



How we will use your data to improve the pathways of care for patients with acute sigmoid volvulus

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 improved for patients with acute sigmoid volvulus. This is a common emergency condition and often recurrent in nature.

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 35 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 acute sigmoid volvulus about?

This study will involve us collecting data from all hospitals that admit and treat patients with acute sigmoid volvulus. We will look at the whole care pathway. For example, we may ask a hospital where you underwent treatment for acute sigmoid volvulus to provide some information about your care.

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.

We will also invite all healthcare professionals who were involved in your care to share their views in a survey on what went well and what could have been improved from their perspective.

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 your care with approved partners (e.g. if you were transferred from one hospital to another, we may request data from both hospitals)
- 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?

In order to carry out this work in England and Wales, we have been given 'section 251' support to collect and use this information under very strict conditions of confidentiality and data security by the Secretary of State for Health and Social Care, on advice from the [Confidentiality Advisory Group \(CAG\) at the Health Research Authority](#). In Northern Ireland the work has been supported by the Privacy Advisory Committee. Access to this information is strictly limited to those who need to process it, and all information in the final report is anonymous. Once the study is complete all data are securely destroyed. More information is [available here](#).

In addition, in England, the [National Data Opt-Out](#) (NDOO) is a process that allows individuals to opt-out of their confidential patient information being used for purposes other than medical care. Because of [reported variations in who is opting-out](#), it is possible that the datasets on which NCEPOD is basing its work are biased, which in turn could impact our study findings. To ensure that NCEPOD recommendations are not affected by this variation, we will not be excluding the data of individuals who have opted out via the NDOO. We have been granted this exemption by the Secretary of State for Health and Social Care, on advice from the [Confidentiality Advisory Group \(CAG\)](#) at the Health Research Authority (HRA). However, individuals still have the right to [contact NCEPOD and ask for their data to be removed and permanently erased](#) (see below).

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.

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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
- Bailiwick of Jersey

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

