable to answer

**5b. If answered "Via GP" to [1] and "Yes" to [5a] then:**

**If YES, what were the reasons for this? (Please tick all that apply)**

- CYP or parent/carer factors (e.g. taking time to research the treatment, appointment cancelled by CYP,
- Referral sent to the wrong specialty
- Administration error
- Service capacity
- Pathway error
- Unable to answer

Please specify any additional options here...

**5c. If answered "Via GP" to [1] and "Yes" to [5a] then:**

**If YES, please give any further details:**

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**FOR ALL MODES OF REFERRAL**

**6a. In your opinion, was there a delay in the parent/carers seeking help?**

- Yes                       No                       Unable to answer

**6b. If answered "Yes" to [6a] then:**

**If YES, please expand on your answer**

---

**7a. In your opinion was there a delay between first presentation with symptoms and referral to rheumatology?**

- Yes                       No                       Unable to answer

**7b. If answered "Yes" to [7a] then:  
If YES, please expand on your answer**

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**First review following referral**

**8a. In your opinion, was there a delay in first assessment following referral?**

- Yes                       No                       Unable to answer

**8b. If answered "Yes" to [8a] then:  
If YES, what were the reasons for this? (Please tick all that apply)**

- CYP or parent/carer factors (e.g. taking time to research the treatment, appointment cancelled by the parent)
- Referral sent to the wrong specialty
- Administration error
- Service capacity
- Pathway error
- Unknown

Please specify any additional options here...

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**9a. Specialty of clinician undertaking the first review: (please tick all that apply)**

- General Paediatrician
- General paediatrician with an interest in rheumatology
- Paediatric rheumatologist
- Adolescent rheumatologist
- Adult rheumatologist
- Orthopaedics
- Unable to answer

Please specify any additional options here...

**9b. In your opinion, was the first review undertaken by the right speciality?**

- Yes                       No                       Unable to answer

**9c. If answered "No" to [9b] then:  
If NO, please give further details**

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**10a. In your opinion was there a delay in assessment by a rheumatologist?**

- Yes                       No                       Unable to answer

**10b. If answered "Yes" to [10a] then:**

**If there was a delay in assessment by a rheumatologist, what was the reason for this?  
(Please tick all that apply)**

- CYP/parent or carer factors (e.g. taking time to research the treatment; appointment cancelled by CYP,
- Referral sent to the wrong specialty
- Administration error
- Service capacity
- Pathway error
- Unable to answer

Please specify any additional options here...

**10c. If answered "Yes" to [10a] then:  
Please expand on your answer**



**At initial assessment by the rheumatologist****1a. Is there evidence in the case notes that the initial assessment included: (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 alternative diagnoses | <input type="checkbox"/> None of these               |
| <input type="checkbox"/> Unable to answer                   |  |

Please specify any additional options here...

**1b. In your opinion, was the initial assessment satisfactory?**

- Yes
  No
  Unable to answer

**1c. If answered "No" to [1b] then:****If NO, please expand on your answer:**

**2a. In your opinion, was there a delay in diagnosis?**

- Yes
  No
  Unable to answer

**2b. If answered "Yes" to [2a] then:****If YES, what was the reason for this delay? (Please tick all the apply)**

- CYP or parent/carer factors (e.g. taking time to research the treatment; appointment cancelled by CYP,
- Referral sent to the wrong specialty
- Administration error
- Waiting for investigations
- Service capacity
- Pathway error
- Unable to answer

Please specify any additional options here...

