



NCEPOD: Juvenile Idiopathic Arthritis (JIA) - Young Person 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 have/or have had JIA and are aged 0-24 years old.

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

Please see our Privacy Notice for more information:

<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 takes roughly 10 minutes but may take longer depending on the answers provided.

Information about yourself

Do you have/have you ever had Juvenile Idopathic arthritis (JIA)?

- Yes
 No

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

How old are you?

Are you:

- Male
 Female
 Non-binary
 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 were you diagnosed with JIA?

Diagnosis of JIA

Thinking back to before you were diagnosed with JIA, did you/or your parent/carer speak to your GP about your JIA symptoms?

- Yes
 No

Why did you or your parent not speak to your GP?

Do you think the GP took you or your parent carer seriously?

- Yes
 No
 Unknown

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

- Yes
 No
 Unknown

Before being diagnosed with JIA, did you (or your parent/carer) 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 doctor
 Other (Please specify)
 Not applicable - did not contact any of the above

When you were told you had JIA, did you see an eye specialist (such as an ophthalmologist)?

- Yes
- No
- Unknown

In your opinion, was there a delay in the doctors diagnosing your JIA?

- Yes
- No
- Unknown

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

Ongoing support

After you were told you had JIA, who was involved in your care? (Please tick all that apply)

- Rheumatology
- Clinical Nurse Specialist (CNS)
- Ophthalmology (i.e. an eye doctor)
- Physiotherapy (Physio)
- Occupational Therapy (OT)
- Psychology
- CAMHS (Child and Adolescent Mental Health Services)
- Adult mental health services
- Podiatry
- GP
- Pharmacist
- No healthcare worker was involved in care

Other (Please specify)

Unknown

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

Yes

No

Unknown

Do/did you feel comfortable talking to them (i.e. were they friendly and understanding)?

Yes

No

Unknown

Were you offered the opportunity to talk to other children or young people with JIA?

Yes

No

Unknown

Medication

Were you prescribed medication for your 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 taking the medication(s)?

- Yes
- No
- Unknown

If you were given a medicine that needed to be injected, were you offered training on how to take the medication?

- Yes
- No
- Unknown
- Not applicable - never had to take medication by injection

Are/were your medications reviewed regularly?

- Yes
- No
- Unknown

Approximately how far (in time) do/did you travel to collect your 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 - my medication is delivered to my home

Were you prescribed pain medication?

- Yes
- No
- Not applicable - pain medication not needed
- Unknown

Have you ever been asked to take part in clinical research and/or trials for JIA?

- Yes
- No
- Unknown

Equipment

Have you ever needed to use equipment (e.g. wheelchair, crutches etc.) due to your 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 given to you for free?

- Yes
- No
- Unknown

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

Schooling and Employment

Are you primarily:

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

Approximately how many days of school, college or university have you missed (in the last year) due to your JIA, if any?

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

- Yes
- No
- Unknown
- Not applicable - have not missed any days due to your JIA

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

- Yes
- No
- Unknown

Approximately how many days of work have you missed (in the last year) due to your JIA?

Are/were work understanding of your JIA (e.g., do/did they understand if you need or needed to miss work due to your JIA or do/did they offer extra help at while at work)?

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

If you want to add more about the impact of JIA on your 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 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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