

Juvenile idiopathic arthritis study: Organisational 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

Organisations providing healthcare to children and young people (CYP) aged between 0 and 24 years with JIA. This will include acute, community and independent organisations.

Who should complete this questionnaire?

This questionnaire has been designed to collect data on the organisational structures surrounding the care provided to CYP with JIA. It should be completed by or with input from, clinician(s) that provide care to this group of CYP.

The questionnaire has been designed to be completed at a Trust level and should be completed for organisations providing tertiary or secondary services. This includes organisations who don't provide rheumatology care for CYP with JIA, but refer patients to other organisations for their rheumatology care.

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.

B. THE ORGANISATION

1. B1. What type of organisation is this? (Please tick all that apply)

- Secondary care Tertiary care Community care
 Independent organisation Unknown

Please specify any additional options here...

2. B2. Does this organisation provide (Please tick all that apply)

- Children's services Young adult service Adult services Unknown

This question is repeated at the start of each section throughout the the questionnaire. It is acting as a filter to bring up the relevant questions in each section based on whether rheumatology services are provided to CYP with JIA in this organisation or not. 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.

3. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown

4a. If answered "Yes - in paediatric services" to [1] then:

B5a. Currently how many children with JIA are under the care of the rheumatology service?

- Not Applicable Unknown

4b. If answered "Yes - in adolescent services" to [1] then:

B5b. Currently how many adolescents with JIA are under the care of the rheumatology service?

- Not Applicable Unknown

4c. If answered "Yes - in adult services" to [1] then:

B5c. Currently how many young adults with JIA are under the care of the rheumatology service?

- Not Applicable Unknown

5. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

B3b. What aspects of JIA care is the organisation generally involved with?

- Making the diagnosis of JIA
 The ongoing rheumatology care of the young person
 Treatment
 Community therapy or community nursing services
 None of the above

Please specify any additional options here...

6. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

B6. Does this organisation share care of patients with JIA? (Please tick all that apply)

- Yes - with tertiary care (i.e. ongoing care at local hospital and going to see paediatric rheumatologist w
- Yes - with tertiary care (i.e. tertiary care provides an outreach clinic at local hospital)
- Yes - with secondary care (i.e. ongoing care at local hospital and going to see paediatric rheumatologis
- Yes - with secondary care (i.e. tertiary care provides an outreach clinic at local hospital)
- No
- Unknown

7. If answered "Secondary care" to [1] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

B7. In secondary care, who sees the patient for their JIA? (Please tick all that apply)

- General paediatrician
- General paediatrician with a special interest in rheumatology
- Paediatric rheumatologist
- Adult rheumatologist
- Other (please specify)
- Unknown

Please specify any additional options here...

8. B3. Does this organisation provide ophthalmology services? (Please tick all that apply)

- | | | |
|--|--|---|
| <input type="checkbox"/> Yes - for paediatrics | <input type="checkbox"/> Yes - for adolescents | <input type="checkbox"/> Yes - for adults |
| <input type="checkbox"/> No | <input type="checkbox"/> Unknown | |

TO BE COMPLETED BY ALL ORGANISATIONS**1. C1a. Does this organisation follow a written protocol, pathway or guideline for the investigation and management of JIA patients? (Please tick all that apply)**

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

If YES for paediatrics**2a. If answered "Yes - for paediatrics" to [1] then:
C2a Is this: (Please tick all that apply)**

- Local guidance
 National guidance
 Other (please specify)
 Unknown

Please specify any additional options here...

**2b. If answered "Yes - for paediatrics" to [1] then:
C2b. Up to what age does this cover**

- Not Applicable
 Unknown

**2c. If answered "Yes - for paediatrics" to [1] then:
C2c. Does this protocol state: (Please tick all that apply)**

- What investigations should be carried out at diagnosis
 Where to refer patients to if the diagnosis is likely to be JIA
 When imaging should be undertaken
 What medications should be used
 How frequently CYP are seen based on stage and type of condition
 When to escalate care
 Access to physiotherapy arrangements
 Access to occupational therapy arrangements
 Access to ophthalmology arrangements
 Access to psychology arrangements
 None of the above

Please specify any additional options here...