**2c. If answered "Yes" to [2a] then:  
If YES, please expand on your answer:**

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**3a. Is there evidence in the case notes that the CYP was referred to ophthalmology at diagnosis?**

- Yes                       No                       Unable to answer

**3b. If answered "No" to [3a] then:  
If NO, is there evidence in the case notes that the CYP was subsequently referred?**

- Yes                       No                       Unable to answer

**3c. In your opinion, was the initial ophthalmology review timely?**

- Yes     No  
 Unable to answer                               NA - not referred to ophthalmology

**3d. If answered "No" to [3c] then:  
If NO, please expand on your answer**

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**4a. Did the CYP have uveitis?**

- Yes                       No                       Unable to answer

**4b. If answered "Yes" to [4a] then:  
If YES, was this a missed diagnosis?**

- Yes                       No                       Unable to answer

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**5. Is there evidence in the case notes of ongoing uveitis screening/ophthalmology review?**

- Yes                       No                       Unable to answer
-

**6a. Is there evidence in the case notes that the CYP was 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"/> Podiatry               |
| <input type="checkbox"/> Paediatric rheumatology clinical nurse specialist |   |
| <input type="checkbox"/> Adult rheumatology clinical nurse specialist      | <input type="checkbox"/> None of these services |
| <input type="checkbox"/> Unable to answer                                  |   |

**6b. If not referred to any of the above services, should they have been?**

- |  |   |
|--|---|
| <input type="radio"/> Yes              | <input type="radio"/> No  |
| <input type="radio"/> Unable to answer | <input type="radio"/> NA - referred to all appropriate services |

**6c. If answered "Yes" to [6b] then:**

**If YES, which services should they have been referred to? (Please tick all that apply)**

- |  |   |
|--|---|
| <input type="checkbox"/> Physiotherapy                                     | <input type="checkbox"/> Occupational therapy |
| <input type="checkbox"/> Psychology  | <input type="checkbox"/> Podiatry             |
| <input type="checkbox"/> Paediatric rheumatology clinical nurse specialist |   |
| <input type="checkbox"/> Adult rheumatology clinical nurse specialist      | <input type="checkbox"/> Unable to answer     |

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**7. Is there evidence in the case notes that a further appointment to offer JIA education booked following the initial assessment? (e.g. in person, as part of a group session, online etc.)**

- |                           |                          |  |
|---------------------------|--------------------------|--|
| <input type="radio"/> Yes | <input type="radio"/> No | <input type="radio"/> Unable to answer |
|---------------------------|--------------------------|--|

**1a. Which specialties were members of the MDT team? (Please tick all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> Paediatric rheumatology                | <input type="checkbox"/> Adolescent rheumatology           |
| <input type="checkbox"/> Adult 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"/> Unable to answer                       |  |

Please specify any additional options here...

**1b. In your opinion, were the essential specialties for this CYP included in the MDT?**

- Yes
  No
  Unable to answer

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

**If NO, which specialties should have been included? (Please tick all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> Paediatric rheumatology                | <input type="checkbox"/> Adolescent rheumatology           |
| <input type="checkbox"/> Adult 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"/> Unable to answer                       |  |

Please specify any additional options here...

**1d. In your opinion, was referral to the MDT team timely?**

- Yes  
 No  
 Unable to answer  
 NA - No evidence in the case notes the CYP was referred to an MDT team

**1e. If answered "No" to [1d] then:**

**If NO, please expand on your answer**

**2. Is there evidence in the case notes that the CYP has: (Please tick all that apply)**

*A key worker is defined as a care professional who takes a key role in co-ordinating the care of the patient and promoting continuity, ensuring the patient knows who to access for information and advice (NHS data model and dictionary)*

- A named rheumatologist
  A key worker
  None of these  
 Unable to answer

**3. Is there evidence in the case notes that a Rheumatology CNS has had contact with the patient?**

Yes

No

Unable to answer

G. Ongoing assessment of disease

**1. Is there evidence in the case notes, that at each rheumatology appointment, inflammation assessed clinically?**

- Yes                       No                       Unable to answer

**2a. Is there any evidence in the notes that JIA is having an impact on the CYP education or work?**

- Yes                       No                       Unable to answer

**2b. If answered "Yes" to [2a] then:  
If YES, please give further details**

**3a. What holistic/psychosocial discussion is documented in the notes?**

- None documented     Other documentation     Unable to answer

**3b. If answered "Other documentation" to [3a] then:  
If other documentation, please give further details**

**4. Is there evidence in the case notes that the patient was offered: (Please tick all that apply)**

- Information leaflets                       Signposted to a website                       Signposted to videos  
 Signposted to charity support     Offered acces to peer support  
 Was offered none of the above     Unable to answer

Please specify any additional options here...

