



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

Patient Information Leaflet

Please read this leaflet carefully. It explains who we are, what we are doing & how we keep your data confidential and you 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 you came in to be seen for your JIA, for information about your care. At the same time, we may ask someone in the rheumatology service for information about your care, so we can also collect information about your care if you were not admitted to hospital but seen in an outpatient service.

What information about me will be collected?

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

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

Is my information secure?

Yes, your information is secure. All the data sent electronically to us will be secured by a password. 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 my information?

- We will also **never** share information that can identify you 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
- Your name will **never appear** in any project publication. It will be **impossible** for you to be recognised from the analysis as we will combine your data with that of lots of other patients

Why haven't I been asked for permission to use my 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 my data not to be used?

Yes, you can ask us to delete your data at **any time** without it affecting the level of care you receive, or you can tell us more generally that you don't want your data used, just in case it is selected.

If you (if aged 16 or over) don't want your data used, you can let us know, or if you are aged under 16* ask your parent or carer to 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

**A parent or carer can also contact us on behalf of a young person aged 16 or over if they are their court appointed Care and Welfare Deputy.*

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 my data has not been used correctly?

If you have concerns about the way your 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

