

General Data Protection Regulation (GDPR) Participant Information

Prion Surveillance in Primary Immunodeficiency Patients

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 you are currently a participant on this clinical research study. The information below details what data is held about you and who holds or stores this.

The University of Edinburgh and NHS Lothian are the co-sponsors for this study based in the United Kingdom. We will use information from you and/or your medical records 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 University of Edinburgh will keep identifiable information about you until a minimum of 5 years past the end of the study, and then its retention will be reviewed with a view to permanent disposal or long-term archiving for future research, audit or as part of your medical record.

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 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 contact you to conduct the research project or audit the data collection process. The University of Edinburgh will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University of Edinburgh and NHS Lothian and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

The University of Edinburgh will keep identifiable information about you until a minimum of 5 years past the end of the study, and then its retention will be reviewed with a view to permanent disposal or long-term archiving for future research, audit or as part of your medical record.

Providing personal data indirectly e.g. from your medical records

The University of Edinburgh will collect information about you for this research study from the NHS Trust or Health Board providing your care. This information will include your name, date of birth and contact details (including your address) and health information, which is regarded as a special category of information. We will use this information to conduct the research project or audit the data collection process.

Use of data for future research

When you agree to take part in a research study, the information about your health and care may be provided 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. 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](#).

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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