H. Treatment

**1. What treatment has been initiated? (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"/> Unable to answer |   |  |

Please specify any additional options here...

---

**IA steroid joint injection**

**2a. If answered "IA steroid joint injection" to [1] then:  
In your opinion, was this treatment appropriate?**

- Yes                       No                       Unable to answer

**2b. If answered "IA steroid joint injection" to [1] and "No" to [2a] then:  
If NO, please expand on your answer:**

**2c. If answered "IA steroid joint injection" to [1] then:  
Is there any evidence in the case notes of delays in this treatment?**

- Yes                       No                       Unable to answer

**2d. If answered "IA steroid joint injection" to [1] and "Yes" to [2c] then:  
If YES, please expand on your answer:**

---

**PO steroids**

**3a. If answered "PO steroids" to [1] then:  
In your opinion, was this treatment appropriate?**

- Yes                       No                       Unable to answer

**3b. If answered "PO steroids" to [1] and "No" to [3a] then:  
If NO, please expand on your answer:**

**3c. If answered "PO steroids" to [1] then:  
Is there any evidence in the case notes of delays in this treatment?**

Yes                       No                       Unable to answer

**3d. If answered "PO steroids" to [1] and "Yes" to [3c] then:  
If YES, please expand on your answer:**

---

**IV steroids**

**4a. If answered "IV steroids" to [1] then:  
In your opinion, was this treatment appropriate?**

Yes                       No                       Unable to answer

**4b. If answered "IV steroids" to [1] and "No" to [4a] then:  
If NO, please expand on your answer:**

**4c. If answered "IV steroids" to [1] then:  
Is there any evidence in the case notes of delays in this treatment?**

Yes                       No                       Unable to answer



**4d. If answered "IV steroids" to [1] and "Yes" to [4c] then:  
If YES, please expand on your answer:**

---

**IM steroids**

**5a. If answered "IM steroids" to [1] then:  
In your opinion, was this treatment appropriate?**

Yes                       No                       Unable to answer

**5b. If answered "IM steroids" to [1] and "No" to [5a] then:  
If NO, please expand on your answer:**

**5c. If answered "IM steroids" to [1] then:  
Is there any evidence in the case notes of delays in this treatment?**

Yes                       No                       Unable to answer

**5d. If answered "IM steroids" to [1] and "Yes" to [5c] then:  
If YES, please expand on your answer:**

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**SC Methotrexate**

**6a. If answered "Methotrexate SC" to [1] then:  
In your opinion, was this treatment appropriate?**

Yes                       No                       Unable to answer

**6b. If answered "Methotrexate SC" to [1] and "No" to [6a] then:  
If NO, please expand on your answer:**

**6c. If answered "Methotrexate SC" to [1] then:  
Is there any evidence in the case notes of delays in initiating this treatment?**

- Yes                       No                       Unable to answer

**6d. If answered "Methotrexate SC" to [1] and "Yes" to [6c] then:  
If YES, please expand on your answer:**

**6e. If answered "Methotrexate SC" to [1] then:  
Is there evidence in the case notes the the patient or parent/carer received training in  
how to give the injection?**

- Yes                       No                       Unable to answer

**6f. If answered "Methotrexate SC" to [1] then:  
Is there evidence in the case notes that blood test monitoring is occurring/has occurred?**

- Yes                       No                       Unable to answer

**6g. If answered "Methotrexate SC" to [1] and "Yes" to [6f] then:  
If YES, who is carrying out the blood test monitoring? (Please tick all that apply)**

- GP                       CCNs                       Secondary care                       Tertiary care  
 Unable to answer

Please specify any additional options here...