If YES for adolescents**3a. If answered "Yes - for adolescents" to [1] then:
C3a. Is this: (Please tick all that apply)**

- Local guidance
 National guidance
 Other (please specify)
 Unknown

Please specify any additional options here...

**3b. If answered "Yes - for adolescents" to [1] then:
C3b. Between what ages does this cover?**

- Not Applicable
 Unknown

3c. If answered "Yes - for adolescents" to [1] then:

C3c. Does this protocol state: (Please tick all that apply)

- What investigations should be carried out at diagnosis?
- Where to refer patients to if the diagnosis is likely to be JIA
- When imaging should be undertaken
- What medications should be used?
- How frequently CYP are seen based on stage and type of condition
- When to escalate care?
- Access to physiotherapy arrangements
- Access to occupational therapy arrangements
- Access to ophthalmology arrangements
- Access to psychology arrangements
- None of the above

Please specify any additional options here...

If YES for adults

4a. If answered "Yes - for adults with JIA" to [1] then:

C4a. Is this: (Please tick all that apply)

- Local guidance
- National guidance
- Other (please specify)
- Unknown

Please specify any additional options here...

4b. If answered "Yes - for adults with JIA" to [1] then:

C4b. From what age does this cover

- Not Applicable
- Unknown

4c. If answered "Yes - for adults with JIA" to [1] then:

C4c. Does this protocol state: (Please tick all that apply)

- What investigations should be carried out at diagnosis?
- Where to refer patients to if the diagnosis is likely to be JIA
- When imaging should be undertaken
- What medications should be used?
- How frequently CYP are seen based on stage and type of condition
- When to escalate care?
- Access to physiotherapy arrangements
- Access to occupational therapy arrangements
- Access to ophthalmology arrangements
- Access to psychology arrangements
- None of the above

TO BE COMPLETED BY ALL ORGANISATIONS

1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)

- Yes - in paediatric services
 Yes - in adolescent services
 Yes - in adult services
 No
 Unknown

2. D1a. Does this organisation have a rheumatology service for CYP with JIA? (Please tick all that apply)

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

If YES for paediatrics

3a. If answered "Yes - for paediatrics" to [2] then:

D2a. Is this service commissioned?

- Yes
 No
 Unknown

3b. If answered "Yes - for paediatrics" to [2] then:

D2b. What is the age range of young people seen by this service?

3c. If answered "Yes - for paediatrics" to [2] then:

D2c. Which specialists does this service have access to? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Paediatric rheumatology | <input type="checkbox"/> Adolescent rheumatology |
| <input type="checkbox"/> Rheumatology | <input type="checkbox"/> Physiotherapy |
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Rheumatology clinical nurse specialist |
| <input type="checkbox"/> Psychology | <input type="checkbox"/> Ophthalmology |
| <input type="checkbox"/> Radiology | <input type="checkbox"/> Podiatry |
| <input type="checkbox"/> Orthotics | <input type="checkbox"/> Play specialist |
| <input type="checkbox"/> Social worker | <input type="checkbox"/> Charity support worker |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Youth worker |
| <input type="checkbox"/> Family support worker | <input type="checkbox"/> Unknown |

Please specify any additional options here...

3d. If answered "Yes - for paediatrics" to [2] and "Rheumatology clinical nurse specialist" to [3c] then:

D2d. If YES for rheumatology clinical nurse specialists, how many does this organisation employ?

