

## **Ethical Tissue Privacy Notice**

Ethical Tissue and the University of Bradford take data privacy very seriously and the information below is especially relevant for patients and volunteers who have kindly agreed to donate samples and data to the biobank.

The University is a public research institution established by royal charter to advance knowledge and education through its teaching and research activities. Our charter can be found on the University website (<https://www.bradford.ac.uk/governance/university-charter-and-statutes/>).

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 (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/> )

### **Under what legal basis does the processing of my personal data take place?**

Under data protection law we have to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research we will process it using explicit consent as the lawful basis.

All patients are required to give consent every time we collect data and tissue samples. A booklet will be given for them to read and they will be given an opportunity to ask questions. They are then asked to sign a consent form for the storing and use of their data for teaching and research purposes.

### **What categories of personal data are used?**

When you agree to donate samples and data to Ethical Tissue we will collect the relevant information from your NHS medical records and/or through consultation. This information may include your name, NHS number, contact details, date of birth, as well as other health-related data required for scientific studies such as previous medical history and medication information. We will use your personal information to make sure we are matching the correct medical record to the correct donated samples.

To safeguard your rights, we will use the minimum personally-identifiable information possible.

Researchers receiving samples and data from Ethical Tissue will NOT receive your personal information.

### **Where do we get your personal data from?**

We collect your personal data through discussions with the donor or alternatively accessing your hospital notes once you have consented for us to do so.

### Who else do we pass this information on to?

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.

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be transferred and held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

### How long do we keep this information for?

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

### What are your rights as a data subject?

As a person whose personal data we are processing, you have certain rights in respect of that personal data; you have the right:

- To withdraw consent
- To access your personal data that we process;
- To rectify inaccuracies in personal data that we hold about you if it is inaccurate or incomplete;
- To request the deletion or removal of your personal data where there is no compelling reason for its continued processing;
- To restrict the processing of your personal data in certain ways;
- To obtain your personal data for reuse;
- To object certain processing of your personal data;
- To complain to the Information Commissioner's Office about the way in which we process your personal data.

### Where can I get more information?

For more information please contact the University's Data Protection Officer, [data-protection@bradford.ac.uk](mailto:data-protection@bradford.ac.uk), University of Bradford, Richmond Rd Bradford BD7 1DP

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