# Research - Privacy Notice

Version: 7
Authored by: Dr Vanshree Patel
Approved by: Information Governance Steering Group and Research & Innovation Operations Board
Effective Date: 13th March 2023

Under data protection law we are legally required to provide information about how we use your information in a way that is:

- concise
- transparent
- easy to understand
- easily accessible
- written in clear, plain language, particularly if addressed to a child
- free of charge

Data protection law says the personal information we hold about you must be:

- used lawfully, fairly and in a transparent way
- collected only for valid purposes that we have clearly explained to you and not used in any way that is incompatible with those purposes
- relevant to the purposes we have told you about and limited only to those purposes accurate and
- kept up to date,
- kept only if necessary for the purposes we have told you about
- kept securely

This privacy notice describes what we do with your personal information for the purposes of health and care research.

It tells you what information we collect about you, how we store it, how long we retain it and with whom we might share it when you consent to taking part in a research study.

By health and care research we mean research which serves the interests of society as a whole. We do this by following the UK policy framework for health and social care research UK Policy Framework for Health and Social Care Research**.**

## Why we need your data

If you are asked about taking part in research, usually someone in the care team looking after you will contact you. People in your care team may look at your health records to check whether you are suitable to take part in a research study, before asking you whether you are interested or sending you a letter on behalf of the researcher.
In some hospitals and GP practices, you may have the opportunity to sign up to a register to hear about suitable research studies that you could take part in. If you agree to this, then research nurses, researchers or administrative staff authorised by the organisation may look at your health records to see if you are suitable for any research studies.
It is important for you to be aware that if you are taking part in research, or information about you is used for research, your rights to access, change or move information about you are limited. This is because researchers need

to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from a study, the sponsor will keep the information about you that it has already obtained. They may also keep information from research indefinitely

We need to collect data during the research session to ensure that we have an accurate record of what happened and what was said. This is important because we then analyse this information and use it to draw conclusions about what we should do next.

## Who we are

Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) is recognised as one of the leading children's research hospitals in Europe and beyond.

Our researchers, many of which are among the world's best in their field, are engaged in broad areas of research activity, often crossing between different specialties.

As a research hospital, GOSH is at the forefront of using innovative technologies in the clinical treatment of patients and in support of pioneering research to find cures of complex and rare conditions. We have set-up the Digital Research Environment (DRE), which is a research and innovation platform within GOSH. The DRE provides routinely collected clinical and other data for use in approved research studies or clinical audits to improve patient health, care and services. The data in the DRE could also be used to identify eligible patients for a research study provided that is authorised by GOSH information governance for patient benefit as agreed by the Research Data Access Group (RDAG). Only anonymised/pseudonymised data are made available to researchers via the DRE. Any published research results will only include anonymised/pseudonymised data.

We are committed to protecting the privacy and security of your personal information. We are registered with the Information Commissioner's Office (ICO) to process personal and special category information.

## Why we collect personal information about you

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

## Our legal basis for processing information about you

Data protection legislation requires us to have a valid legal reason to process and use personal data about you. This is often called a 'legal basis'. The General Data Protection Regulations (GDPR) requires us to be explicit with you about the legal basis upon which we rely to process information about you.

As a publicly funded organisation we have to ensure that it is a public task in the public interest when we use personally identifiable information from people who take part in one of our research projects. This is known as our "legal basis" for the collection and processing of personal data under current data protection regulations (Article 6 GPDR).

Due to the sensitive nature of healthcare information, it is further categorised, under current data protection regulations, as special category data. Where we collect this type of data we do so when "the processing is necessary for archiving purposes in the public interest, scientific or historical research purposes…." (Article 9 GDPR)

In addition, confidential information which you have shared with our staff to enable them to provide your care is governed by the common law duty of confidentiality. We use your data because you have consented to take part in a particular piece of research.

## Codes of practice for handling information in health and social care

Patient recruitment to research studies is carried out by an "informed consent" process, which means that we advise you about the benefits and risks associated with a particular research study to enable you to decide whether you wish to participate in (consent to) the research study or not. Where you have formally consented to take part in research, this consent process will also satisfy the common law duty of confidentiality. In situations where it has been impracticable to obtain your consent, 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.

Certain research studies also have to be approved by the Research Ethics Committees (REC) which is another independent group which ensures that all our research is ethical. The Health Research Authority (HRA) has published guidance about research and the general use of patient information, which can be found at HRA patient information.

## What personal information about you we need to collect and how we collect it

Where you have consented to take part in a particular research study the participant information leaflet would have been given to you as part of the consent process (see "our legal basis for processing personal information about you"). The sponsor will collect the minimum personally identifiable information needed for the purposes of the research project. Information about you will be used in the ways needed to conduct and analyse the research study. NHS organisations may keep a copy of the information collected about you. Depending on the needs of the study, the information that is passed to the research sponsor may include personal data that could identify you. You can find out more about the use of patient information for the study you are taking part in from the research team or the study sponsor. You can find out who the study sponsor is from the information you were given when you agreed to take part in the study.