- Unknown

3e. If answered "Yes - for paediatrics" to [2] and "Rheumatology clinical nurse specialist" to [3c] then:

D2e. Please give any further details (including whether these are part time or full time roles)

3f. If answered "Yes - for paediatrics" to [2] and "Rheumatology clinical nurse specialist" to [3c] then:

D2f. Do any of the rheumatology clinical nurse specialists have their own clinic list where they see CYP autonomously

Yes No Unknown

3g. If answered "Yes - for paediatrics" to [2] and "Rheumatology clinical nurse specialist" to [3c] then:

D2g. Are there any identified gaps in staffing this service?

Yes No Unknown

3h. If answered "Yes - for paediatrics" to [2] and "Yes" to [3g] then:

D2h. If YES, please give details:

If YES for adolescents

4a. If answered "Yes - for adolescents" to [2] then:

D3a. Is this service commissioned?

Yes No Unknown

4b. If answered "Yes - for adolescents" to [2] then:

D3b. What is the age range of young people seen by this service?

4c. If answered "Yes - for adolescents" to [2] then:

D3c. Which specialists does this service have access to? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Paediatric rheumatology | <input type="checkbox"/> Adolescent rheumatology |
| <input type="checkbox"/> Rheumatology | <input type="checkbox"/> Physiotherapy |
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Rheumatology clinical nurse specialist |
| <input type="checkbox"/> Psychology | <input type="checkbox"/> Ophthalmology |
| <input type="checkbox"/> Radiology | <input type="checkbox"/> Podiatry |
| <input type="checkbox"/> Orthotics | <input type="checkbox"/> Play specialist |
| <input type="checkbox"/> Social worker | <input type="checkbox"/> Charity support worker |
| <input type="checkbox"/> Pharmacist | <input type="checkbox"/> Youth worker |
| <input type="checkbox"/> Family support worker | <input type="checkbox"/> Unknown |

Please specify any additional options here...

4d. If answered "Yes - for adolescents" to [2] and "Rheumatology clinical nurse specialist" to [4c] then:

D3d. If YES for rheumatology clinical nurse specialists, how many does this organisation employ?

Unknown

4e. If answered "Yes - for adolescents" to [2] and "Rheumatology clinical nurse specialist" to [4c] then:

D3e. Please give any further details (including whether these are part time or full time roles)

4f. If answered "Yes - for adolescents" to [2] and "Rheumatology clinical nurse specialist" to [4c] then:

D3f. Do any of the rheumatology clinical nurse specialists have their own clinic list where they see CYP autonomously?

- Yes No Unknown

4g. If answered "Yes - for adolescents" to [2] and "Rheumatology clinical nurse specialist" to [4c] then:

D3g. Are there any identified gaps in staffing this service?

- Yes No Unknown

4h. If answered "Yes - for adolescents" to [2] and "Rheumatology clinical nurse specialist" to [4c] and "Yes" to [4g] then:

D3h. If YES, please give details:

If YES for adults

5a. If answered "Yes - for adults with JIA" to [2] then:

D4a. Is this service commissioned?

- Yes No Unknown

5b. If answered "Yes - for adults with JIA" to [2] then:

D4b. What is the age range of young people seen by this service?

5c. If answered "Yes - for adults with JIA" to [2] then:

D4c. Which specialists does this service have access to? (Please tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Rheumatology | <input type="checkbox"/> Physiotherapy |
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Rheumatology clinical nurse specialists |
| <input type="checkbox"/> Psychology | <input type="checkbox"/> Ophthalmology |
| <input type="checkbox"/> Radiology | <input type="checkbox"/> Podiatry |
| <input type="checkbox"/> Orthotics | <input type="checkbox"/> Social worker |
| <input type="checkbox"/> Charity support worker | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Youth worker | <input type="checkbox"/> Family support worker |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

5d. If answered "Yes - for adults with JIA" to [2] and "Rheumatology clinical nurse specialists" to [5c] then:

D4d. If YES for rheumatology clinical nurse specialists, how many does this organisation employ?

