Privacy Notice For Patients Included In The Office For Rare Conditions (ORC) Registries Projects

Your Personal Data

The University of Glasgow will be known as 'Joint Data Controller' alongside your local Health Care Provider that acts as the Reporting Centre in relation to the ORC Registries project. The purpose of these projects is to collect health data from approved Reporting Centres across the world for a group of rare conditions. These data are entered into the Registry by the Reporting Centres after they obtain consent locally and are then stored on a secure server at the University of Glasgow. These data are then shared with approved researchers for the purpose of improving care and long-term health outcomes for these rare conditions. The University of Glasgow is responsible for approving the Reporting Centres, for receiving and storing the data, for approving the researchers and for sharing the data with the approved researchers. The Reporting Centre is responsible for obtaining consent and for providing the data to the University of Glasgow.

This privacy notice will explain how The University of Glasgow will process your personal data. The general information published here is intended to supplement the specific information that you have already been given in the participant information study and consent form for the projects which are run by academic researchers at the University of Glasgow.

Why we need the data

Although the local Reporting Centre will collect detailed personal data, the Registry only holds date of birth and information about the health condition and its treatment. This data is held in the Registry under an ID code and the key that links the data to personal data such as name is kept at the Reporting Centre. So, the Registry does not keep names and addresses.

If you would like to view your data in the Registry, you can either ask the Reporting Centre to provide you a print-out or you have the option to view your data in the Registry. For the second option, you must provide an email to your Reporting Centre who will enter this email in the Registry so that your access to your data in the Registry can be activated. An email is also required if you would like to receive updates on the activities of the Registry or if your Reporting Centre wants you to complete any questionnaires. Your email address is not used for any other activities and is not shared with researchers. All activities that require you to provide an email are optional.

Legal basis for processing your data

The University of Glasgow, under its Charter and Statutes, is a public authority that conducts and promotes research in the public interest as part of its official functions. Research projects are intended to add to existing knowledge and the outcomes of those projects may be shared through reports and publications. The legal basis for processing personal data collected from research participants is therefore that such processing falls within the ‘public task’. The legal basis for collecting and processing the health data is that we consider it is necessary in the public interest for scientific or historic research purposes.

What we do with it and who we share it with

The data collected in the Registry are stored on a secure server in the University of Glasgow and might be used to perform research or develop new research studies.

The data will also be shared with approved researchers who want to perform research using these data. To obtain data from the Registry, the researchers will need to apply to the Data Access Committee and complete a Data Sharing Agreement. The data that are shared will be relative to achieving the specific research project’s objectives, and with all appropriate safeguards in place to ensure the security of the information. The activities of the researchers are carefully monitored by the University of Glasgow through regular meetings and progress reports.

Personal data may be accessed by third party developers of the Registry, but approved contracts are in place.

None of the researchers or any results that they publish will be able to personally identify any person whose data have been entered. They will also not be able to contact the person because the name, address and other hospital identification numbers will not be recorded. Only the hospital doctor at the Reporting Centre will be able to link the data in the Registry to the hospital records. Nobody else will be able to identify the person in the Registry, not even the staff who manage the Registry at the University of Glasgow. For some projects, the data collected in the Registry may be shared with a researcher who is based in a country that does not have data adequacy agreements with the UK. If this happens, the University of Glasgow will ensure that appropriate safeguards are in place.

How long do we keep it for

As the Registry is designed to look at long-term outcome, the data shall be stored indefinitely even after the registered person has passed away. Every 5 years, the Registry and its activities undergo a full ethical review in the UK.

What are your rights?*

Under data protection legislation, you have the following rights relating to the processing of your personal information:

- To be informed about the collection and use of your data
- To request access to the data we hold about you
- To request to have your personal data rectified if it is inaccurate or incomplete
- To restrict the processing of your personal data
- To object to your data being processed
- Not to have automated decision making and profiling made about you or using your personal data.

However, please note the following points: -

- The rights to erasure or data portability do not apply to the public task lawful basis under which we are processing your personal information for research.
- For research projects it may not be possible to provide all these rights if doing so would prevent or seriously impair the purpose of the research. For example, if the research has progressed to a later stage of analysis, or findings have already been published, removal of one individual's personal data may have an adverse effect on the entire dataset or on future exercises that check research integrity.
- When researchers publish data, they will irreversibly anonymise the data, and once this has happened, we will no longer be able to identify the specific information on any one person in the published data.
- Research often builds on earlier research, including re-analysis of existing data. If it is compatible with the original public task, which would be academic research in the public interest, we can continue to process a person's personal information for research including archiving purposes in the public interest, scientific research or statistical analysis.

If you have any queries, would like to access your records or you would like this notice in another language, please contact through the form that can be accessed at the following links:-

https://sdmregistries.org/contact/
https://globe-reg.net/contact/

If you wish to exercise any of your rights, you can also submit your request via the webform or contact dp@gla.ac.uk.

Complaints

If you wish to raise a complaint on how we have handled your personal data, you can contact the University Data Protection Officer who will investigate the matter.
Our Data Protection Officer can be contacted at dataprotectionofficer@glasgow.ac.uk
If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law, you can complain to the Information Commissioner's Office (ICO) https://ico.org.uk/

20th August 2023