Biobanks in the Department of Surgery

Privacy Notice

Introduction

The purpose of this Privacy Notice is to explain to you, our participants how we in the Gastrointestinal Biobanks (including the Upper GI, Lower GI, Barrett's Oesophagus, Inflammatory Bowel Disease and Pancreatic Biobanks) (biobank/'we'/'us') collect, store, use and share, any samples (blood, tissue and other bodily fluids) and healthcare data about you that you have agreed to share with us.

Participants are data subjects of the biobank for the purposes of GDPR and as such, the biobank fully respects your right to privacy and actively seeks to preserve your rights under EU and Irish laws.

Who are we?

The Biobanks (listed above) in the Department of Surgery are jointly managed by St. James's Hospital ('the Hospital' / 'SJH') of (James's Street, Dublin 8, Ireland D08 NHY1) and Trinity College Dublin, the University of Dublin ('Trinity College' / 'the University') of College Green, Dublin 2, Ireland.

St. James's Hospital and Trinity College Dublin are the joint data controllers of these biobank and are responsible for keeping your biomaterial and personal data secure.

These Biobanks are governed by clinical and scientific staff.

For more information, please contact Professor Jacintha O'Sullivan on +353 1 8962149 or by email: osullij4@tcd.ie.
For queries specifically about the pancreatic biobank, please contact Professor Stephen Maher on +353 1 896 2104 or by email: maherst@tcd.ie.

What are the Gastrointestinal Biobanks?

The Gastrointestinal Biobanks are a large collection of biological samples (blood and tissue taken from biopsies and surgeries and other bodily fluids) and relevant healthcare data (taken from your medical records) donated by you, our participants, for use in health research to learn more about, gastrointestinal diseases and gastrointestinal cancer.

Your biological samples and related healthcare data information will only be shared for research projects which we hope will improve the prevention, diagnosis and treatment of gastrointestinal cancer and gastrointestinal diseases.

Research projects may include early detection, diagnosis, new treatments, cancer genomic research, medical devices, how cancer changes over time, cancer prevention and the causes of cancer in families.

Your donated samples and related healthcare data may be included in many international research studies to speed up developments to improve outcomes for all those with gastrointestinal diseases and gastrointestinal cancer.

Any samples and information that you share with the gastrointestinal biobanks will be treated with the highest standards of security and confidentiality, in accordance with data protection law.

We will only use, your biological samples and healthcare data for the purposes explained in this privacy notice.

This Privacy Notice explains the following:

- What personal data do we need?
- How do we collect your personal data?
- What is our legal basis for processing your personal data?
- How do we securely store your personal data?
- Who do we share the personal data and/or samples with?
- Will genetic/genomic research be carried out?
- How long do we store your personal data and samples?
- How can you withdraw from the biobank?
- What are your rights under data protection law?

What personal data do we need?

Personal Data

We collect information such as your name, gender, date of birth, hospital record number, and contact details, such as your postal address, email address and phone number.

Special Category Data

We collect information about your health from your medical records, such as your medical history, histology (e.g. type of condition/cancer, details of treatment, previous illnesses and procedures, family medical history and health related lifestyle data).

We also need information about any tests you have undergone such as X-ray, ultrasound, CT, MRI, genetic and molecular diagnostic tests.

Biological Samples

In addition to the samples you donate, we will ask your permission to access and store historical samples and information relating to that sample) for example if you had an operation or biopsy in the past).

How do we collect your personal data?

We collect your personal data from the following sources: 1) directly from you, 2) from St. James's Hospital, 3) through linkage with other databases/bioresources as appropriate.

Directly from you

We will collect your name, date of birth, contact details, medical history and related healthcare data directly from you.

We may provide you with a questionnaire which will ask information such as your weight, height, where you were born, and your past medical history. These questionnaires can be compared with other studies internationally.

From St. James's Hospital

We will collect healthcare data from your hospital chart, hospital electronic patient records and other hospital databases such as diagnostic scans and laboratory results.

With your permission, we will access your biological samples (which may include blood, or other bodily fluids and tissue samples) provided by you.

Linkage with other databases/bioresources

Other national databases exist such as the National Cancer Registry, which may hold important and relevant cancer related information about you and with your permission, we will request that this cancer related information is shared with us.

What is our legal basis for processing your personal data?

Any samples or associated personal data will only be used to advance research, which can improve healthcare outcomes for all. The legal basis under the General Data Protection Regulation (GDPR) for processing your personal data is in the public interest Article 6(1) (e) and for scientific research under Article 9(2) (j).
We will ask for your explicit consent as an extra safeguard.

How do we securely store your personal data and samples?

Any data we collect from you will be stored confidentially and securely. We are committed to ensuring all access to, use of, information and /or samples is performed in a secure manner.

We are committed to ensuring that any use of your personal data is safeguarded by appropriate technical and organisational security measures in accordance with Article 32 GDPR requirements.

All information in the biobank is stored using a unique code instead of your name to reduce the risk of you being identified if there were any accidental or unlawful disclosure.

It is this unique biobank code that will be used when analysing and sharing information with researchers.

We keep your contact information (your name, address, phone number) separate to the information about your health that the biobank stores. The key to the code to link back to you is stored with this on a secure computer and is restricted to a limited number of approved biobank staff.

All information required by the biobank is entered onto a secure database by authorised personnel. The database is stored on a secure, password protected hospital computer located in the Trinity Centre in the St. James's Hospital campus. Access to this location is restricted. All hard copy personal data is stored securely in premises which has access restricted to approved personnel.
All staff accessing information are required to sign a confidentiality agreement in addition to their employment contractual agreements. Biological samples are stored securely. Access is restricted to approved personnel only.

