

Privacy Notice for the IRONMAN Study

Your Personal Data

The University of Glasgow will be what's known as the 'Data Controller' of your personal data processed in relation to data collected in the record linkage phase of the IRONMAN Study. This privacy notice will explain how The University of Glasgow will process your personal data.

Why we need it

We are collecting your basic personal data such as name, address, telephone number, email address, date of birth and NHS or Community Health Index number, and limited special category data (health data) to conduct the IRONMAN study and facilitate safety reporting as required by the clinical trial regulatory authorities. We will only collect data that we need to carry out the study.

Legal basis for processing your data

We must have a legal basis for processing all personal data. In this instance, the legal bases are:

For personal data: *Article 6(1)(e) Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.*

For special category data: *Article 9(2)(j) processing is necessary for archiving purpose in the public interest, scientific or historical research purposes or statistical purposes*

What we do with it and who we share it with

We collect personal information about you when you voluntarily submit it to us e.g. providing information to our study team during study visits or when you give permission to others to share your personal information with us.

All IRONMAN data are stored in a secure database within the Robertson Centre for Biostatistics, University of Glasgow, who are contracted as the Data Management Centre for the study. All personal details are kept in a separate, more restricted, linked database and only visible to appropriately trained and authorised study team members.

Information collected from public or third-party information sources

We may collect personal information from GPs and hospitals to verify and supplement information that you have provided (e.g. confirming contact details or details of hospital admissions with your GP). We will also supplement our existing study participant database with information from centrally held NHS datasets. To obtain these data, the Study will send NHS Digital in England and the electronic Data Research and Innovation Service (eDRIS) in Scotland, details of your IRONMAN ID number, NHS or community health index (CHI) number, Name, Postcode and Date of Birth so that they can tell us about any hospitalisations or other events you may have had. The actual data that will be provided by the NHS in your country of residence will be hospital admission and discharge details including dates, diagnoses with diagnostic codes, dates and causes of death, if appropriate, and details of the hospital you were admitted to.

How does the IRONMAN Study use your personal information?

Your personal information will be used only to allow the conduct of the IRONMAN Study. We will not use automated decision-making tools including profiling during the study.

Your data will also be used for safety reporting purposes as required by the Medical and Health products Regulatory Agency (MHRA).

Does the IRONMAN Study share personal information with third parties?

We will not share your personal information with any third parties without your consent to do so. If you contact us to report additional study information, we may contact you for follow-up information. Any information that we do transfer or share will be used and disclosed in a manner consistent with the terms of this privacy notice, the fair processing statement, and with the study Participant Information Sheet (PIS) and consent form.

Who will have access to my personal information?

The study is legally sponsored by the University of Glasgow and NHS Greater Glasgow and Clyde, and your personal information will only be accessible to appropriately trained and authorised IRONMAN Study team members including statisticians at the Robertson Centre for Biostatistics, University of Glasgow. These individuals will usually see only de-identified data.

What steps does the IRONMAN Study take to protect personal information?

The IRONMAN Study database adheres to ISO 27001 and endeavours to use reasonable technical and administrative safeguards to protect your personal information from unauthorised access, use, loss, or destruction. For example, our website connection is encrypted and our internal network is fully protected and monitored. We undertake regular reviews of who has access to information that we hold to ensure that your information is only accessible by appropriately trained staff. Any backed-up data will be encrypted and not accessible by any personnel external to the IRONMAN Study.

All members of the study team at the University of Glasgow who have access to the study data have carried out relevant information governance training.

How long do we keep it for

Your personal data will be retained by the University for 11 years after the end of the study so that long term follow up can be conducted. After this time, your data will be securely deleted.

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.

It is your choice to provide or not to provide personal information to the IRONMAN Study. You may choose not to disclose some personal information to your study nurse or other member of the study team. However, to take part in the IRONMAN Study you must consent to providing certain personal information.

You may change your study participation preferences at any time by contacting us or by speaking to your nurse during a study visit.

You may withdraw from the study at any time by contacting your local IRONMAN Study team. Withdrawal from the study will not impact on your medical care.

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/>