

Juvenile Idiopathic Arthritis (JIA) FAQ

Which organisations should be participating in the study?

All acute, tertiary, community and independent care organisations that provide rheumatology care for children and young adults aged 0-24 years with JIA. Organisations are being asked to return data on all patients who they provided care for over the 2-year study period (1st April 2021 to 31st March 2023).

Primary care practices that are identified as involved in the care of the sample of patients selected for further review, will be sent a 'Primary care combined clinician and organisational questionnaire' for completion.

Are patients with an old diagnosis of JIA, who have been referred to the organisation included?

Yes, all patients, whether they have been diagnosed with JIA in another organisation or newly diagnosed in your organisation are included in the study. The diagnosis of JIA does not need to have been made within the 2-year study period.

How are patients identified for the study?

Two patient identifier spreadsheets will be used to identify children and young adults to include in the study:

a) Study contact patient identifier spreadsheet:

In order to identify a sample of patients from the outpatient community, the study contact has been asked to provide the details of the last 50 children and young adults (aged 0-24 years) referred to the rheumatology service, up to the 31st March 2023, and no earlier than the 1st April 2021, where a diagnosis of JIA has been made.

b) Local Reporter patient identifier spreadsheet:

The Local Reporter has been asked to provide the details of all children and young adults (0-24 years) who presented to their organisation between 1st April 2021 – 31st March 2023 with at least one of the included ICD10 codes recorded in any position. This should include day case admissions and outpatient attendances where available.

Why are you requesting the patient identification spreadsheets to be requested from both the study contact and the local reporter? Is this not duplication of work?

We are asking study contacts for the details of the last 50 patients referred to the rheumatology service. As some organisations will have more than 50 patients referred over the 2-year period, asking for the details of admissions as well will potentially enable us to identify any additional patients not included on the study contact spreadsheet. In addition to this we will also be tracking patients across multiple organisations (where applicable) and so the local reporter spreadsheet will help with this.

We also understand that not all rheumatology departments will keep an electronic record of their patients, and so where this is the case, we would potentially still be able to identify some patients for inclusion from the local reporter spreadsheet.

We will be checking all spreadsheets for duplication to ensure each patient is only included once for each organisation.

How are patients being tracked across multiple organisations?

In the selected sample of patients identified for the study, the NHS number and date of birth will be used to track healthcare across multiple organisations.

The details of providers of care outside the organisation submitting the data will be requested in both the Study contact and Local Reporter patient identifier spreadsheet spreadsheets, and in the clinician questionnaires. If a child or young adult is identified as receiving care from an organisation, but was not included on their initial data spreadsheet, the local reporter of that organisation will be contacted, before questionnaires are sent out, and asked to confirm whether they are known to them based on the available NHS number.

I work in adult services. Do I only include patients where the diagnosis of JIA has been made under the care of adult services?

No, please also include the details of patients who have an existing diagnosis (made whilst under the care of paediatric services) who have subsequently been transferred into adult services.

Our organisation's ICD10 codes are limited to four digits. For the included condition: L40.54, Psoriatic juvenile arthropathy can I substitute it with L405, Arthropathic psoriasis?

Yes

How to fill in the Juvenile Idiopathic Arthritis (JIA) Clinician Questionnaire (CQ)

Separate questionnaires will be sent to all teams involved in the young person's rheumatology care.

Sections A, B, C and D are to be completed by all teams involved in the rheumatology care of the CYP:

- **A – Introduction**
- **B – Organisation details**
- **C – Clinician details & a structured commentary**
- **D – Child or Young Person's Details**

When you get to **SECTION E** the Clinician Questionnaire (CQ) is then separated into four areas of the JIA pathway:

- The diagnosis of JIA
- The ongoing rheumatology care of the CYP
- Treatment
- Community therapy or community nursing services

Please complete the sections of the questionnaire that are relevant to the rheumatology care this team has provided to this CYP. The table below gives further information:

<u>PARTS OF THE PATHWAY</u>	<u>SECTIONS OF CQ</u>	<u>INFORMATION ON WHO SHOULD COMPLETE THE SECTIONS</u>
<u>THE DIAGNOSIS OF JIA</u>	<ul style="list-style-type: none"> • E - Pathway of care • F - Diagnosis 	To be completed by a member of the team who made the jia diagnosis.
<u>THE ONGOING RHEUMATOLOGY CARE OF THE CYP</u>	<ul style="list-style-type: none"> • G – The rheumatology team • H – Ongoing assessment of disease • J – Follow-up • K – Transition 	To be completed by a member of the team was involved in ongoing the rheumatology care of the CYP.
<u>TREATMENT</u>	<ul style="list-style-type: none"> • I – Treatment 	To be completed by a member of the team involved in the treatment of the CYP, including their medication management.
<u>COMMUNITY THERAPY AND COMMUNITY NURSING SERVICES</u>	<ul style="list-style-type: none"> • L – Community therapy and community nursing services 	To be completed by a member of the team involved in the community therapy or community nursing services.

Question C2 asks what aspects of this CYP's rheumatology care has this team been involved with. When you answer this question it will open the relevant sections of the questionnaire for completion. Once these have all been completed you will be able to submit the questionnaire.

If there are any other teams regularly involved in the rheumatology care of this CYP, please indicate this in **question B1c**. This will enable us to send a separate questionnaire on to these teams for completion.