- Unknown

5e. If answered "Yes - for adults with JIA" to [2] and "Rheumatology clinical nurse specialists" to [5c] then:

D4e. Please give any further details (including whether these are part time or full time roles)

5f. If answered "Yes - for adults with JIA" to [2] and "Rheumatology clinical nurse specialists" to [5c] then:

D4f. Do any of the rheumatology clinical nurse specialists have their own clinic list where they see CYP autonomously?

- Yes No Unknown

5g. If answered "Yes - for adults with JIA" to [2] and "Rheumatology clinical nurse specialists" to [5c] then:

D4g. Are there any identified gaps in staffing this service?

- Yes No Unknown

5h. If answered "Yes - for adults with JIA" to [2] and "Rheumatology clinical nurse specialists" to [5c] and "Yes" to [5g] then:

D4h. If YES, please give details:

6. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

D5. Does this organisation have a lead for paediatric/adolescent rheumatology?

- Yes No Unknown

7. D6. Does this organisation have: (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> A paediatric acute pain team | <input type="checkbox"/> An adolescent acute pain team |
| <input type="checkbox"/> An adult acute pain team | <input type="checkbox"/> A paediatric chronic pain team |
| <input type="checkbox"/> An adolescent chronic pain team | <input type="checkbox"/> An adult chronic pain team |
| <input type="checkbox"/> No pain team | <input type="checkbox"/> Unknown |

TO BE COMPLETED BY ORGANISATIONS PROVIDING RHEUMATOLOGY CARE TO CYP WITH JIA**1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)**

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown

2a. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**E1a. Does this organisation hold scheduled MDT meetings to discuss JIA patients? (Please tick all that apply)**

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

If YES for paediatrics**2b. If answered "Yes - for paediatrics" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:****E1b. Who typically attends these meetings? (Please tick all that apply)**

- Paediatric rheumatology
 Rheumatology
 Physiotherapy
 Occupational therapy
 Clinical nurse specialists
 Psychology
 Ophthalmology
 Podiatry
 Orthotics
 Radiology
 Other clinicians involved in JIA care of CYP from within this organisation
 Other clinicians involved in JIA care of CYP from outside this organisation
 Unknown

Please specify any additional options here...

2c. If answered "Yes - for paediatrics" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**E1c. How often does this team meet?**

- Once a week Once a month Unknown

If not listed above, please specify here...

If YES for adolescents

2d. If answered "Yes - for adolescents" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

E1d. Who typically attends these meetings? (Please tick all that apply)

- Paediatric rheumatology
- Rheumatology
- Physiotherapy
- Occupational therapy
- Clinical nurse specialists
- Psychology
- Ophthalmology
- Podiatry
- Orthotics
- Radiology
- Other clinicians involved in JIA care of CYP from within this organisation
- Other clinicians involved in JIA care of CYP from outside this organisation
- Unknown

Please specify any additional options here...

2e. If answered "Yes - for adolescents" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

E1e. How often does this team meet?

- Once a week Once a month Unknown

If not listed above, please specify here...

If YES for adults

2f. If answered "Yes - for adults with JIA" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

E1f. Who typically attends these meetings? (Please tick all that apply)

- Paediatric rheumatology
- Rheumatology
- Physiotherapy
- Occupational therapy
- Clinical nurse specialists
- Psychology
- Ophthalmology
- Podiatry
- Orthotics
- Radiology
- Other clinicians involved in JIA care of CYP from within this organisation
- Other clinicians involved in JIA care of CYP from outside this organisation
- Unknown

Please specify any additional options here...

2g. If answered "Yes - for adults with JIA" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

E1g. How often does this team meet?

- Once a week Once a month Unknown

If not listed above, please specify here...

TO BE COMPLETED BY ALL ORGANISATIONS**1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)**

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown

2a. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**F1a. Does this organisation hold rheumatology clinics for CYP with JIA? (Please tick all that apply)**

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

If YES for paediatrics**2b. If answered "Yes - for paediatrics" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:****F1b. In general which speciality does the patient see at these clinic appointments? (Please tick all that apply)**

- Paediatric rheumatology Rheumatology Clinical nurse specialist
 Physiotherapist Occupational therapist Psychologist
 Unknown

Please specify any additional options here...

