



Introduction

The purpose of this Privacy Notice is to explain how the Cancer Biobank collects, stores, uses, and shares samples (blood, tissue and other bodily fluids) and healthcare information from participants. In accordance with GDPR, the Cancer Biobank fully respects participant rights to privacy and actively seeks to preserve participant rights under EU and Irish laws.

Who is the Cancer Biobank?

The Cancer Biobank is under the joint controllership of HSE West and North West and the University of Galway. A data protection impact assessment (DPIA) and joint controller agreement (JCA) are in place for HSE West and North West and University of Galway. The Cancer Biobank is governed by the Clinical Research and Development Office who support biobanking activities and monitor regulatory compliance.

What is the Cancer Biobank?

The Cancer Biobank is a long-term research resource of biological samples (blood and tissue taken from biopsies/surgeries) and relevant healthcare information.

Donated samples and information allow researchers to conduct studies to discover better methods of prevention, diagnosis and treatment of cancers. Only researchers who have received ethical approval for their studies are allowed access to donated samples and information.

Any samples and information donated to the Cancer Biobank will be treated with the highest standards of security and confidentiality, in accordance with data protection law.

The Cancer Biobank will only use donated biological samples and healthcare and personal information for the purposes explained in this Privacy Notice.

This Privacy Notice explains the following:

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

What personal information do we need?

Personal Information: We collect information such as your name, sex, date of birth, hospital ID number, and contact details such as your postal address and phone number.

Special Category Information: We collect information about your health from your medical records, such as your medical history, type of cancer, treatment details, family medical history, quality of life and lifestyle information. We may also need information about any tests you have undergone such as 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, for example tissue from an operation or biopsy you had in the past.

What is the legal basis for processing your information?

Any samples or associated personal information will only be used to advance research in biobanking and cancer research. 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 also ask for your explicit consent.

How do we securely store your personal information and samples?

Any information collected from you will be stored confidentially and securely. The Cancer Biobank is committed to ensuring that any use of your personal information is safeguarded by appropriate technical and organisational security measures in accordance with Article 32 GDPR requirements.

All information in the Cancer Biobank is stored with a unique code (instead of your name) to reduce the risk of identification. This unique code will be used when analysing and sharing information with researchers.

All personal information is entered onto a secure database by authorised personnel. The database is stored on a secure, password protected hospital computer located in Lambe Institute for Translational Research. Access to this location is restricted.

All hard copy personal information is stored securely in premises accessible to approved personnel only. All staff accessing information are required to sign the Cancer Biobank Data Protection Policy Agreement in addition to their employment contractual agreements.

Biological samples are stored securely. Access is restricted to approved personnel only.

Who do we share your personal information and/or samples with?

The Cancer Biobank collaborates with academic researchers who may work in universities, hospitals, or research institutes as well as researchers working in industry, such as pharmaceutical companies.

Researchers may be located in Ireland or abroad.

To be approved for access to coded samples and information, researchers must:

- Apply to the Cancer Biobank steering committee (Clinical Research and Development Office and Cancer



Biobank management) who will decide if the research will advance developments in cancer research.

- Apply and be approved by the Galway University Hospital Clinical Research Ethics Committee
- Get approval from the Data Protection Officers (University of Galway and HSE West and North West)

Researchers must sign legal agreements that restrict the use of biological samples and related information to a specific approved research project. They must also agree that re-identification of individuals is not permitted.

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

Transfers outside the EEA

We may need to transfer Personal information 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 is research that examines peoples' genetic information or genes to better understand how diseases behave. This research may be carried out on samples donated to the Cancer Biobank. Approved researchers may extract DNA or RNA from your blood or other samples to carry out research on cancer.

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

How long will your personal information and samples be stored?

Research takes many years, and advances in medical science are only possible through research studies that take place over periods of time. For this reason, healthcare information is stored indefinitely. Information about your health is useful to researchers even after your samples have been used up.

Your samples will be stored until they have been used up.

You are free to withdraw your consent to the use of your samples and information at any time.

How can you withdraw from the Cancer Biobank?

You can withdraw from the Cancer Biobank at any time. Withdrawal will be accepted without question, and withdrawal will not impact your clinical care.

If you would like to withdraw, please contact the Cancer Biobank on adminbiobank@universityofgalway.ie or on +353 (091) 544202.

We will send you a withdrawal of consent form to be filled in and returned to the Cancer Biobank, Lambe Institute for Translational Research. We will provide you with a paid return envelope.

What are your rights as a data subject under GDPR?

You have the following rights in relation to any use of your personal information by the Cancer 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 the information that we hold about you (inaccurate or incomplete information).

Right of erasure: In certain circumstances, you can ask for the information we hold about you be erased from our records (unless it would seriously impair research that is already underway).

Right to restriction of processing: You have the right to restrict the use of your information 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).

Contact Details

Cancer Biobank Website:

www.universityofgalway.ie/biobank

Cancer Biobank Email:

adminbiobank@universityofgalway.ie

University of Galway Data Protection Officer Email:

dataprotection@universityofgalway.ie

HSE West Deputy Data Protection Officer Email:

ddpo.west@hse.ie

If you wish to make a complaint about how your personal data is being processed by us or how your complaint has been handled, you have the right to lodge a complaint directly with the supervisory authority:

Data Protection Commissioner

Office of the Data Protection Commissioner. Canal House, Station Road, Portllington, Co. Laois, R32 AP23, Ireland.

Phone: +353 (0761)104 800

Email: info@dataprotection.ie

