

PRIVACY NOTICE:

USE OF PERSONAL DATA IN RESEARCH

The Academic and Clinical Central Office for Research and Development (ACCORD) is a partnership between the University of Edinburgh and NHS Lothian Health Board. We act as joint data controllers for the personal data used in research that we sponsor.

Why do we use your personal data?

As University & NHS organisations, we carry out research to improve health, care and services. We use personal information from people who have agreed to take part in research studies.

We will only use your data in ways that are necessary to carry out the research study and to answer the research question.

What is our legal basis?

Under the UK General Data Protection Regulations (UK GDPR), our legal basis for processing personal data for research is:

- Article 6(1)(e): processing is necessary for performance of a task carried in the public interest
- Article 9 (2)(j): processing of special category data (such as health information) is necessary for scientific research purposes, subject to appropriate safeguards.

Health and social 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](#).

What personal data do we use?

Depending on the study, we may use:

- Your name and contact details
- Identifiers such as date of birth, Community Health Index (CHI) or NHS number
- Information about your health and care
- Demographic information such as age, gender or ethnicity
- Information collected during the research study

We only collect and use the minimum personal data necessary to carry out the research.

How is your data used?

When you agree to take part in a research study, we will use your data to:

- Carry out the research
- Analyse the results and produce research findings
- Share data with other researchers working on related research studies
- Ensure the safety and quality of the research

To support high quality research, your information may continue to be used even if you withdraw from the study, where this is necessary to ensure the research remains accurate and reliable.

How do we protect your data?

Our staff have a legal and contractual duty to keep personal information secure, and confidential. The following security measures are in place to protect personal information:

- Only authorised staff have access to your data
- Staff are trained in Data Protection and Information Security.
- We follow NHS Lothian and University of Edinburgh Information Security Policies, as appropriate
- We follow the ACCORD Data Protection and Confidentiality policy
- We apply access controls, risk assessment and electronic system audits, where appropriate

Where possible, we will use coded (pseudonymised) data so that you cannot be directly identified.

Sharing your data

Your data may be shared with:

- Researchers within ACCORD, the University of Edinburgh and NHS Lothian
- Partner organisations such as universities, NHS organisations and companies involved in health and care research
- Regulatory bodies or auditors where required

Where possible, information shared will be coded so that you cannot be directly identified.

In some cases, your data may be transferred outside the UK. Where this happens, we ensure appropriate safeguards are in place in accordance with UK GDPR.

Your data will only be used for research purposes. It will not be used to contact you (unless you have agreed separately), and it will not be used to make decisions about your care or services, such as insurance.

How long do we keep your data?

Research data is retained in accordance with regulatory and legal requirements. This is typically for a defined period after the study ends, e.g. between 5 and 25 years, depending on the type of research and applicable guidance.

What are your rights

Under data protection law, you have rights over your personal data, including:

- The right to access the data we hold about you
- The right to request correction of inaccurate data
- The right to restrict use of your data in certain circumstances

Some rights, such as the right to have your data erased, object to processing or move your data, may be limited where necessary to ensure the research remains reliable and accurate, in accordance with UK GDPR.

Who can you contact?

If you have any questions or concerns about how your personal data is used, you can contact our Data Protection Officers:

University of Edinburgh

Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL
Tel: 0131 651 4144

Email: dpo@ed.ac.uk

NHS Lothian

Data Protection Officer
IT Governance
Woodlands House
74 Canaan Lane
Edinburgh
EH9 2TB
Tel: 0131 465 5444

Email: loth.dpo@nhs.scot

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you have the right to lodge a complaint with the [Information Commissioner's Office \(ICO\)](#): www.ico.org.uk.

Further information

For more information about how personal data is used in health and care research, please visit the [Health Research Authority \(HRA\) website](#).

For further information on the full NHS Lothian Privacy Notice, please visit the [NHS Lothian website](#).