



NCEPOD Privacy Notice

Introduction

This page is intended to provide information for patients, clinicians, parents/carers of service users whose information may be used for NCEPOD's work. It explains what type of information we collect, why we collect it and what we do with it.

This privacy policy was updated in February 2020 to meet the requirements of the National Data Opt-Out in England. We will update this privacy policy whenever we change the type of processing we carry out. Please regularly come back to this page and check this policy for any changes.

Our legal basis for collecting information

The legal bases for collecting and using personal data are:

Public Task

We collect only the information that is necessary to carry out our function and avoid collecting information that will not be used. This is received from healthcare providers, such as NHS Trusts and Health Boards. To see what information is held in your healthcare record please contact your local Trust or Board.

Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

Consent

Where people sign up to receive newsletters and updates, attend events or work with NCEPOD consent is received for us to store and process personal data.

Contract

For example, this is the basis we use when it is necessary for us to take specific steps before entering into a contract with you to supply you a service or vice versa.

Legal obligation

For example, this is the basis we use when it is necessary for us to comply with the law (not including contractual obligations) because we are required to keep documentation to produce in court proceedings.

Legitimate interests

This basis is used to allow us to hold information as evidence should we need it in the future, for example, if you ask us to unsubscribe you from our newsletter.

Common Law Duty of Confidentiality

We apply the Common Law Duty of Confidentiality to all data we hold.

Article 9 condition for processing special category data:

- 2(i) - processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis

of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy

When we collect your information

If you are a patient, we may collect your NHS number and date of birth early in the study when we collect a list of patients meeting certain criteria from your healthcare provider.

If you are a clinician, we will ask for your name and email address, and possibly other information, when you:

- Complete a questionnaire
- Sign up for updates on the NCEPOD work programme
- Become a study contact, Local Reporter, Ambassador, Case Note Reviewers, Advisory Group member
- Attend an event organised by or involving NCEPOD.

Most of the personal information we collect has been received directly from you. You may give us your name and contact information or other personal data:

- When you fill out a form on our website
- When you communicate with us, for example if you make an enquiry
- When you engage with us on social media
- When you attend an event
- When you complete any surveys or feedback forms we send you
- When you fill in any forms
- When you apply for a job with us
- If you work for us or with us
- If you enter into a contract with us, for example if you are one of our suppliers, or if we are one of your suppliers
- If you buy one of our services or products, or if we buy from you
- Claim expenses from us
- We may also receive information about you from third parties, for example our service providers and suppliers, or from third parties who may have gathered your consent on our behalf, or from publically available sources, such as social media.

The information we collect

Study data

We collect a large sample of patient cases directly from hospitals for each study. From this we randomly pick cases to be included in a detailed review by clinicians, such as doctors, nurses, physiotherapists.

The information we collect for the case note review includes:

- A questionnaire completed by the clinician involved in the patient's care
- Copies of hospital medical records, reports and test results
- Letters and medical records from other doctors and other health care organisations such as GPs.

Once this information is received it is completely anonymised and we remove any information relating to the identity of the patient including name, address, date of birth, hospital and/or NHS number or any relatives that might have been noted in the case record.

Once each study has finished we destroy all questionnaires and copies of case notes. All the clinician and patient information we collect during the study is also destroyed.

Patient identifiable information is collected without obtaining consent from the patient under Section 251 of the NHS Act 2006 in England and Wales and under approval from the Public Benefit and Privacy Panel for Health and Social Care in Scotland. In Northern Ireland Privacy Advisory Committee have declared that only anonymous data is to be used without consent.

Data collected not related to specific studies

- Your name
- Your contact details
- Your job role and your organisation
- Information from other publically available sources (such as social media)
- If you apply for a job with us we will collect information about your employment history, qualifications and references
- If you work for us we will collect and use additional personal information, such as health details and financial details
- If you claim expenses from us, such as travel expenses for attending a meeting, we will hold your name and address for the purposes of accounting and auditing
- If you fill in any questionnaires, surveys or feedback forms we will collect your experiences, opinions and any health information you are happy to share with us
- If you interact with our website we may collect certain technical information, such as your browsing activity across our website and your IP address. An IP address provides the location of server you are contacting us from. We only use this information to ensure website security.

How and why we use the information

The primary purpose of NCEPOD's work is to examine factors that can be changed about the quality of care provided to patients to improve the care of future patients. Direct or ongoing individual patient care will not be affected. We publish a report at the end of the study recommending where improvements can be made to improve care for future patients.

To identify patients/service users to whom the studies are relevant we need to use information which includes personal information such as date of birth and NHS number and postcode. The number of cases involved in each study can be from 500-20,000 cases over a short time period (to ensure we get enough cases from every UK hospital) so it is not possible for us to obtain the consent of every patient.

In order to carry out this work we have been given permission to collect and use this information under very strict conditions of confidentiality and data security by the Health Research Authority in England and Wales, the Privacy Advisory Committee in Northern Ireland and the Public Benefit and

Privacy Panel in Scotland. Access to this information is strictly limited to those who need to process it and all information is anonymous in the final report. Once the study is complete all data are securely destroyed.

During the case note review, clinicians trained for the study look at the care provided to each patient and compare the quality of care received with national standards, such as legal requirements or NICE guidance, and with the standard of care they would expect to find. The case reviewers do not know who the individual patients are and they never review cases from their own hospital.

