

Privacy Notice - Biorepository

The Norfolk and Norwich University Hospitals NHS Foundation Trust (the Trust) processes information about you in order to carry out research, and in doing so has to comply with the requirements of the UK Data Protection Law and the EU General Data Protection Regulation. This means data held about you must only be used for specific purposes as defined by law. This Privacy Notice has been created to inform you about the types of information held about you, why that information is held about you, and to whom the information may be shared with. If we have to share information which identifies you as an individual, for any other purpose, we will seek your explicit consent.

Why do we collect information about you?

The Norwich Research Park (NRP) Biorepository is an invaluable resource for clinical research. It is a source of human tissue samples, provided by consenting patients, for studies into the causes and treatments of diseases. Our staff are experts in obtaining samples with the informed consent of participants and ensuring that the maximum value is obtained from them through ethical, impactful, high quality research that benefits us all. Our ethical approval also allows us to collect left over (surplus) material from diagnostic archives within the hospital, the only data we collect when using diagnostic archive samples is data produced in the laboratory from the tests already carried out. With all samples and data these are supplied to researchers with ethically approved studies using a unique code, we never supply your personal data to them.

Our research activity works across a range areas. Our key strengths include:

- Gut Health
- Gastroenterology
- Oncology (Breast, GI, Skin)
- Dermatology
- Orthopaedic
- Gynaecology
- Cardiovascular

We use your personal information to carry out health and social care research in the public interest. This means that we have to demonstrate that our research serves the society as a whole, for example by improving existing services or introducing new treatments.

You are not legally or contractually obliged to supply us with your personal information or to agree that information we already hold about you for care purposes, may be used for research purposes.

Should you not wish information about you to be used for research, you can opt out via the [national data opt-out programme](#), or by speaking to the clinical team who are treating you and informing them of your wishes.

We will not:

- share your identifiable data with third parties for marketing purposes
- sell your identifiable data

Information we collect

Where you have agreed to the use of your information in a particular research project, the participant information sheet would have been given to you as part of the process. This document will tell you what types of personal information we will use in connection with the specific research study or project (if applicable) you are participating in.

We will often get the necessary information directly from you. In other cases, we might already hold the required information due to the healthcare we provide to you. For information we are likely to already hold about you due to the care we provide, please refer to our main privacy notice for Direct Care.

Certain research studies also have to be approved by the National Research Ethics Committees (NREC) which is an independent group which ensures that all our research is ethical.

In situations where it has been impracticable to obtain your agreement, we will have sought approval from the Secretary of State via the Confidentiality Advisory Group under section 251 of the National Health Service Act 2006 ('CAG approval'). The Confidentiality Advisory Group provides independent advice on specific research projects which will use confidential medical information.

In some instances, we will apply to the [Health Research Authority](#) (HRA) who may approve that we can use pseudonymised information for research. Pseudonymised information is personal data which has had the identifiers removed, for example your name replaced with a research number and your data of birth changed an age. Where there are other fields which will be able to identify you, these will also be appropriately pseudonymised.

How we keep your information confidential and secure.

Everyone working for the NHS has a legal duty to keep information about you confidential and secure.

As with all hospital records it is important that we protect your identity. If you consent to donate your samples and/or data, we will give you a unique number in the Biorepository database held at the hospital. This will be protected in the same way as all your medical information and held by the NHS. The Biorepository number will be linked to your NHS number, so we will be able to link the samples you donate to the data we retrieve from the hospital records. This is a process called **pseudo-anonymisation**, we will only ever supply your samples and data anonymously meaning no researchers will be able to identify you.

Who we share your information with.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running research studies at the trust and

other third-party organisations. These external organisations may be non-commercial partners such as universities or other hospitals or commercial companies involved in health and care research in this country or abroad. For further details of our commercial and non-commercial partners can be found here: www.biorepository.org.uk/about-biorepository/

Our lawful basis

In order to legally be able to process your personal data, we must have a lawful basis under the United Kingdom General Data Protection Regulation. Our lawful basis for the purpose of processing data in our stated purpose is:

UK GDPR

Article 6 (1)(a) the data subject has given consent to the processing of his or her personal data for one or more specific purposes

Article 6 (1)(e) processing is necessary for the performance of a task carried out in the public interest.

