



NCEPOD: Juvenile Idiopathic Arthritis (JIA) - Parent/carer survey

Who is NCEPOD?

NCEPOD is a national organisation who reviews clinical care and the organisation of services. We do this by undertaking confidential surveys on different areas of healthcare and produce reports, which include recommendations for clinicians and management to implement, with the aim of improving the quality of the care delivered.

What is this study about?

This study will review the quality of care for children and young people (CYP), (aged 0-24 years) with Juvenile Idiopathic Arthritis (JIA). The study will be used to produce a report for clinicians and other healthcare staff about how to improve the future care of CYP with JIA. The recommendations will also inform CYP with JIA and their families and care givers on what standard of care they should expect to receive. Information will be collected across England, Wales, Northern Ireland, and Jersey.

Throughout the questionnaire Juvenile Idiopathic Arthritis will be shortened to JIA.

To find out more about the study, please visit:

<https://www.ncepod.org.uk/JIA.html> or email arthritis@ncepod.org.uk

Who should complete this survey?

Please complete this survey if you are the parent or carer of someone who has/or has had JIA and is aged 0-24 years old.

ALL RESPONSES GIVEN AS PART OF THIS STUDY ARE CONFIDENTIAL AND WE ARE UNABLE TO COMMENT ON INDIVIDUAL CASES

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<https://www.ncepod.org.uk/pdf/current/Privacy%20notice%20for%20website%20v9.pdf>

We recognise that different people will have different experiences. You might find some questions easier to answer than others. If you feel unable to respond to certain questions, please tick the box "Unknown" in the answer questions.

This survey take roughly 10 minutes to complete but may take longer depending on the answers given.

Background information

Does/has the child or young person you care for have/had Juvenile Idiopathic arthritis (JIA)?

- Yes
- No

If NO, please do not answer any more of this survey

How old is your child?

Are they:

- Male
- Female
- Non-binary
- Other (Please specify)
- Prefer not to say

Ethnicity

- White British/ White other
- Black/ African/ Caribbean/ Black British
- Asian/ Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)
- Mixed/ Multiple ethnic groups
- Prefer not to say
- Other (Please specify)

At what age was your child diagnosed with JIA?

Diagnosis of JIA

Thinking back to before your child was diagnosed with JIA, did you speak to a GP about your child's JIA symptoms?

- Yes
 No

Why didn't you speak to a GP?

Do you think the GP took you or your child seriously?

- Yes
 No
 Unknown

Did your GP refer your child directly to a rheumatologist (i.e., a doctor who can treat JIA)?

- Yes
 No
 Unknown

Before your child's diagnosis of JIA, did you contact any of the following? (Please tick all that apply)

- Private GP
 Physiotherapist
 Osteopath
 Chiropractor
 NHS hospital (e.g., Urgent Care or an Emergency Department)
 Private hospital

Other (please specify)

Not applicable - did not contact any of the above

At diagnosis was your child referred to an eye specialist (such as an ophthalmologist)?

Yes

No

Unknown

In your opinion, was there a delay in diagnosing your child's JIA?

Yes

No

Unknown

If you want to add more about the process of getting your child's diagnosis of JIA, please do here:

Ongoing support

After your child was diagnosed, who is/was involved in your child's care? (Please tick all that apply)

Rheumatology

Clinical nurse specialist (CNS)

Ophthalmology (i.e. an eye specialist)

Physiotherapy

Occupational Therapy

Psychology

CAMHS (Child and Adolescent Mental Health Services)

Adult mental health services

Podiatry

GP

- Pharmacist
- No healthcare professional
- Other (Please specify)
- Unknown

Do/did you have health or social care professional who you could contact directly about your child's JIA? (e.g., if their symptoms suddenly got worse?)

- Yes
- No
- Unknown

Do/did you feel you could talk to them openly in an understanding and tolerant environment?

- Yes
- No
- Unknown

Has your child been offered the opportunity to talk to other children or young people with JIA?

- Yes
- No
- Unknown

Have you been offered the opportunity to discuss your child's condition with other parents/carers of children and young people with JIA?

- Yes
- No
- Unknown

Medication

Was your child prescribed medication for their JIA? (excluding pain medication)

- Yes

- No
- Unknown

Were the potential benefits and side effects discussed with you by a doctor or nurse?

- Yes
- No
- Unknown

Did the conversation make you feel better about your child taking the medication(s)?

- Yes
- No
- Unknown

If your child was given a medicine that needed to be injected, were you offered training on how to administer the medication?

- Yes
- No
- Not applicable - not prescribed medicines by injection
- Unknown

Are/were your medications reviewed regularly?

- Yes
- No
- Unknown

Approximately how far do/did you travel to collect the medication?

- 0-30 minutes
- 30-60 minutes
- More than 1 hour
- More than 2 hours
- More than 3 hours
- More than 5 hours

- Unknown
- Not applicable - delivered to my home

Was your child prescribed pain medication?

- Yes
- No
- Unknown
- Not applicable - no medication needed

Has your child ever been offered the opportunity to participate in clinical research and/or trials for JIA?

- Yes
- No
- Unknown

Equipment

Has your child used equipment (e.g. wheelchair, crutches etc.) due to their JIA?

- Yes
- Yes - but I could not access the equipment I needed
- No
- Unknown

Do/did you know who to contact to get the equipment?

- Yes
- No
- Unknown

Is/was the equipment provided for free?

- Yes
- No
- Unknown

If there is more you want to add about access to equipment, please do here:

Schooling and Employment

Is your child primarily:

- In education
- In work
- Other (please specify)

How many days of school, college or university has your CYP you missed (in the last year) due to their JIA, if any??

Were the school, college or university understanding if your child needed to miss days due to their JIA?

- Yes
- No
- Unknown
- Not applicable - no days missed due to their JIA

Did the school put together a plan to support your child when in school that you, your child and your healthcare team were able to input into and update over time?

- Yes
- No
- Unknown

Approximately how many days of work has your child missed (in the last year) due to their JIA, if any?

Are/were work understanding of your CYP's JIA (e.g., do/did they understand if they need/needed to miss work to attend appointments)?

- Yes
- No
- Unknown
- Not applicable - no days missed due to JIA

If you want to add more about the impact of JIA on your child's education or work, please do here:

Overall

Do you feel society understands the challenges for children and young people living with JIA?

- Yes
- No
- Unknown

What do you feel can done to change the way people think about JIA?

Overall, what one thing do you think could change to improve the care of people with JIA?

Thank you for completing this survey.

Your answers will help inform the recommendations in the final report and hopefully help to improve the experience of children and young people with JIA.

If you have any questions regarding this survey, or the Juvenile Idiopathic Arthritis (JIA) study, please email arthritis@ncepod.org.uk.

To receive a copy of this report, please email info@ncepod.org.uk.

The NCEPOD Juvenile Idiopathic Arthritis (JIA) Team.

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