

Privacy Notice For The Office For Rare Conditions (ORC) Registries

Your Personal Data

The University of Glasgow will be what is known as the 'Data Controller' of your personal data processed in relation to the ORC Registries project (referred to as the Registry). The purpose of the project is to collect health data from approved reporting centres across the world for a group of rare conditions that affect sex development and maturation. 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.

This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need the data

We are collecting your basic personal data including name, email address and contact details to assess your suitability to use the Registry platform for supporting and performing research and scientific activity. Your data will be used stay in contact with you for Registry related activities such as studies, surveys, newsletters and CPD events that promote research. We are only collecting data that we need to provide and oversee this service to you.

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 you is therefore that such processing falls within the 'public task'.

What we do with it and who we share it with

All the personal data you submit is processed by staff at the University of Glasgow in the United Kingdom. Personal data may be accessed by third party developers of the Registry but approved contracts are in place.

How long do we keep it for

All users of the Registry need to have an active account, ie they should have logged in at least once in a calendar year. An annual audit is performed of all accounts and all inactive account holders are sent an email. For those centres that do not have cases in the Registry and the account is not re-activated, the account is deleted. For those centres that have cases in the Registry, the account is disabled but not deleted as it affects the audit trail that is linked to the case datasets that are associated with the account.

What are your rights? *

You can request access to the information we process about you at any time. If at any point you believe that the information we process relating to you is incorrect, you can request to see this information and may in some instances request to have it restricted, corrected or, erased. You may also have the right to object to the processing of data and the right to data portability.

If you wish to exercise any of these rights, please submit your request via the [webform](#) or contact dp@gla.ac.uk.

*Please note that the ability to exercise these rights will vary and depend on the legal basis on which the processing is being carried out.

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/>

14th August 2023