

General Data Protection Regulation (GDPR) Participant Information

The Lothian Bowel Symptoms Study (LABSS)

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.

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 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. Your local recruiting NHS site will keep identifiable information about you from the LABSS study for a minimum of 3 years from the protocol defined end of study point. When the minimum retention period has elapsed, study documentation will not be destroyed without permission from the sponsors.

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

Your local recruiting NHS site will keep your name, NHS or Community Health Index (CHI) number and contact details confidential and will not pass this information to the University of Edinburgh. Your local recruiting NHS site will use this information as needed, 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. Certain individuals from University of Edinburgh and regulatory organisations may look at your medical and research records to check the accuracy of the research study. University of Edinburgh will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS or CHI number or contact details.

Your local recruiting NHS site will keep identifiable information about you from the LABSS study for a minimum of 3 years from the protocol defined end of study point. When the minimum retention period has elapsed, study documentation will not be destroyed without permission from the sponsor.

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

University of Edinburgh will collect information about you for the LABSS study from recruiting NHS sites. NHS local sites will not provide any identifying information about you to University of Edinburgh. We will use this information to obtain study specific information only.

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](#).

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of healthcare research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

ACCESS AND USE OF DATA FROM NHS NATIONAL SERVICES SCOTLAND

You will be asked to consent to give permission for NHS National Services Scotland to provide the research team with any medically relevant information they may hold on you. An application to the Public Benefit and Privacy Panel for Health and Social Care (PBPP) will be obtained to access this data.

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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