

Juvenile idiopathic arthritis study: Primary care 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
- 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.
- Questionnaires have been sent for young people where the arthritis diagnosis was made between the 1st April 2019 – 31st March 2023.

Exclusions

Young people subsequently identified as not having JIA.

Who should complete this questionnaire?

This questionnaire should be completed by a member of the primary care team providing care to this young person. The questions should be answered in relation to the care provided by your organisation to the young person, and should be completed in relation to the care provided up to the 31/03/2023.

Please do not include any patient identifiers in the free text boxes

This questionnaire has been split into two parts.

Part 1 - asks questions about the organisation of services

Part 2 - ask clinical questions about a specific young person

Definitions

- A list of definitions can be found here: (this is not available yet - to be updated with link)
- 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

Clinicians who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for clinicians to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual clinicians. Consequently, NCEPOD recommends that clinicians who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence as part of the annual appraisal portfolio.

Once your questionnaire has been completed if you would like a certificate which can be used as evidence of involvement in quality improvement, please email arthritis@ncepod.org.uk.

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, Primary Care 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

Key recommendations from recent NCEPOD reports relevant to primary care include:

- Hard to Swallow? (2021) - Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital.
- Delay in Transit (2020) - Minimise delays to diagnosis and treatment for acute bowel obstruction. Development of an evidence-based pathway for acute bowel obstruction could facilitate this.
- Know the Score (2019) - All patients who have presented to hospitals with an acute pulmonary embolism

should be provided with a follow-up plan including the likely cause of the PE, details of the anticoagulant and length of prescription and a patient information leaflet.

- Failure to Function (2018) - All heart failure patients should have access to a heart failure multidisciplinary team. Core membership of this team should include the primary care team.
- Chronic neurodisability (2018) - General Practitioner Networks, Federations, Clusters, Health Boards and Partnerships, should consider developing Clinical Champions for neurodisabled patients to lead and help 'bridge the gap' between specialist neurodisability teams and primary/community care. Leads could be engaged in care from the early teens and function as an essential link with the wider paediatric multidisciplinary teams.
- Just Say Sepsis (2015) - To facilitate the transition from primary to secondary care, a standard method of referral should be introduced in primary care for patients who are in need of a hospital admission for, or thought to be at risk of, sepsis. This should include a full set of observations/ vital signs/risks/relevant history (such as previous sepsis) and any early warning scores used.

Further information and recommendations that may be of interest to primary care clinicians can be found: <https://www.ncepod.org.uk/pdf/publications/Common%20themes%20document.pdf>

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

Pathways of care

1a. B1a. Does this practice have a protocol for the investigation and management of JIA patients? (Please tick all that apply)

- Yes - for paediatrics
 Yes - for adolescents
 Yes - for adults
 No
 Unknown

1b. If answered "Yes - for paediatrics" to [1a] then:

B1b. If YES to paediatrics, does this protocol state: (please tick all that apply)

- What initial investigations should be carried out?
 What firstline medications should be used?
 Pathway of referral (who to refer to)?
 None of the above
 Unknown

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

B1c. If YES to adolescents, does this protocol state: (please tick all that apply)

- What initial investigations should be carried out?
 What firstline medications should be used?
 Pathway of referral (who to refer to)?
 None of the above
 Unknown

1d. If answered "Yes - for adults" to [1a] then:

B1d. If YES to adults, does this protocol state: (please tick all that apply)

- What initial investigations should be carried out?
 What firstline medications should be used?
 Pathway of referral (who to refer to)?
 None of the above
 Unknown

2a. B2a. In ALL patients with a suspected JIA diagnosis, is an ANA checked?

- Yes
 No
 Unknown

2b. B2b. In ALL patients with a suspected JIA diagnosis, are inflammatory markers (ESR and/or CRP) checked?

- Yes
 No
 Unknown

3a. B3a. Do the rheumatology team(s) to which patients are referred have set criteria for accepting referrals?

- Yes
 No
 Unknown

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

B3d. If YES to referral criteria, do these referral criteria lead to delays in CYP being seen by the rheumatology team (E.g. outcome of investigations prior to referral)?

- Yes
 No
 Unknown

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

B3d. If YES to referral criteria, do referral criteria state the patient should be referred prior to receiving the investigation results?

- Yes
 No
 Unknown

Training

4a. B4a. Does this organisation or individuals within this organisation participate in a rheumatology CPD programme?

Yes

No

Unknown

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

B4b. If YES, does this cover: (please tick all that apply)

Paediatric care

Adolescent care

Adult care

Unknown

Practice details

1. C1. Is this CYP known to you/this practice?

- Yes No

If NO please notify NCEPOD and return this questionnaire (hand your assignment back)

The young person's details

2. C2. Age (on the 31st March 2023)

years Unknown

3. C3. Sex

- Male Female Other Unknown

4. C4. 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. C5. What classification of Juvenile Idiopathic Arthritis (JIA) did/does the CYP have?