2c. If answered "Yes - for paediatrics" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**F1c. When are these clinics held? (Please tick all that apply)**

- Normal working hours (Monday - Friday, 8am-6pm)
 Evenings Saturdays
 Sundays Unknown

Please specify any additional options here...

If YES for adolescents**2d. If answered "Yes - for adolescents" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:****F1d. In general which speciality does the patient see at these clinic appointments? (Please tick all that apply)**

- Paediatric rheumatology Rheumatology Clinical nurse specialist
 Physiotherapist Occupational therapist Psychologist
 Unknown

Please specify any additional options here...

2e. If answered "Yes - for adolescents" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**F1e. When are these clinics held? (Please tick all that apply)**

- Normal working hours (Monday - Friday, 8am-6pm)
 Evenings Saturdays
 Sundays Unknown

Please specify any additional options here...

If YES for adults

2f. If answered "Yes - for adults with JIA" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F1f. In general which speciality does the patient see at these clinic appointments? (Please tick all that apply)

- | | | |
|---|--|--|
| <input type="checkbox"/> Rheumatology | <input type="checkbox"/> Clinical nurse specialist | <input type="checkbox"/> Physiotherapist |
| <input type="checkbox"/> Occupational therapist | <input type="checkbox"/> Psychologist | <input type="checkbox"/> Unknown |

Please specify any additional options here...

2g. If answered "Yes - for adults with JIA" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F1g. When are these clinics held? (Please tick all that apply)

- | | |
|--|------------------------------------|
| <input type="checkbox"/> Normal working hours (Monday - Friday, 8am-6pm) | |
| <input type="checkbox"/> Evenings | <input type="checkbox"/> Saturdays |
| <input type="checkbox"/> Sundays | <input type="checkbox"/> Unknown |

Please specify any additional options here...

3. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F3. Does this organisation have a dedicated urgent access clinic for CYP with JIA? (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Yes - for paediatrics | <input type="checkbox"/> Yes - for adolescents | <input type="checkbox"/> Yes - for adults with JIA |
| <input type="checkbox"/> No | <input type="checkbox"/> Unknown | |

4a. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F4a. In this organisation, do JIA clinics always happen in an age appropriate place? (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Yes - for paediatrics | <input type="checkbox"/> Yes - for adolescents | <input type="checkbox"/> Yes - for adults with JIA |
| <input type="checkbox"/> No | <input type="checkbox"/> Unknown | |

4b. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F5a. In this organisation, do JIA clinics always happen in the same place? (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Yes - for paediatrics | <input type="checkbox"/> Yes - for adolescents | <input type="checkbox"/> Yes - for adults with JIA |
| <input type="checkbox"/> No | <input type="checkbox"/> Unknown | |

5. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F6. Does this organisation offer remote (e.g. video, telephone or virtual) follow-up appointments for CYP with JIA? (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Yes - for paediatrics | <input type="checkbox"/> Yes - for adolescents | <input type="checkbox"/> Yes - for adults with JIA |
| <input type="checkbox"/> No | <input type="checkbox"/> Unknown | |

6. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F7. Does this organisation have sufficient follow-up appointments for when CYP with JIA need to be seen? (Please tick all that apply)

- | | | |
|--|--|--|
| <input type="checkbox"/> Yes - for paediatrics | <input type="checkbox"/> Yes - for adolescents | <input type="checkbox"/> Yes - for adults with JIA |
| <input type="checkbox"/> No | <input type="checkbox"/> Unknown | |

7. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

F8. Does this organisation provide patient initiated follow up for CYP with JIA? (Please tick all that apply)

- Yes - for paediatrics
 No

- Yes - for adolescents
 Unknown

- Yes - for adults with JIA

8a. F2a. Does this organisation hold ophthalmology clinics for patients with JIA? (Please tick all that apply)

- Yes - for paediatrics
 No

- Yes - for adolescents
 Unknown

- Yes - for adults

8b. If answered "Yes - for paediatrics" to [8a] then:

F2b. If YES for paediatrics, is this a joint ophthalmology/rheumatology clinic?

