

ORB POL-017 Oxford Radcliffe Biobank General Data Protection Regulation – updated privacy information

The UK General Data Protection Regulation (GDPR) is the retained EU law version of the EU GDPR which came into force on 25th May 2018 and concerns individual privacy and data protection. To comply with this regulation's focus on greater transparency, we are required to provide the following information to anyone being approached about agreeing to samples being collected and stored for health and care research:

The Oxford Radcliffe Biobank (ORB) is a part of the University of Oxford with a specific responsibility to ensure that human tissue samples are collected, stored and managed as required by the Human Tissue Act. We will be using information from you and your medical records in order to ensure that all samples obtained from you are used only in ways for which you have given valid consent, and that any restrictions you have placed are recorded and respected. We will also be using such information to describe the samples in ways to maximise their usefulness to researchers. The University of Oxford will act as the data controller for these purposes. This means that we are responsible for looking after your information and using it properly. The University of Oxford will keep sufficient identifiable information about you to demonstrate that your sample has been obtained and used only in ways to which you have agreed for as long as is required by the Human Tissue Act. Other information about your samples will be kept until twelve months after the Biobank ceases to exist, in which event samples and data will be destroyed by a disposal procedure which conforms to Human Tissue Authority licensing requirements.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order to demonstrate that your samples have been collected and used only in ways to which you have consented. You may withdraw all or part of your consent to use your samples at any time, but we have to keep the information about you that we have already obtained in order to demonstrate any past use of the samples was legal at the time of use, and to avoid possible future approaches to seek your consent. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting the ORB manager at orbmanager@ndcls.ox.ac.uk

Information about any consent you have given, and any limitations or exclusions you want to include, will be recorded in your medical record. Individuals from the University of Oxford and regulatory organisations may look at your medical and research records to ensure that the process of obtaining consent and managing samples is fully compliant with Human Tissue Act requirements.

The only people in the University of Oxford who will have access to information that identifies you will be people who need to contact you to follow up or audit the data collection process. Anyone requesting access to samples you have provided, and information about them, will not be able to identify you, nor find out your name or contact details.

When you agree to the use of samples for research purposes, 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.