# General Data Protection Regulation (GDPR) Participant Information

# Resolution of Organ Injury in Acute Pancreatitis (RESORP Study)

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 Scotland. 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 co-sponsors will keep identifiable information about you for 10 years after the study has finished.

As a university/ NHS organisation 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

NHS Lothian will use your name, contact details, date of birth and NHS Community Health Index (CHI) number 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/NHS Lothian and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NHS Lothian will pass these details to the University of Edinburgh along with the information collected from you and your medical records. The only people in University of Edinburgh/NHS Lothian who will have access to information that identifies you will be people who need to contact you for follow-up purposes or those involved in data linkage or auditing the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, CHI number or contact details.

NHS Lothian will keep identifiable information about you from this study for 10 years after the study has finished.

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

University of Edinburgh/NHS Lothian will collect information about you for this research study from your medical records. This information will include your name, contact details, date of birth, NHS Community Health Index (CHI) number and health information, which is regarded as a special category of information. This information will be used to help answer the research question in this study.

## 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.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee and/ or the sponsor.

## 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:

**University of Edinburgh**
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