- Yes - combined clinics
 Yes - same day clinics
 Yes - other clinic
 No - separate clinic
 Unknown
 NA - rheumatology care for CYP with JIA not provided at this hospital

8c. If answered "Yes - for adolescents" to [8a] then:

F2c. If YES for adolescents, is this a joint ophthalmology/rheumatology clinic?

- Yes - combined clinics
 Yes - same day clinics
 Yes - other clinic
 No - separate clinic
 Unknown
 NA - rheumatology care for CYP with JIA not provided at this hospital

8d. If answered "Yes - for adults" to [8a] then:

F2d. If YES for adults, is this a joint ophthalmology/rheumatology clinic?

- Yes - combined clinics
 Yes - same day clinics
 Yes - other clinic
 No
 Unknown
 NA - rheumatology care for CYP with JIA not provided at this hospital

G. TREATMENTS

TO BE COMPLETED BY ORGANISATIONS PROVIDING RHEUMATOLOGY CARE TO CYP WITH JIA

1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown
-

2. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

G1a. Is this organisation commissioned to prescribe biological treatments for CYP with JIA? (Please tick all that apply)

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

TO BE COMPLETED BY ALL ORGANISATIONS

1a. H1a. Is this organisation a member of a network of care for JIA? (Please tick all that apply)

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

If YES for paediatrics

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

H1b. Is this network:

- Formal
 Informal
 Unknown

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

H1c. Do members of this network meet on a regular basis?

- Yes
 No
 Unknown

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

H1e. Does this network include primary care and/or community providers?

- Yes
 No
 Unknown

1e. If answered "Yes" to [1d] then:

H1f. If YES to includes primary/community providers, which specialties are included? (Please tick all that apply)

- Primary care
 Community physiotherapy
 Community occupational therapy
 Unknown

Please specify any additional options here...

If YES for adolescents

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

H1g. Is this network:

- Formal
 Informal
 Unknown

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

H1f. Do members of this network meet on a regular basis?

- Yes
 No
 Unknown

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

H1o. Does this network include primary care and/or community providers?

- Yes
 No
 Unknown

1i. If answered "Yes - for adolescents" to [1a] and "Yes" to [1h] then:

H1k. If YES to includes primary/community providers, which specialties are included? (Please tick all that apply)

- Primary care
 Community physiotherapy
 Community occupational therapy
 Unknown

Please specify any additional options here...

If YES for adults

1j. If answered "Yes - for adults with JIA" to [1a] then:

H1l. Is this network:

- Formal
 Informal
 Unknown

1k. If answered "Yes - for adults with JIA" to [1a] then:

H1m. Do members of this network meet on a regular basis?

- Yes
 No
 Unknown

1l. If answered "Yes - for adults with JIA" to [1a] then:

H1n. Does this network include primary care and/or community providers?

- Yes No Unknown

1m. If answered "Yes - for adults with JIA" to [1a] and "Yes" to [1l] then:

**H1p. If YES to includes primary/community providers, which specialties are included?
(Please tick all that apply)**

- Primary care Community physiotherapy
 Community occupational therapy Unknown

Please specify any additional options here...

I. TRANSITION

TO BE COMPLETED BY ORGANISATIONS PROVIDING RHEUMATOLOGY CARE TO CYP WITH JIA

1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown

2a. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

J1a. Does this organisation have a process for the transition of JIA patients from paediatric to adult care?

- Yes No Unknown

2b. If answered "Yes" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

J1b. If YES, does this organisation follow NICE guidelines for transition?