Article 9 (2)(j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes

in accordance with Article 89(1) [(as supplemented by section 19 of the 2018 Act)] based on domestic law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

By processing your health data, we will also recognise your rights established under English case law, collectively known as the “Common Law Duty of Confidentiality”. This means that we only use your personal data in ways that would reasonably be expected, including where we share your information with your consent or where we can reasonably expect that you would consent in order to provide you with care, or for reasons of substantial public interest, or where you cannot be identified from the information.

Our processors

Processors are organisations who act on our behalf and under our authority. They carry out some of the technical processes, for example, providing a system that stores information. We do not allow our Processors to use your information for their own purposes or allow them to link this to other personal data they may.

The category of our processors are organisations who:

- Provide of our IT systems;
- Dispose of confidential waste (paper records, laptops or other IT equipment).
- Provide some of our clinical service under contract with us.

How long will we keep your data

We follow the Trust and the DOH policies and guidance in regards to the retention periods of data and information which we hold - the NHS [Records Management Code of Practice for Health and Social Care](#).

Records that enable traceability must be maintained at least until the tissue has been disposed of, used to extinction or otherwise brought outside of the regulatory framework, or will never be used again in research.

<https://www.hta.gov.uk/guidance-professionals/regulated-sectors/public-display/record-retention-faqs>

Your rights

Data protection laws give you a number of rights over your personal data. These rights are detailed below. However, for the purpose of research your rights to access, object, change, transfer and or delete/erase your information are limited. This is because we need to manage the data in specific ways to ensure the research we conduct is reliable and accurate, and that we are accountable to those organisations which fund and monitor our research.

Data Protection legislation gives individuals rights in respect of the personal information which we hold about you. These are:

1. To be informed why, where and how we use your information.
2. To ask for access to your information.
3. To ask for your information to be corrected if it is inaccurate or incomplete.
4. To ask for your information to be deleted or removed where there is no need for us to continue processing it.
5. To ask us to restrict the use of your information.
6. To ask us to copy or transfer your information from one IT system to another in a safe and secure way, without impacting the quality of the information.
7. To object to how your information is used.
8. You have the right to refuse /withdraw consent to information sharing and tissue retention at any time. The possible consequences will be fully explained to you.

Data Controller

Norfolk and Norwich University Hospital Foundation Trust is the Data Controller responsible for keeping your information confidential, safe and secure and can be contacted at:

Norfolk and Norwich University Hospital Foundation Trust
20 Rouen Road
Norwich
NR1 1QQ.

Telephone: **01603 286286**

Email: info.gov@nnuh.nhs.uk

Notification

The GDPR and Data Protection Act legislation requires organisations which process personal information to lodge a notification with the Information Commissioner to describe the purposes for which they process personal information.

These details are publicly available from:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
SK9 5AF

Telephone: **0303 123 1113**

Website: www.ico.org.uk

Freedom of Information

The Freedom of Information Act 2000 (FOIA) provides any person with the right to obtain recorded information held by the Norfolk and Norwich University Hospital NHS Foundation Trust, subject to a number of exemptions.

If you would like to request information from us, please visit the Freedom of Information section of our website:

<http://www.nnuh.nhs.uk/departments/freedom-of-information/>

OR

email foi.requests@nnuh.nhs.uk

Please be aware that you cannot use the FOIA to obtain access to your personal information – such requests are handled under the Data Protection Act, as described above.

Contacts

Should you have any further queries on the uses of your information, please speak to your health professional or our PALS Department on 01603 289036 Monday to Friday or our Data Protection Officer Vimmi Lutchmeah-Beeharry at info.gov@nnuh.nhs.uk or call **01603 286286**.

Should you wish to lodge a complaint about the use of your information, please contact our complaints team on **01603 289686**.

If you are still unhappy with the outcome of your enquiry you can write to:

The Information Commissioner,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire
SK9 5AF
Telephone: 01625 545700

