

Data Protection Information Sheet

Early support in primary care for people starting treatment for cancer (GI-ACP)

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

You are receiving this as you are considering being a participant on this clinical research study. The information below tells you what data will be held about you and who will hold or store this data.

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 university will keep identifiable information about you for 3 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 research team based at the University of Edinburgh will use your name, Community Health Index (CHI) number and contact details [telephone number, postal address, email address] 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 University of Edinburgh and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Your hospital team (in NHS Lothian or NHS Fife) or GP practice will pass these details to University of Edinburgh along with the study information collected from you and/ or your medical records. The only people in University of Edinburgh who will have access to information that identifies you will be people who need to contact you to discuss the study, receive consent to take part or arrange or carry out a study interview or audit the data collection process. The people who analyse the information from the questionnaires you have completed will not be able to identify you and will not be able to find out your name, CHI number or contact details.

University of Edinburgh will keep identifiable information about you from this study stored securely for 3 years after the study has finished.

B: Where participants are providing information indirectly e.g. being obtained from previously collected medical records or database. NOTE that special category data includes identifiers such as a name, an identification number, location data, an online identifier or to

one or more factors specific to the physical, physiological, genetic, biometric, mental, economic, cultural or social identity of that natural person

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

University of Edinburgh research team will collect information about you for this research study from your hospital and GP health records. This information will include your name, Community Health Index (CHI) number and health information relating to your illness, treatment and care, which is regarded as a special category of information. We will use this information to determine study outcome measures and obtain health and care process measures relevant to the purposes of this study.

C. Where data is intended to or likely to be used for future research

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:

University of Edinburgh
Data Protection Officer
Governance and Strategic Planning
University of Edinburgh
Old College
Edinburgh
EH8 9YL
Tel: 0131 651 4114
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