Through this process the reviewers identify aspects of care which could be done better in the future to improve care for patients in the study areas. We are careful to ensure that the final report does not contain any information that could lead to the identification of any person.

All patient identifiable information is destroyed or deleted as soon as possible, and no more than three months after the report is published.

For a detailed poster explaining about the information NCEPOD collects, please [click here](#). Please [click here](#) to view a diagram that details how we use your data.

How we protect your information

We take the responsibility of holding people's personal data very seriously. We have internal policies which set out and guide our data security. All staff adhere to this approach and are regularly trained in data protection.

Electronic patient and organisational information (such as databases, online questionnaires or scanned health records etc.) are kept on secure servers and only NCEPOD non-clinical staff have access to patient identifiable data. Access to your personal data is password-protected and our servers are regularly monitored for possible vulnerabilities and attacks.

Our supplier for the online questionnaire web server has been granted access to Local Reporter names and NHS email addresses only via the online portal to allow technical support whilst it is in development. Our online questionnaire server is also secured by SSL encryption.

Physical information (such as printed copies of health records) are stored in locked cupboards in the NCEPOD office which is protected by an alarm system connected to the police. Only anonymised information is used in case note review meetings. We aim to anonymise personal data within two months of receipt.

NCEPOD holds all records that are supplied by NHS organisations in the strictest confidence. Information Security and Information Governance requires clear and effective management and accountability structures, governance processes, documented policies and procedures, trained staff and adequate resources. As such we have created the following documentation to clearly detail the policies and procedures we have in place.

To view our Information Security policies please [click here](#).

To view our Information Security procedures please [click here](#).

To view our Information Governance Framework please [click here](#).

Information about how NCEPOD complies with the General Data Protection Regulations (and previously the Data Protection Act 1998), Confidentiality and Ethical Approval can be found [here](#).

Who we share your personal data with

We do not share patient data with anyone. We may share anonymised and processed data with third parties under a data sharing agreement for additional analysis but this never includes personal data, case notes or anything that could identify an individual.

Names of Clinicians, Local Reporters, Ambassadors, Study Advisory Group members and Case Note Reviewers as well as staff will be shared in the necessary running of NCEPOD.

What are your rights over your personal data?

The right to erasure

You can request that we don't use personal information about you in our studies and we will ensure that any of your information we hold is destroyed. This will need to be done on a study by study basis otherwise the only way we could remove you from all studies would be to hold personal data about you to compare with the patient information that we receive.

You also have the right to restriction of processing and to object to processing. We treat these the same way as the right to erasure and remove all information about you.

If you decide that you would prefer that your information is not used please let us know by contacting us in writing at the postal address or use this email address link mmason@ncepod.org.uk

The right of access

You have the right to see what information is held about you. If you are a patient, we don't use names and addresses so you would have to know your NHS number. You have the right to rectify any data that is incorrect but rectifying it with us would not change the information in your health record and you may want to contact your healthcare provider directly.

To see what information we hold about you please contact mmason@ncepod.org.uk. There is no charge for this.



We do:

- use personal data to help improve health care services
- keep all personal data secure and confidential
- give you the right to opt out of any of our studies



We do not:

- share your personal data with third parties
- use personal or identifiable data in our reports

National data opt-out (England only)

Whenever you use a health or care service, such as attending Accident & Emergency or using Community Care services, important information about you is collected in a patient record for that service. Collecting this information helps to ensure you get the best possible care and treatment. The information collected about you when you use these services can also be used and provided to other organisations such as NCEPOD for purposes beyond your individual care, for instance to help with:

- improving the quality and standards of care provided
- monitoring safety
- planning services

This may only take place when there is a clear legal basis to use this information. NCEPOD has approval to collect such data. All these uses help to provide better health and care for you, your family and future generations.

You have a choice about whether you want your confidential patient information to be used in this way. If you are happy with this use of information you do not need to do anything. If you do choose to opt out your confidential patient information will still be used to support your individual care. To find out more or to register your choice to opt out, please visit www.nhs.uk/your-nhs-data-matters

You can change your mind about your choice at any time.

Data being used or shared for purposes beyond individual care does not include your data being shared with insurance companies or used for marketing purposes and data would only be used in this way with your specific agreement.

Data Protection Officer

The Data Protection Officer at NCEPOD is Dr Neil Smith. Further information is available by emailing nsmith@ncepod.org.uk or by contacting the NCEPOD office on 0207 251 9060.

Contact the Information Commissioner's Office

If you are unhappy with the way we handle your data or have dealt with a request, you have the right to lodge a complaint with the Information Commissioner's Office at <https://ico.org.uk/concerns/> or telephone 0303 123 1113.

Contact NCEPOD

If you have any questions or want to request that your data is not included in a study please contact:

Dr Marisa Mason

Chief Executive

NCEPOD

Ground Floor, Abbey House

74-76 St John Street

London. EC1M 4DZ

Telephone: 0207 251 9060

Email: mmason@ncepod.org.uk

More detailed information about the work of NCEPOD can be found using the following links:

[About NCEPOD](#)

[NCEPOD Studies](#)

[NCEPOD Publications](#)