**6h. If answered "Methotrexate SC" to [1] and "Yes" to [6f] then:  
If YES, is there evidence in the case notes that blood tests have been reviewed by the  
Rheumatology team?**

- Yes                       No                       Unable to answer

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**PO Methotrexate**

**7a. If answered "Methotrexate PO" to [1] then:  
In your opinion, was this treatment appropriate?**

- Yes                       No                       Unable to answer

**7b. If answered "Methotrexate PO" to [1] and "No" to [7a] then:  
If NO, please expand on your answer:**

**7c. If answered "Methotrexate PO" to [1] then:  
Is there any evidence in the case notes of delays in initiating this treatment?**

- Yes                       No                       Unable to answer

**7d. If answered "Methotrexate PO" to [1] and "Yes" to [7c] then:  
If YES, please expand on your answer:**

**7e. If answered "Methotrexate PO" to [1] then:  
Is there evidence in the case notes that blood test monitoring is occurring/has occurred?**

- Yes                       No                       Unable to answer

**7f. If answered "Methotrexate PO" to [1] and "Yes" to [7e] then:  
If YES, who is carrying out the blood test monitoring? (Please tick all that apply)**

- GP                       CCNs                       Secondary care                       Tertiary care  
 Unable to answer

Please specify any additional options here...

**7g. If answered "Methotrexate PO" to [1] and "Yes" to [7e] then:  
If YES, is there evidence in the case notes that blood tests have been reviewed by the  
Rheumatology team?**

- Yes                       No                       Unable to answer

---

**Other DMARDs**

**8a. If answered "Other DMARDs" to [1] then:  
In your opinion, was this treatment appropriate?**

- Yes                       No                       Unable to answer

**8b. If answered "Other DMARDs" to [1] and "No" to [8a] then:  
If NO, please expand on your answer:**

**8c. If answered "Other DMARDs" to [1] then:  
Is there any evidence in the case notes of delays in initiating this treatment?**

Yes                       No                       Unable to answer

**8d. If answered "Other DMARDs" to [1] and "Yes" to [8c] then:  
If YES, please expand on your answer:**

**8e. If answered "Other DMARDs" to [1] then:  
Is there evidence in the case notes that blood test monitoring is occurring/has occurred?**

Yes                       No                       Unable to answer

**8f. If answered "Other DMARDs" to [1] and "Yes" to [8e] then:  
If YES, who is carrying out the blood test monitoring? (Please tick all that apply)**

GP                       CCNs                       Secondary care                       Tertiary care  
 Unable to answer

Please specify any additional options here...

**8g. If answered "Other DMARDs" to [1] and "Yes" to [8e] then:  
If YES, is there evidence in the case notes that blood tests have been reviewed by the Rheumatology team?**

Yes                       No                       Unable to answer

---

**Biologics**

**9a. If answered "Biologics" to [1] then:  
In your opinion, was this treatment appropriate?**

Yes                       No                       Unable to answer

**9b. If answered "Biologics" to [1] and "No" to [9a] then:  
If NO, please expand on your answer:**

**9c. If answered "Biologics" to [1] then:  
Is there any evidence in the case notes of delays in initiating this treatment?**

- Yes                       No                       Unable to answer

**9d. If answered "Biologics" to [1] and "Yes" to [9c] then:  
If YES, please expand on your answer:**

**9e. If answered "Biologics" to [1] then:  
Is there evidence in the case notes the the patient or parent/carer received training in  
how to give the injection?**

- Yes                       No                       Unable to answer

**9f. If answered "Biologics" to [1] then:  
Is there evidence in the case notes that blood test monitoring is occurring/has occurred?**

- Yes                       No                       Unable to answer

**9g. If answered "Biologics" to [1] and "Yes" to [9f] then:  
If YES, who is carrying out the blood test monitoring? (Please tick all that apply)**

- GP                       CCNs                       Secondary care                       Tertiary care  
 Unable to answer

Please specify any additional options here...