- Systemic-onset JIA Persistent or extended oligoarthritis
 RF-negative polyarthritis RF-positive polyarthritis
 Psoriatic JIA Enthesitis-related arthritis
 Undifferentiated Unknown

If not listed above, please specify here...

6. C6. Date of arthritis diagnosis:

Unknown

We are including CYP diagnosed with JIA between the 1st April 2019 - 31st March 2023. If diagnosed before 1st April 2019, please notify NCEPOD at arthritis@ncepod.org.uk.

Structured commentary

7. C7. Please use the box below to provide a brief summary of this case, adding any additional comments or information you feel is 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.

Specialist services are defined as services offered in secondary, tertiary or independent care organisations

1. D1. Did the patient present to this practice with symptoms prior to referral to specialist services?

- Yes No Unknown

If YES

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

D2. How many times did the CYP present with JIA symptoms (e.g. joint stiffness, rash, musculoskeletal involvement, swelling, eye problems) before being referred to secondary, tertiary or independent care?

Unknown

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

D3a. Were any treatments initiated before referral?

- Yes No Unknown

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

D3b. If YES, which of the following treatments were initiated? (Please tick all that apply)

- NSAIDs Unknown

Please specify any additional options here...

4a. If answered "Yes" to [1] then:

D4a. Were any investigations undertaken prior to referral?

- Yes No Unknown

4b. If answered "Yes" to [4a] and "Yes" to [1] then:

D4b. If YES, which of the following were requested? (Please tick all that apply)

- Blood tests X-ray Ultrasound MRI
 Unknown

Please specify any additional options here...

4c. If answered "Yes" to [4a] and "Blood tests" to [4b] and "Yes" to [1] then:

D4c. 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 | | |

5a. If answered "Yes" to [1] then:

D5a. Were any referrals to therapies made before referral?

- Yes No Unknown

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

D5b. If YES; which therapy services was the patient referred to? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Occupational therapy |
| <input type="checkbox"/> Child & Adolescent Mental Health services | <input type="checkbox"/> Unknown |

Please specify any additional options here...

1. E1. Was the patient referred to specialist services via this primary care practice?

- Yes No Unknown

If YES

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

E2. Which specialist service was the CYP initially referred to?

- Paediatric rheumatology Rheumatology General paediatrics
 Orthopaedics Ophthalmology Oncology
 Unknown

If not listed above, please specify here...

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

E3a. Was the first referral accepted?

- Yes No Unknown

3b. If answered "No" to [3a] and "Yes" to [1] then:

E3b. If NO, why was the first referral rejected?

3c. If answered "No" to [3a] and "Yes" to [1] then:

E3c. If NO (first referral not accepted), was the patient referred to the same service again?

- Yes No Unknown

4. If answered "Yes" to [1] then:

E4. Where was the patient seen by the paediatric rheumatologist/rheumatologist? (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 sp
 General paediatric clinic (with other non-rheumatological patients)
 Adult rheumatology clinic (with mixed non-JIA patients)
 Unknown

Please specify any additional options here...

**1a. F1a. What treatment(s) for JIA has the patient received? (Up to the 31st March 2023)
(Please tick all that apply)**

- NSAIDS IA joint injection Methotrexate SC Methotrexate PO
 Other DMARDS Biologics Unknown

Please specify any additional options here...

1b. F1b. Have you (your colleagues in this practice) prescribed any of these treatments?

- Yes No Unknown

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

F1c. If YES, which treatments have you prescribed? (Please tick all that apply)

- NSAIDS IA joint injection Unknown

Please specify any additional options here...

2. F2. Have you prescribed any supplementary medications for this patient (E.g. Vitamin D, folic acid, PPIs, calcium)?

- Yes No Unknown

3a. F3a. Do/Did you carry out blood test monitoring for the CYP?

- Yes No Unknown

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

F3b. If YES, do/Did you review the blood test results for the CYP?

- Yes No Unknown

4a. F4a. Have you referred the CYP for other therapeutic services following diagnosis?

- Yes No Unknown

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

F4b. If YES, which services? (Please tick all that apply)

- Physiotherapy Occupational therapy
 Child & Adolescent Mental Health services Unknown

Please specify any additional options here...

5. F5a. Is the patient under the care of ophthalmology?

- Yes No Unknown

5. If answered "No" to [5] then:

F5b. If NO, have they ever been seen by an ophthalmologist?

- Yes No Unknown

1. G1. Do/Did you attend any JIA MDT meetings for this patient?

Yes

No

Unknown

2. G2. Do you feel informed regarding the on-going rheumatology care of this patient?

Yes

No

Unknown

1a. H1a. Is the CYP aged over 13 years?

Yes

No

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

H1b. If YES, have you been involved in transition planning for this patient?

Yes

No

Unknown

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