- Yes No Unknown

3. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

J1c. Does this organisation hold joint clinics where paediatric and adult staff see patients with JIA who are transitioning?

- Yes No Unknown

TO BE COMPLETED BY ORGANISATIONS PROVIDING RHEUMATOLOGY CARE TO CYP WITH JIA

1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)

- Yes - in paediatric services
 Yes - in adolescent services
 Yes - in adult services
 No
 Unknown

2a. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

K1a. Does this organisation routinely give patients and carers information on JIA? (Please tick all that apply)

- Yes - at the time of diagnosis
 Yes - at treatment initiation
 Yes - at transition from child to adult services
 No
 Unknown

2b. If answered "Yes - at the time of diagnosis", "Yes - at treatment initiation" or "Yes - at transition from child to adult services" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

K1b. If YES, what information is provided? (Please tick all that apply)

- Information on the disease
 Information on the side effects of medicine
 Information on whom to contact and how (If there are any problems)
 Information on how to access charities and other third sector organisations
 Unknown

Please specify any additional options here...

3. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

K2. Does this organisation signpost CYP with JIA as to where to access peer support? (Please tick all that apply)

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

4. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

K3. Does the organisation have information for patients on how to contact their rheumatology team? (Please tick all that apply)

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

TO BE COMPLETED BY ORGANISATIONS PROVIDING RHEUMATOLOGY CARE TO CYP WITH JIA**1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)**

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown
-

2. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**L1. Are clinicians looking after CYP with JIA able to access a rheumatology CPD programme about CYP with JIA? (Please tick all that apply)**

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

3. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**L2. Do clinical nurse specialists in this organisation provide training to young people and parent carers in the self-administration of medication and/or injections?**

- Yes No Unknown
-

4. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**L3. Does this organisation enable CYP to participate in clinical research and/or trials for JIA? (Please tick all that apply)**

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

TO BE COMPLETED BY ORGANISATIONS PROVIDING RHEUMATOLOGY CARE TO CYP WITH JIA**1. B4. Does this organisation provide rheumatology care to children and young people with JIA? (Please tick all that apply)**

- Yes - in paediatric services Yes - in adolescent services Yes - in adult services
 No Unknown

2a. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**M1a. Does this organisation audit the care of JIA patients? (Please tick all that apply)**

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

If YES for paediatrics**2b. If answered "Yes - for paediatrics" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:****M1b. What is audited? (Please tick all that apply)**

- Time from referral to being seen Patient satisfaction surveys
 Other quality outcome measures Unknown

Please specify any additional options here...

2c. If answered "Yes - for paediatrics" to [2a] and "Other quality outcome measures" to [2b] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:**M1c. If YES to other quality outcome measures, please specify:**

If YES for adolescents**2d. If answered "Yes - for adolescents" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:****M1d. What is audited? (Please tick all that apply)**

- Time from referral to being seen Patient satisfaction surveys
 Other quality outcome measures Unknown

Please specify any additional options here...

2e. If answered "Yes - for adolescents" to [2a] and "Other quality outcome measures" to [2d] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

M1e. If YES to other quality outcome measures, please specify:

If YES for adults

2f. If answered "Yes - for adults with JIA" to [2a] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

M1f. What is audited? (Please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Time from referral to being seen | <input type="checkbox"/> Patient satisfaction surveys |
| <input type="checkbox"/> Other quality outcome measures | <input type="checkbox"/> Unknown |

Please specify any additional options here...

2g. If answered "Yes - for adults with JIA" to [2a] and "Other quality outcome measures" to [2f] and "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

M1g. If YES to other quality outcome measures, please specify:

3. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

M2. Are PROMS/PREMS routinely collected for CYP with JIA?

- Yes No Unknown

4. If answered "Yes - in paediatric services", "Yes - in adolescent services" or "Yes - in adult services" to [1] then:

M3. Does this organisation participate in a programme of continuous quality improvement for CYP with JIA?

- 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.