**9h. If answered "Biologics" to [1] and "Yes" to [9f] then:  
If YES, is there evidence in the case notes that blood tests have been reviewed by the  
Rheumatology team?**

- Yes                       No                       Unable to answer

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**10a. Is there evidence in the case notes of any barriers to the continuation of medication on  
transfer to adult services?**

- Yes                       No  
 Unable to answer                       NA - not currently in the transfer process

**10b.If answered "Yes" to [10a] then:  
If YES, please give further details**

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**11a.Is there evidence in the case notes that the CYP or parent/carer given information regarding treatment?**

- Yes - for all treatments       Yes - for some treatments       No  
 Unable to answer

**11b.Please give further information regarding information given regarding treatment**

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**12. Is there evidence in the case notes that the CYP had counselling regarding treatment?**

- Yes       No       Unable to answer  
 Not applicable - too young

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**13. Is there evidence in the case notes that the parent/carer had counselling regarding treatment?**

- Yes       No       Unable to answer       Not applicable

**1. 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 in rheumatology
- General paediatric clinic (with other non-rheumatological patients)
- Adult rheumatology clinic (with mixed non-JIA patients)
- Unable to answer

Please specify any additional options here...

**2a. Based on the evidence in the case notes, how frequently does the CYP have follow-up appointments with the rheumatologist?**

- 3-monthly       6-monthly       Annually       Unable to answer

If not listed above, please specify here...

**2b. In your opinion, is this appropriate to the care of the CYP?**

- Yes       No       Unable to answer

**2c. Please expand on your answer:**

**3. Based on the case notes, what support is offered to the CYP during their follow up appointments? (Please tick all that apply)**

- Information regarding treatment options
- Information regarding general health issues (to maximise their physical, psychosocial and emotional d
- None of the above
- Unable to answer

Please specify any additional options here...

**4. Is there evidence in the case notes that the patient was asked about adherence to medication at each appointment?**

- Yes       No       Unable to answer

**5. Is there evidence in the case notes that the patient was asked about side effects of treatment at each appointment?**

- Yes                       No                       Unable to answer
- 

**6a. Is there evidence in the case notes that the CYP has had follow up with physiotherapy?**

- Yes                       No                       Unable to answer

**6b. If answered "No" to [6a] then:  
If NO, should they have done?**

- Yes                       No                       Unable to answer

**6c. If answered "No" to [6a] and "Yes" to [6b] then:  
If YES, please expand on your answer:**

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**7a. Is there evidence in the case notes that the CYP has had follow up with occupational therapy?**

- Yes                       No                       Unable to answer

**7b. If answered "No" to [7a] then:  
If NO, should they have done?**

- Yes                       No                       Unable to answer

**7c. If answered "No" to [7a] and "Yes" to [7b] then:  
If YES, please expand on your answer:**

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**8a. Is there evidence in the case notes that the CYP has had mental health follow up with:**

- Psychology
- CAMHs
- Adult mental health services
- Other (e.g. school counsellor, private therapy, art therapy, music therapy etc.)
- No follow up
- Unable to answer



**8b. If answered "Other (e.g. school counsellor, private therapy, art therapy, music therapy etc.)" to [8a] then:  
If other, please specify**

**8c. If answered "No follow up" to [8a] then:  
If the CYP had no mental health follow-up, should they have done?**

Yes                       No                       Unable to answer

**8d. If answered "Yes" to [8c] and "No follow up" to [8a] then:  
If YES, please expand on your answer:**

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**9. Is there evidence in the case notes that the CYP has missed any appointments?**

Yes                       No                       Unable to answer

**1a. Is the CYP aged over 13yr?**

- Yes                       No                       Unable to answer

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

**If YES, is there evidence in the case notes that/of: (Please tick all that apply)**

*A key worker is defined as a care professional who takes a key role in co-ordinating the care of the patient and promoting continuity, ensuring the patient knows who to access for information and advice (NHS data model and dictionary)*

