



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 personally-identifiable information to conduct research to improve health, care and services. As an office working within publicly funded organisations, and acting as data controllers, we must ensure that it is in the public interest and necessary for scientific research when we use personally-identifiable 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 is 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 use the minimum personally-identifiable information possible.

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](#).

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 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](#).

Information we share will not identify you and will not be combined with other information in a way that could identify you, unless a Caldicott Guardian has overseen these arrangements for the use and sharing of personal identifiable information. 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; <https://www.hra.nhs.uk/information-about-patients/>

For further information on the full NHS Lothian Privacy Notice, please link to the NHS Lothian website; <https://www.nhslothian.scot.nhs.uk/YourRights/DataProtection/Pages/default.aspx>

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) at <https://ico.org.uk/>



Data Protection Officer contact information;

**University of Edinburgh**

Data Protection Officer  
Governance and Strategic Planning  
University of Edinburgh  
Old College  
Edinburgh  
EH8 9YL  
Tel: 0131 651 4144  
[dpo@ed.ac.uk](mailto:dpo@ed.ac.uk)

**NHS Lothian**

Data Protection Officer  
NHS Lothian  
Waverley Gate  
2-4 Waterloo Place  
Edinburgh  
EH1 3EG  
Tel: 0131 465 5444  
[Lothian.DPO@nhs.net](mailto:Lothian.DPO@nhs.net)