

INSERT NHS LOGO

**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 of this study. NHS GG&C will use information from you and your medical records in order to undertake this study with University of Glasgow. The University and the NHS will act as the joint data controllers for this study. This means that both organisations are responsible for looking after your information and making decisions as to how it is used. Both organisations are using the research data to perform a task which is in the public interest.

NHS GG&C will keep identifiable information about you indefinitely 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.

You can find out more about how we use your information Stewart Whyte – Information Governance Manager at 01413552020 or email [data.protection@ggc.scot.nhs.uk](mailto:data.protection@ggc.scot.nhs.uk).

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

The NHS Health Board where you were recruited will keep your name and contact details confidential and will pass this information to NHS GG&C (as sponsor organisation). The NHS Health Board where you were recruited 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. We will retain your Community Health Index number (NHS Number) in a secure database at the University of Glasgow to use to follow up how you are doing over the next X years remotely; using CHI we can obtain this information from National Health database so that you would not need to attend any further visits. Certain individuals from NHS GG&C (as sponsor organisation) and regulatory organisations may also 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.

All information that is collected about you during the course of the research will be kept strictly confidential and will be processed in accordance with the UK General Data Protection Regulation (UKGDPR) (2018). All study data will be held electronically on a secure database within the University of Glasgow. All personal details are kept in a separate, more restricted, linked database and only visible to appropriately trained and authorised study team members.

# **What will happen to the results of the research study?**

If you agreed to take part in this research, anonymised information we have gathered as part of this study (information that won’t identify you) 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](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/) and with appropriate ethical approval in place**.**

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.***