Privacy Notice

Information you need to know:

The CCLG Tissue Bank, hosted by the Leicester Cancer Research Centre, Department of Genetics and Genome Biology is part of the University of Leicester. Further information on the institution can be found here: https://le.ac.uk/. The University of Leicester is the Data Controller for your information.

As a university organisation we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

The Data Protection Officer is: Parmjit Gill, Information Assurance Services Manager, Information Assurance Services, University Of Leicester, University Road, Leicester, LE1 7RH. Tel: 0116 229 7945. Email: pg170@le.ac.uk.

This privacy notice explains how we use your personal information and your rights regarding that information.

What information are we collecting?

Personal information is what can be used to identify you. The CCLG Tissue Bank will be collecting the following personal information about a participant:

- First name
- Last name
- Date of Birth
- Date of Death

The CCLG Tissue Bank will also be collecting Special Category data. Health information is Special Category data. The following personal information linked to health information will be collected about all participants:

- Hospital or NHS number
- Diagnosis
- Clinical trial number

Why are we collecting your data?

Your information is collected for the purpose of research only. It will not be disclosed to any third parties. Only anonymised (coded) data is released to researchers for the purpose of research.
How we will use this data?

We will use this data for:
- confirming samples banked by a participant and/or their parent/guardian (if under the age of 16);
- confirming and correcting data about participants and their samples;
- research (where is will be fully anonymised before releasing to a researcher)

When we collect your personal information we use strict procedures and security features to prevent any unauthorised access.

What is the legal basis for processing the data?

- Public Task
- Explicit Consent (approved by NHS Health Research Authority research ethics committee)

If we are sharing your data with others who are we sharing it with?

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. 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.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

How long we will process your data for?

Due to the long term research value of the data we are retaining, we will hold this data permanently.

What are your rights and how to enforce them?

Your rights under the Data Protection legislation are as follows:

- **Right to withdraw consent** - Where we use your personal information based on your prior consent, such information about your health, you can withdraw your consent at any time and for whatever reason, by contacting us.

- **Right to be informed** – You have the right to be informed about the collection and use of their personal data.
- **Right of access** – You have the right to know that we are processing your personal data and, in most circumstances, to have a copy of the personal data of yours that we hold. You can also ask for certain other details such as what purpose we process your data for and how long we hold it.

- **Right of rectification** - You have the right to request that we correct inaccurate data or complete incomplete data that we hold on you.

- **Right to restrict processing** – You have the right to ‘block’ or suppress processing of your personal data.

**How to complain to the Information Commissioner’s Office?**

The Information Commissioner can be contacted on:

Post: Information Commissioners Office, Wycliffe House, Water lane, Wilmslow, Cheshire, SK9 5AF
Tel: 0303 123 1113. Email contact can be made by accessing [www.ico.org.uk](http://www.ico.org.uk)