



Academic and Clinical Central Office for Research and Development



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.

As University & NHS organisations, we use personal information to conduct research to improve health, care and services. As a joint office working within publicly funded organisations and acting as joint data controllers, we must ensure that it is in the public interest and necessary for scientific research when we use personal information from people who have agreed to take part in research. These are our legal bases when using personal information for 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. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will retain the minimum personal information possible, and for no longer than is necessary for the purposes of the research.

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](#).

We take care to ensure your personal information is only accessible to authorised people. 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:

- Staff undertake training in Data Protection and Information Security.
- Compliance with NHS Lothian Digital IT Policy and University of Edinburgh Information Security Policy, as appropriate.
- ACCORD policy for Data Protection and Confidentiality.
- Access controls and risk assessment and/or audits of electronic systems, where applicable.

When you agree to take part in a research study, information about your health and care may be provided to researchers running other research studies in our organisations and other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. When personal information is shared with other organisations within the UK or outside the UK, we will do so in full compliance with the UK General Data Protection Regulations (GDPR) and local policies.



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Information we share will not identify you and will not be combined with other information in a way that could identify you. We will only share personal information where appropriate, relevant and proportionate, and in compliance with the law and local policies. The information will only be used for the purpose of 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.

For further information on the use of personal data by NHS sites, please link to the [Health Research Authority \(HRA\) website](#).

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

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the [Information Commissioner's Office \(ICO\)](#).

Data Protection Officer contact information:

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NHS Lothian

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