



## How we will use your data to improve the care provided to patients with Juvenile Idiopathic Arthritis (JIA)

### Parent/Carer Information Leaflet

Please read this leaflet carefully. It explains who we are, what we are doing & how we keep data confidential and anonymous.

This hospital is taking part in a confidential enquiry to see where care can be made better for future children and young people who have JIA.

#### What is NCEPOD?

NCEPOD is a national organisation that runs confidential enquiries to improve the quality of care for future patients in England, Wales and Northern Ireland. For over 30 years we have run studies, in different areas of healthcare, that have had a real impact on how healthcare is now delivered. NCEPOD looks at areas of care that we think could be improved by reviewing the care that patients have received.

#### What is the study on JIA about?

This study will involve us collecting data from all organisations where someone with JIA may be cared for. For example, we may ask a hospital where your child or young person came in to be seen for their JIA, for information about their care. At the same time, we may ask someone in the rheumatology service for information about their care, so we can also collect information about their care if they were not admitted to hospital but seen in an outpatient service.

#### What information about the young person you provide care for will be collected?

At the start we will collect their NHS/Hospital number, date of birth and sex.

If their data is randomly chosen for inclusion in the study, we will go to the clinicians involved in their care and ask them to complete a questionnaire and return copies of parts of their case notes so that we can ask other clinicians to show us where they think planning went well and where it could have been improved. At this point all the data that would identify them, such as name, address, date of birth etc. will have been removed from what the clinicians see, so they will not know who they are.

#### Is their information secure?

**Yes**, their information is secure. All data sent electronically to us will be secured by a password. Any questionnaires sent to us in the post will not include any identifiable information. Access to the information we collect is limited to the small NCEPOD team. All personal information in the case notes we collect will be removed. All data is kept in a secure, alarmed office, either in locked cabinets or on secure computers.

#### What will happen to their information?

- We will also **never** share information that can identify them with any other organisations for any reason other than for linking datasets with approved partners
- All patient data, including case notes, will be securely disposed of at the end of the study

- Their name will **never appear** in any project publication. It will be **impossible** for them to be recognised from the analysis as we will combine their data with that of lots of other patients

## Why haven't I been asked for permission to use their information?

We have approval from the Secretary of State for Health for the purpose of this confidential enquiry to store and use patient information without consent. More information is [available here](#).

## Can I ask for their data not to be used?

**Yes**, if the young person is aged under 16 years, or over 16 years and you are their court appointed Care and Welfare Deputy, you can ask us to delete their data at **any time** without it affecting the level of care they receive, or you can tell us that they don't want their data used, more generally, just in case it is selected.

You can contact the person below, and she will make a note that it should not be included if it is selected.

**MARISA MASON**  
**GROUND FLOOR, ABBEY HOUSE**  
**74-76 ST JOHN STREET**  
**LONDON, EC1M 4DZ**  
**0207 2519060**  
[\*\*mmason@ncepod.org.uk\*\*](mailto:mmason@ncepod.org.uk)

## Who is commissioning and funding the work?

NCEPOD's work is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of the funding bodies listed below and additional funding by independent sector hospitals:

- NHS England
- Welsh Government
- Department of Health, Northern Ireland

## What do I do if I think the data has not been used correctly?

If you have concerns about the way the young person's personal data is being handled please contact Marisa Mason as detailed above. If you feel it is serious enough, you also have the right to contact the Information Commissioner's Office, the authority in the UK responsible for data protection law. They can be contacted by telephone 0303 123 1113 or via their website <https://ico.org.uk/concerns/>

## Contact details

NCEPOD is a Registered Charity in England and Wales:  
1075588 and a company limited by guarantee: 3019382

[www.ncepod.org.uk](http://www.ncepod.org.uk)

