

General Data Protection Regulation (GDPR) Informant Information



The EU General Data Protection Regulation (GDPR), along with the new UK Data Protection Act, will govern the processing (holding or use) of personal data in the UK.

You are receiving this as your friend or relative is currently a participant on this clinical research study and suggested you as an informant. The information below details what data is held about you and who holds or stores this. Your friend/relative has also received information detailing what data is held about them and who holds or stores this.

University of Edinburgh and NHS Lothian are the co-sponsors for this study based in the United Kingdom. We will use information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The co-sponsors will keep identifiable information about you for at least 5 years after the study has finished.

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in 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 use the minimum personally-identifiable information possible.

Providing personal data directly e.g. verbally, in a questionnaire or from your care provider

The NHS Hospital Trust where your friend/relative took part in the trial and members of the central Trial office will use your name and contact details to contact you about the research study and to oversee the quality of the study. Individuals from the co-sponsor organisation (University of Edinburgh and NHS Lothian) and regulatory organisations may look at your data to check the accuracy of the research study. The only people in the University of Edinburgh and NHS Lothian who will have access to information that identifies you will be people who need to monitor or audit the data collection process. The people who analyse the information you provide about your relative/friend will not be able to identify you and will not be able to find out your name or contact details.

The University of Edinburgh and NHS Lothian will keep identifiable information about you from this study for at least 5 years after the study has finished.

Use of data for future research

When you agree to take part in a research study, the information you provide about your friend's/relative's health and care may be passed on 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. The information you provide 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.

Contact for further information

You can find out more about how we use your information and our legal basis for doing so in our Privacy Notice at www.accord.scot.

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/>.

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:

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