

NCEPOD uses patient data collected from hospitals, GPs, and the community to help improve the quality of care for future patients.

Getting involved

If you would like to hear more about what we do or would like to be involved with our work we would like to hear from you - please email info@ncepod.org.uk or call us on 0207 251 9060

Opting out

All patients (aged 16 or over) or relatives/carers representing the patient (aged under 16*) have the right to opt out of NCEPOD using personal information for the purpose described here. To do so please contact us by post, email or by telephone. We do not collect patient names so will require your NHS number to identify your data.

(NB this right is not affected by NCEPOD being exempt from applying the National Data Opt-Out)

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**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.*



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

What is NCEPOD?

NCEPOD is a national organisation that undertakes confidential enquiries to improve the quality of care for future patients. For nearly 40 years we have run studies in different areas of healthcare that have had a real impact on how healthcare is now delivered. You can read about what we do on our website www.ncepod.org.uk, and see [some of our impact](#).

What patient information NCEPOD collects

Contacts in every hospital identify a large sample of patients relevant to each study. This information is supplied to us electronically, and will include data such as NHS number/hospital number/date of birth/ethnicity/age and date of discharge. From this larger sample we pick a random sample of patients for inclusion of their data into a more detailed review by clinicians.

For each patient included we ask that a questionnaire is completed by the clinician involved in the patient's care, and that copies of extracts of case notes, reports and test results are returned to us. We may also request copies of letters and medical records from other doctors such as GPs; this is so we can look across the whole pathway of care to spot any areas that could be improved, such as delays in referral, or access to particular services.

When we first receive this data it will be identifiable, however as we would never need to contact a patient, all identifiers are removed before any case is reviewed. And once all cases have been reviewed, and the study written up, the data are all securely destroyed.

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). NCEPOD has also been granted exemption from the National Data Opt-Out in England because of [reported variations in who is opting-out](#), and the impact this might have on the datasets we use and the study findings.

We currently collect information for two work programmes

1. The Medical and Surgical Clinical Outcome Review Programme

This programme has been running since 1987 and has been influential in:

Reducing surgery being performed out of hours

An improvement in trauma and cancer services

Improving recognition of very sick patients who are getting worse

2. The Child Health Clinical Outcome Review Programme

This programme has been running since 2011 and has been influential in:

The transition of young people from child to adult healthcare services

Improving the care of young people with juvenile idiopathic arthritis

Boys with testicular torsion

Both work programmes are commissioned by HQIP as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). The programme is funded by NHS England, the Welsh Government, Northern Ireland Government and Jersey www.hqip.org.uk/national@programmes.