**Edinburgh Clinical Trials Unit Privacy Policy**

**Information about you:  how we use your personally identifiable information for trial participants**

The information published here applies to the processing (holding or use) of personally identifiable information of trial participants by the Edinburgh Clinical Trials Unit (ECTU) of the University of Edinburgh. The information in this notice is general and project specific information can be found in the patient information sheet (PIS) relating to the trial.

Personally identifiable information is information about an individual that, alone or linked with other data, can reveal the identity of a person. Where information relates to the living, the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act (DPA, 2018) require us to be clear about the lawful basis of our data processing.

In general terms, we use information from you and/or your medical records to undertake research that serves the public interest. This information is used for reasons of public interest in public health and for the purposes of scientific research and archiving.

**Your privacy**

The University of Edinburgh acting through ECTU has overall responsibility for looking after your information and using it properly with technical and organisational measures in place to ensure personally identifiable information is protected. Information is held securely at all times and our staff have the same duty to maintain confidentiality and are trained in data protection and security, and to treat personally identifiable information in the strictest confidence. Any deliberate or negligent breaches of this duty are disciplinary offences. This is in compliance with the DPA 2018, the UK GDPR, the Common Law on Confidentiality and national Caldicott principles, as well as the requirements of the University of Edinburgh and its relevant Codes of Practice.

We will use your data in the ways needed to conduct this work and manage your information in specific ways so that the work is reliable and accurate. This means that we will only collect what personally identifiable information we need and use it as the law allows, and we will make sure nobody has access to it who shouldn’t. No automatic decision-making or profiling is done with your data.

We hold information for as long as it is needed for processing, and in accordance with the permitted retention schedule.

**Your rights**

You have rights regarding the use of your personally identifiable information by ECTU.

To find out what information we hold about you please contact, in writing, the University Records Management Section, providing your contact details and describing the information you want. You will need to tell us what project or research study you believe we hold this information for.

University of Edinburgh

Old College

Edinburgh EH8 9YL

Tel: 0131 651 4099

Email: recordsmanagement@ed.ac.uk Records Manager - Rob.Don@ed.ac.uk

<https://data-protection.ed.ac.uk/records-management/contact-us>

You have the right to ask for information about you that you think is inaccurate to be changed or for its use to be restricted. You can also ask for information about you to be deleted, or not to be used, and for information to be transferred to another organisation or given to you. These are not absolute rights and we may need to continue to use your information. We will tell you why if this is the case and to safeguard your rights we will use the minimum personally-identifiable information possible.

**When we share information**

In the course of doing our research, information about you may be shared with one or more third parties within the University of Edinburgh or with other organisations, depending on the study involved and where we are required or permitted to do so by law.

In these situations, the only people who will have access to information that identifies you will be those who need access to conduct their work. This will include staff and students of Edinburgh University and our collaborators, or individuals from the University of Edinburgh, NHS Lothian and regulatory organisations who may need to monitor or check the accuracy of a study. We also work with third parties who provide services to support our work, such as document scanning, destruction or information technology support. All organisations go through strict data protection, security and privacy checks and are held to the same standards as ourselves under data protection and common law. You can request to know which organisation your data has been shared with by contacting the University Records Management Section, as above.

For much of the work we will only share de-personalised or anonymous grouped information. This is information about you, but which does not include information such as names or dates of birth or other details that could identify anyone, either directly or in conjunction with other information. If we need to share personally identifiable information, then the minimum information necessary will be shared and will be subject to data protection safeguards.

We never publish any information that could be used to identify you.

**Sharing information for research purposes**

We may share your personally identifiable information for research purposes within and also outside the University of Edinburgh if there is research approval from an ethics committee or other special permission to do so. The third parties may, for example, include other academic collaborators in the UK and overseas. In this situation then the minimum information necessary will be shared and will be subject to data protection safeguards. However, for most research we only use de-personalised or anonymous grouped information.

**How to report a concern**

If you have any questions about the data, we hold about you or wish to raise a complaint on how we have handled your information, you can contact the University of Edinburgh’s Data Protection Officer who will investigate the matter. Either e-mail dpo@ed.ac.uk or write to:

Data Protection Officer

Governance and Strategic Planning

University of Edinburgh

Old College

Edinburgh EH8 9YL

Tel: 0131 651 4114

<https://governance-strategic-planning.ed.ac.uk/>

You also have the right to report any concerns about the way we process your personal information to the Information Commissioner’s Office (ICO) at [https://ico.org.uk](https://ico.org.uk/).

**This privacy statement is continued on the University of Edinburgh website at:**[**www.data-protection.ed.ac.uk/guidance/privacy-notices**](http://www.data-protection.ed.ac.uk/guidance/privacy-notices)