



How we will use personal data to improve the pathway of care for patients with a learning disability

INFORMATION LEAFLET

PLEASE READ THIS LEAFLET CAREFULLY. IT EXPLAINS WHO WE ARE, WHAT WE ARE DOING AND HOW WE KEEP DATA CONFIDENTIAL AND PEOPLE ANONYMOUS.

This hospital is taking part in a confidential enquiry to see where care can be made better in the future, for people with a learning disability when they go to hospital as an emergency.

WHAT IS NCEPOD?

NCEPOD is a national organisation that runs confidential enquiries to improve the quality of care for people 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 people have received.

WHAT IS THE STUDY ON LEARNING DISABILITY ABOUT?

In this study, we will collect data from acute hospitals with emergency departments to understand how to improve care for patients with a learning disability who need hospital treatment when they are unwell.

So, for example we may ask whether reasonable adjustments in hospitals are made. This could be changes to routines, communication methods, or the physical environment that makes care more accessible for patients with different needs. This could include offering quieter waiting areas or providing easy-read information.

WHAT INFORMATION WILL BE COLLECTED?

At the start, we will collect the NHS and 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 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 someone, such as name, address, date of birth etc will have been removed from what the clinicians see, so they will not know who anyone is.

IS THE CONFIDENTIAL, PERSONAL INFORMATION SECURE?

Yes, all personal 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 clinical 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 THE INFORMATION?

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

WHY DOES NCEPOD NOT HAVE TO GET CONSENT TO USE PERSONAL INFORMATION?

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

CAN I ASK FOR MY DATA TO NOT 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.

MARISA MASON - mmason@ncepod.org.uk - 0207 251 9060

GROUND FLOOR, ABBEY HOUSE, 74-76 ST JOHN STREET, LONDON, EC1M 4DZ

Who is commissioning and funding the work?

NCEPOD's work is commissioned and funded as part of the Health Quality Improvement Partnership (HQIP) Medical Surgical Review Programme. More information can be found here: <https://www.ncepod.org.uk/medicalsurgical>

What do I do if I think any data has not been handled correctly?

If you have concerns about the way personal data are being handled, please contact Marisa Mason via email mmason@ncepod.org.uk. 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 www.ncepod.org.uk - 020 7251 9060 Learning@ncepod.org.uk

GROUND FLOOR, ABBEY HOUSE, 74-76 ST JOHN STREET, LONDON,
EC1M 4DZ

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