For some research studies, you may be asked to provide information about your health to the research team, for example in a questionnaire. Sometimes information about you will be collected for research at the same time as for your clinical care, for example when a blood test is taken. In other cases, information may be copied from your health records. Information from your health records may be linked to information from other places such as central NHS records, or information about you collected by other organisations. You will be told about this when you agree to take part in the study. This document will tell you what types of personal information we will use in connection with the specific research study or project you are participating in and (where applicable) its sources.

The personal data we collect from you at this stage could include information about your:

- name
- age
- gender
- ethnicity
- disabilities, such as details of any condition that can affect your ability to use a computer
- job title
- email address
- phone number

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 Trust privacy notice for patients.

### During the research session

In most cases, we will collect personal data during the research session. This could be in the form of:

- audio recordings
- video recordings
- screen recordings
- written notes
- photos

### Privacy notices for patients

You are not legally or contractually obliged to supply us with your personal information or to agree that personal 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, please let us know via email, or by speaking to the clinical team treating you or by registering your choice on the NHS National Data Opt-Out.

### What we do with your personal information

For research purposes, we may use your information anonymously in reports or presentations or share such information with other NHS bodies. Publicly available information will always be presented in aggregated format, which means that you will not be identifiable from this information.

When using your responses in reports or presentations, or sharing with other government departments, we will make sure you cannot be identified from your data. Each person taking part in a piece of research will be assigned a number, and any names or other personal and identifiable data will be removed.

We may use information collected as part of one research project for further research. However, where this information identifies you, we can only use the information for new purposes which are compatible with the original purpose to which you have consented or ethical (CAG) approval was granted (see "our legal basis for processing personal information about you"). Where the new purpose is substantially different, we will obtain separate consent from you or seek new ethical (CAG) approval.

### We will not:

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

Where we are required to transfer identifiable information about you internationally outside the UK/EU, we will make sure that an adequate level of protection is to be satisfied before the transfer.

Additional information on the nature of the research project and specifics of how your data will be managed will be contained within the participant/patient information sheet and/or supplementary research transparency information sheet you are provided with during the informed consent process. Please feel free to ask the researchers for clarification.

For more information about the general use of patient data in research in the health service please visit the Health Research Authority website https://www.hra.nhs.uk/

## Who we share your information with and why

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 here at GOSH and at other 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.

## Our partners

Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

There will be someone called a chief investigator responsible for the overall research study. This is usually someone who works directly with you, such as a doctor or nurse.

The principal investigator is the person responsible for the conduct and day-to-day running of a research study and will lead a team to carry out the research. The principal investigator will also ensure that only appropriate staff and third parties will be able to access your personal information, in line with the approved research protocol.

Please also refer to our main Trust patient privacy notice which explains when we might have to share information about you with the Care Quality Commission or other regulatory/law enforcement authorities.

## How we retain and re-use your information

Information about you that is collected during a research study may be kept securely to be used in future research in any disease area, including research looking at social and economic factors affecting health. This may include combining it with information about you held by other health or government organisations such as NHS Digital. Usually, the information is combined by matching information that has the same NHS number. Doing this makes maximum use of the information you have provided and allows researchers to discover more.
Researchers may not be able to specify all the potential future uses of the information they keep. It could include providing the information to other researchers from NHS organisations, universities or companies developing new treatments or care. Wherever this happens it will be done under strict legal agreements. The information about you will be depersonalised wherever possible so that you cannot be identified. Where there is a risk that you can be identified, your data will only be used in research that has been independently reviewed by an ethics committee.
On rare occasions NHS organisations may provide researchers with confidential patient information from your health records when we are not able to seek your agreement to take part in the study, for example because the number of patients involved is too large or the NHS organisation no longer has your contact details. Researchers must have special approval before they can do this.

Your personal data will be stored on our IT systems, which are provided by third party, document management and storage service providers.

Research studies may also store anonymised/pseudonymised data in their DRE workspace. Retention periods in the DRE follow the applicable retention schedule for each study.

## Your rights

Under current data protection regulations, you do have certain rights to manage your data as you see fit. However, for the purpose of research your rights to access, object, change, move 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 the charities and funders provided to the organisation to undertake the research. If you withdraw your consent to participate in a research project, we may not remove all your data. We may keep the information about you that we have already obtained to ensure research integrity is maintained in the public's interest, and that publicly funded research meets is goals. To safeguard your rights, we will strive to use the minimum personally identifiable information possible.

Additional information on the nature of the research project and specifics of how your data will be managed if you participate will be contained within the participant/patient information sheet and or supplementary research transparency information sheet with which you are provided. Please feel free to ask the researchers for any clarification you may require.

For more information about the general use of patient data in research in the health service please visit https://www.hra.nhs.uk/information-about-patients/

Where research has been conducted, based on a section 251 of the National Health Service Act 2006, via CAG approval (see "our legal basis for processing personal information about you"), you may have a right to opt-out. The national data opt-out right emanates from the Caldicott principles and entitles you to object to be contacted about new research for which it was not possible to obtain your informed consent unless this right has been waived by the Secretary of State for Health and Social Care or the Health Research Authority.

Individuals can choose to opt-out of confidential information from their health record being shared for research and/or planning, by registering your choice on the NHS National Data Opt-Out.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).
Our Data Protection Officer can be contacted at your.data@gosh.nhs.uk