

Introduction



What is this study about?

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

The study will be used to produce a report for clinicians and other healthcare professionals about how to improve the care they deliver.

Data collection methods include:

- Patient and parent care views (surveys and focus groups)
- Clinician views (survey)
- Case note review

Information is being collected across England, Wales, and Northern Ireland. It is essential that we hear the views and

experiences of clinicians who treat these patients directly. If you would like a copy of the final report, please email: arthritis@ncepod.org.uk

Who should complete this survey?

Please complete this survey if you are or could be involved in the care of children and young people with JIA. Please answer the questions in this survey based on your current role and organisation, based on your day-to-day practice.

All responses given as part of this study are confidential

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.

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

Clinician details

We recognise that some staff groups will have different experiences and will feel better able to answer some questions. Where you are unable to answer a question, please indicate this by marking your response as 'unknown'

Please state your job role:

- Doctor
- Clinical nurse specialist
- Physiotherapist
- Occupational therapist
- Other (please specify)

Please state your specialty:

- General paediatrics
- General paediatrics with an interest in rheumatology
- Paediatric rheumatology
- Adolescent rheumatology
- Adult rheumatology
- General practitioner
- Other (please specify)

Which type of setting do you work in? (Please tick all that apply)

- Primary care
- Secondary care
- Tertiary care
- Community care
- Independent care
- Other (please specify)

Does your organisation provide: (Please tick all that apply)

- Paediatric services
- Adolescent services
- Adult services
- Other services

Pathway of care

In your opinion, for children and young people (CYP) with suspected Juvenile Idiopathic Arthritis (JIA) how well

does the referral process work?

- Not well at all
- Slightly well
- Moderately well
- Very well
- Extremely well
- Unknown

Can you refer patients with suspected JIA to directly the rheumatology service?

- Yes
- No
- Unknown
- Not applicable

For new referrals, can you always see patients in the specified time frame (i.e. within 4 weeks of referral from primary care)

- Yes
- No
- Unknown
- Not applicable

What is the length of time given for the first appointment with a new patient?

How frequently do you have to overbook clinics for new patients?

- Never
- Sometimes
- About half the time
- Most of the time
- Always
- Unknown
- Not applicable

How frequently do you have to overbook clinics for follow up appointments?

- Never
- Sometimes
- About half the time
- Most of the time
- Always
- Unknown
- Not applicable

Do you always refer CYP with a new diagnosis of JIA to ophthalmology at diagnosis?

Yes

No

Not applicable

If not, why not?

Do you always refer CYP with a new diagnosis of JIA to physiotherapy at diagnosis?

Yes

No

Not applicable

If not, why not?

Do you always refer CYP with a new diagnosis of JIA to occupational therapy at diagnosis?

Yes

No

Not applicable

If not, why not?

Job planning/The MDT

If you are a rheumatologist or general paediatrician with an interest in rheumatology, how many of your Programmed Activities (PAs) are dedicated to the rheumatology service?

In your opinion, is this enough time?

Yes

No

If you're a clinical nurse specialist, physiotherapist or occupational therapist, how many hours per week are dedicated to the rheumatology service?

In your opinion, is this enough time?

Yes

No

Are you involved in a regular MDT about rheumatology patients?

Yes

No

Unknown

If YES, how frequently is this held?

Weekly

Monthly

Other (please specify)

Unknown

In your opinion, are there any identified gaps in staffing the rheumatology service?

Yes

No

Unknown

If YES, please give further details

Treatment

Do you prescribe: (Please tick all that apply)

- Methotrexate
- Other DMARDs
- Biologics (including biosimilars)
- None of the above
- Unknown

Do you train parents/carers/patients on how to give Methotrexate injections?

Yes

No

Do you provide education on other medications?

Yes

No

Do you think there are delays in the initiation of treatments?

Yes

No

Unknown

If YES, why are there delays? (Please tick all that apply)

- Administrative delays
- Prescribing delays
- Delivery delays
- Training delays
- Patient delays
- Other (please specify)
- Unknown

Do you think there are delays with continuing treatments?

Yes

No

Unknown

If YES, why are there delays? (Please tick all that apply)

- Administrative delays
- Prescribing delays
- Delivery delays
- Training delays
- Patient delays
- Other
- Unknown

In your opinion are any barriers to the continuation of medication on transfer to adult services?

- Yes
- No
- Unknown

If YES, please give further details

Ongoing support around the patients diagnosis

Where do you refer CYP with JIA to for support? (Please tick all that apply)

- Charities
- Peer support
- Websites
- Youth worker
- Family support worker
- Play specialist
- Other (please specify)
- Unknown

Does your organisation provide: (please tick all that apply)

- A dedicated telephone helpline for CYP with JIA
- A dedicated email helpline for CYP with JIA
- Other (please specify)
- None
- Unknown

Is there enough capacity to respond to all enquiries that come through helpline?

Yes

No

Unknown

What mental health support are you able to offer CYP with JIA? (Please tick all that apply)

- None
- Trust/Health Board psychologist
- Referral to CAMHs
- Referral to adult mental health service
- Referral to third sector organisation
- Other (please specify)
- Unknown
- Not applicable

Training & research

Have you had any additional training in the care of CYP with JIA

Yes

No

Do you feel this training provided you with enough education to manage patients with JIA?

Yes

No

Unknown

Are you able to offer CYP the opportunity to participate in clinical research and/or trials for JIA?

- Yes
- No
- Unknown
- Not applicable

Overall

In your opinion, what one change would most improve the treatment of patients with JIA?

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY

Your responses will contribute to a report and

recommendations that aim to improve the care of patients with JIA

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