- Clinic letters are addressed to the young person
- Wider psychosocial aspects have been addressed
- Ready Steady Go or equivalent transition documentation has been addressed
- Young people are given the opportunity to attend clinics out of school hours
- The CYP is given the opportunity to be seen alone
- There has been a discussion of transfer to adult services
- A joint appointment with paediatric and adult rheumatology
- A key worker
- A transition coordinator
- None of the above
- Unable to answer

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

**Please give any further information regarding the transition process (i.e transition into adolescent/young adult services)**

## K. Overall quality of care

### Please use the following grading to rate the overall quality of care received by this patient

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 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 NCEPOD to assess the quality of care

#### 1a. Please rate the overall quality of care using the grading system provided

- Good practice
- Room for improvement in clinical aspects of care
- Room for improvement in organisational aspects of care
- Room for improvement in clinical AND organisational aspects of care
- Less than satisfactory
- Insufficient data to grade

#### 1b. Please provide reasons for this grade

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#### 2a. Are there any themes/ issues from this case you feel should be highlighted in the final report?

- Yes  No

#### 2b. If answered "Yes" to [2a] then: If YES, please expand on your answer

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#### 3. Do you think we should use this case as an illustrative vignette/ case study in the report?

- Yes  No

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#### 4a. During review of this case did you notice any evidence of one or more health inequality or bias that impacted on the care provided?

- Yes  No  Unable to answer

**4b. If answered "Yes" to [4a] then:**

**What health inequalities exist in relation to this patient? (Please tick all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> Age  | <input type="checkbox"/> Disability - physical       |
| <input type="checkbox"/> Disability - learning/cognitive                | <input type="checkbox"/> Gender reassignment         |
| <input type="checkbox"/> Marriage and civil partnership                 | <input type="checkbox"/> Pregnancy and maternity     |
| <input type="checkbox"/> Race   | <input type="checkbox"/> Religion or belief          |
| <input type="checkbox"/> Sex  | <input type="checkbox"/> Sexual orientation          |
| <input type="checkbox"/> Socioeconomic status                           | <input type="checkbox"/> Geographic deprivation      |
| <input type="checkbox"/> Part of a vulnerable or inclusion health group | <input type="checkbox"/> Severe mental illness       |
| <input type="checkbox"/> Chronic respiratory disease                    | <input type="checkbox"/> Chronic respiratory disease |
| <input type="checkbox"/> Early cancer diagnosis                         | <input type="checkbox"/> Hypertension case finding   |
| <input type="checkbox"/> English not first language                     | <input type="checkbox"/> Travel time to hospital     |

Please specify any additional options here...

**4c. If answered "Yes" to [4a] and "Part of a vulnerable or inclusion health group" to [4b] then:**

**If 'part of a vulnerable or inclusion health group' which group? (Please tick all that apply)**

- |  |  |
|--|--|
| <input type="checkbox"/> Homelessness              | <input type="checkbox"/> Drug and alcohol dependence               |
| <input type="checkbox"/> Vulnerable migrants       | <input type="checkbox"/> Gypsy, Roma and Traveller communities     |
| <input type="checkbox"/> Sex workers               | <input type="checkbox"/> People in contact with the justice system |
| <input type="checkbox"/> Victims of modern slavery |  |

Please specify any additional options here...

**4d. If answered "Yes" to [4a] then:**

**If YES to J4a, please provide any further details**

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**CAUSE FOR CONCERN**

Occasionally NCEPOD will refer cases that have been identified as 'LESS THAN SATISFACTORY' when it is felt that further feedback to the Trust/ Health Board concerned is warranted. This is usually due to an area of concern to the hospital or clinician involved, and not for issues highlighted across the body of case notes. This process has been agreed by the NCEPOD Steering Group and the GMC. The medical director of the Trust/ Health Board is written to by the Chief Executive of NCEPOD explaining our concerns. This process has been in operation for 10 years and the responses received have always been positive in that they feel we are dealing with the concerns in the most appropriate manner.

**5. If answered "Less than satisfactory" to [1a] then:**

**Do you feel that this case should be considered for such action?**

- Yes                       No