

Notice to update you on General Data Protection Regulations (GDPR) 2018.

Study Title: Scottish Early Rheumatoid Arthritis (SERA) inception cohort and biobank

IRAS ID: 41406

The introduction of the GDPR regulations brings with it stricter requirements around how organisations inform people of how their personal data is being used for health and care research.

To meet this requirement the Health Research Authority (HRA) has issued guidance to those organisations to explain to you how we are using your personal data, and what your rights are under the law.

This information is outlined below and separate additional text has been published by the HRA on behalf of the NHS, to ensure that patients can find consistent transparency information. Website page: <https://www.hra.nhs.uk/information-about-patients/>

How will information about me be stored and kept confidential?

NHS Greater Glasgow and Clyde (NHS GG&C) is the sponsor for this study based in the United Kingdom. We will be using 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. NHS GG&C will keep identifiable information about you indefinitely.

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.

You can find out more about how we use your information Isobel Brown – Information Governance Manager at 01413552020 or email data.protection@ggc.scot.nhs.uk.

The NHS Health Board under which you were recruited will collect information from you and your medical records for this research study in accordance with our instructions.

The site you attend will keep your name, CHI and contact details confidential and will not pass this information to NHS GG&C (as sponsor organisation). Your 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 NHS GG&C (as sponsor organisation) and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NHS GG&C (as sponsor organisation) 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, CHI or contact details.

The site you attend will keep identifiable information about you from this study indefinitely.

NHS GG&C will collect information about you for this study from your medical records. Your medical records will not provide any identifying information about you to NHS GG&C. We will use this information to confirm and collect data required as part of your participation in this study.

What will happen to the results of the research study?

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.

Thank you for taking the time to read this notice.