Who do we share personal data and/or samples with?

The gastrointestinal biobanks are an important resource as they allow researchers to access biological samples and related healthcare for research projects to improve outcomes for patients with gastrointestinal conditions. By sharing widely, we can speed up developments in the area of gastrointestinal cancer and disease to improve outcomes for all.

We collaborate with both academic researchers who may work in universities, hospitals, or research institutes around the world and also researchers working in industry, such as pharmaceutical companies, on approved research projects on gastrointestinal cancer and disease only.

Currently, all studies are collaborations with the biobank. Results are shared back to us, so that we can use these to improve outcomes for all.

In order to be approved for access to coded samples and data - the researchers must:

- Fill in a Sample Access Request Form, and the Principal Investigators of the biobank will assess the project request and decide if the research will advance developments in the area of gastrointestinal cancer and disease
- Apply and be approved by the Tallaght University Hospital and St. James's Hospital Joint Research Ethics Committee and each of the following approvers:
    - The Office of Research & Innovation (Trinity College Dublin and St James's)
    - The Department of Legal & Insurance (St James's)
    - The Data Protection Officers (Trinity College Dublin and St James's) and

- Researchers must sign legal agreements which restrict the use of the samples and related information to a specific approved research project and must agree that no re-identification of individuals is permitted.

Any healthcare data or biological samples shared with researchers will not include your name or other direct identifiers. All information and samples is identified by a unique identifier code, and only limited information is given to researchers (i.e. the information they need for their research project). They must justify why they need this information in their application.

TRANSFERS OUTSIDE THE EEA

We may need to transfer Personal Data outside the European Economic Area (EEA) if the project is approved for access. We will ensure that any transfer of information or samples outside the EEA is only permitted if a comparable level of protection to the GDPR is guaranteed.

Will genetic/genomic research be carried out?

Genetic/genomic research (research which examines peoples' genetic information (genes) to help us understand how diseases behaves) on gastrointestinal diseases and cancer may be carried out on samples donated to the biobank.

Approved researchers may extract DNA from your blood and potentially from other samples to carry out research on gastrointestinal diseases.

Only researchers who have been approved following the process outlined above will be able to access samples and related healthcare data for genetic or genomic research.

How long do we store your personal data and samples?

Research takes many years, and advances in medical science are only possible through research studies which take long periods of time. For this reason, healthcare data is stored indefinitely as a valuable resource supporting gastrointestinal research.

The data about your health will always be useful to researchers even after your samples have been used up.

Your samples will be stored for as long as they are viable, or until the sample has been used up. After this, the sample is recorded as exhausted.

You are free to withdraw your consent to our use of your samples and data as outlined below at any stage.

How can you withdraw from the Biobank?

You can withdraw from taking part in the biobank at any time. If you would like to withdraw, please contact Professor Jacintha O'Sullivan on 01 8962149 or osullij4@tcd.ie.
From this point on, your samples and healthcare data will not be used for research. However, it will not be possible to destroy samples and healthcare data already shared for research, before this date.

Any research which is currently underway will continue to completion (as to remove the information from an ongoing study, would impact on the integrity of that research study, and prevent publication).

We will keep a record that you changed your mind and record the destruction of your samples and healthcare data.

For further information regarding withdrawal from the pancreatic biobank, please contact Professor Stephen Maher (+353 1 896 2104 or maherst@tcd.ie).

What are your rights as a data subject under data protection law?

You have the following rights in relation to any use of your personal data (health data, contact information etc.) by the biobank.

Right of access

You have the right to request a copy of the information that we hold about you.

Right of rectification

You have the right to correct data that we hold about you that is inaccurate or incomplete.

Right of erasure

In certain circumstances, you can ask for the data we hold about you to be erased from our records (unless it would seriously impair research which is underway already)

Right to restriction of processing

You have the right to restrict the use of your data where certain conditions apply, to have the right to restrict the processing e.g. transferring data to third parties

Right to object

You have the right to object to any use of your information (for example if it is inaccurate).

Data Protection Training

All biobank staff complete data protection training delivered by TCD and/or St James's Hospital. The SJH / TCD contract of employment, both of which are signed by the employee, provide information about the required procedures relating to data protection and confidentiality. Confidentiality agreements must be signed by all biobank staff.

Contact Details and More information

If you have any queries relating to the processing of your personal data for the purposes outlined above or you wish to make a request in relation to your rights, you can contact:

- Professor Jacintha O'Sullivan on 01 8962149 or osullij4@tcd.ie.
- For further information regarding the pancreatic biobank, please contact Professor Stephen Maher (+353 1 896 2104 or maherst@tcd.ie).

- Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2
  Email dataprotection@tcd.ie
- Data Protection Officer, St James's Hospital, Dublin 8
  Email dataprotection@stjames.ie

If you are not satisfied with the information we have provided to you in relation to the processing of your data or you wish to raise a concern with the Data Protection Commission. The contact details are:

Data Protection Commission
21 Fitzwilliam Square South
Dublin 2
Ireland
D02 RD28

Tel: **076 110 4800**
057 868 4800
Email: **info@dataprotection.ie**
Contact form: https://forms.dataprotection.ie/contact

Changes to the privacy notice

We regularly review and, where necessary, update this privacy notice.

Version: 1.0. 10th April 2025