

The Join Us Register is managed by The George Institute for Global Health (we, us and our), and we are committed to handling personal information in accordance with applicable privacy laws, including the Australian Privacy Principles set out in the Australian Privacy Act 1988 (Cth).

This Privacy Policy gives you information on how we collect and process your personal information through your use of this website, including any data you may provide through this website when you register to participate in the Join Us Register.

Neither the Join Us Register nor this website is intended for children, and we do not knowingly collect data relating to children.

It is important that you read this Privacy Policy together with any other privacy policy we may provide on specific occasions when we are collecting or processing personal information about you, so that you are fully aware of how and why we are using your data. This Privacy Policy supplements other notices, statements, consents and privacy policies in relation to the Join Us Register and is not intended to override them.

## What types of personal information do we collect and why?

### The register

We collect the information you provide when you register to participate in the Join Us Register. This includes your name, some demographic information, email address and some health information.

We collect this information to:

- enable us to use your de-identified health data to try and answer future research questions;
- determine your likely eligibility for a research project;
- contacting you about participation in current or future research projects relevant to your situation (based on the information provided);
- responding to your inquiries and requests;
- communicating with you on the status of the Join Us Register or new developments, including via newsletters; and
- improve the services provided by Join Us (by asking you to provide a review, take a survey or analysing data);
- to seek any further personal information and/or consent to use your data;

- send you important information regarding changes to our services, out terms and conditions and other administrative, technical or commercial information
- to comply with applicable laws and/or regulations; and
- for any other lawful, legitimate business purpose, including maintaining records and reporting for monitoring, evaluation and learning.

### The website

We may collect information about how you access, use and interact with this website. This information may include: your user service address and internet provider name and address, the date and time of your visit, the pages you accessed and any documents downloaded, any website visited prior to accessing our site and the type of browser used.

This information (which is unlikely to contain personal information) is collected to monitor the activity on the website, and to distinguish you from other users of the website in order to optimise and simplify your use of the site.

## Can you deal with us anonymously?

You will not be able to register to participate in the Join Us Register anonymously or by using a pseudonym, but where lawful and practical (e.g., when inquiring about the Join Us Register), you will be given the option to deal with us without identifying yourself or by using a pseudonym.

## How do we collect and hold your personal information?

### The register

We collect your personal information directly from you when you register to participate in the Join Us Register.

### The website

This website uses cookies, which are small text files that are stored in your local browser cache when you visit a website. Using cookies makes it possible to recognise the visitor's browser to optimise the particular website and simplify its use. Information collected via cookies is not used by us to determine the personal identity of a visitor. Most browsers are set up to accept these cookies automatically. You can deactivate the storing of cookies or adjust your browser to inform you before a cookie is stored on your computer.

## How do we store and hold your personal information?

We store and hold your personal information in electronic records and systems operated either by us or our external service providers who are performing services in relation to the Register and responsible to us. Similarly, any personal information held or managed by the University of New South Wales will be in electronic records and systems operated either by the University of New South Wales or its external service providers who are performing services in relation to the Register and responsible to it.

We use physical security and other measures to ensure that personal information we hold is protected from misuse, interference and loss, and from unauthorised access, modification and disclosure. Please refer to the section under Data Security below.

## How do we disclose your personal information?

We may need to reveal or disclose your personal information to authorised Join Us staff and external service providers, such as those who provide IT, analytics, cloud storage or technical support or delivery services or who are performing services in relation to the Register and responsible to us.

Our Register staff and all external service providers must comply with relevant privacy and confidentiality terms regarding the protection of your personal information as part of their employment or engagement.

We may share your personal information as directed or permitted by law or court order or otherwise with law enforcement bodies, regulators, our insurers, external legal advisors, government agencies, courts or other third parties where we believe disclosure is necessary to: (i) comply with applicable law; (ii) exercise, establish or defend our legal rights; (iii) protect your rights or vital interests or those of any other person; or (iv) detect, prevent or otherwise address security, fraud or technical issues.

We may also share or need to reveal your personal information with: (i) other parties with your consent and in accordance with this Privacy Policy; and/or (ii) third parties who are or may be involved in any actual assignment, reorganisation or transition of all or any Join Us Register service to another provider provided that we have taken all reasonable steps to ensure that those parties are bound by relevant

privacy and provider provided that we have taken all reasonable steps to ensure that those parties are bound by disclosure is conducted in compliance with applicable laws and they are informed that they must use your personal information only for the purposes disclosed in this Privacy Policy.

## Data Security

We have put in place measures to protect the security of your personal information on the Join Us Register. We limit access (by physical and technical safeguards) to your personal information to those staff and external service providers who have a business or legal need to know.

We maintain computer and network security by using firewalls, user identifiers and passwords to control access to our computer system.

We have also put in place procedures to deal with any suspected data breach and will notify you and any applicable regulator of a suspected breach where we are legally required to do so.

## Newsletters and Marketing

You will not be able to register to participate in the Join UYou will receive a regular electronic newsletter with updates about the 'Join Us Register, but you can unsubscribe if you wish by following the opt-out instructions provided in the communication.

Where you receive electronic marketing communications such as event communications and newsletters from us, you may opt out of receiving further marketing communications by following the opt-out instructions provided in the communication.

## Do we disclose personal information to overseas recipients?

We do not disclose your personal information to recipients who are located outside Australia.

## How long will we keep your information?

The Join Us Register is intended to be a long-term project and has no end date, with data intended to be stored indefinitely or until you request to be removed from the Register.

We will retain your personal information for as long as reasonably necessary to fulfil the purposes we collected it for, to resolve disputes, establish legal defences, conduct audits, pursue legitimate business

purposes, enforce our agreements and to satisfy any legal, regulatory, or reporting requirements.

To determine the appropriate retention period for personal information, we consider the amount, nature and sensitivity of the information, the potential risk of harm from unauthorised use or disclosure of your personal information, the purposes for which we process your personal information and whether we can achieve those purposes through other means, and the applicable legal, regulatory, tax, accounting or other requirements.

When we are no longer required to retain the personal information as described above, we will destroy, erase, or de-identify it. Legal requirements, however, may require us to retain some or all of the personal information we hold for a period of time that is longer than that for which we might otherwise hold it.

### Your consent

If we have collected and process your personal information with your consent (including any sensitive or special category data), then you can withdraw your consent at any time by filling out the participant withdrawal form. Please note, such withdrawal will not affect the lawfulness of any collection, processing, use or transfer effected prior to your withdrawal.

### How can you access and seek correction of your personal information held by us?

You may request access to, or seek correction of, your personal information that is held by us in the Join Us Register, by writing to the Privacy Officer:

**Address:**

Level 18, International Tower 3  
300 Barangaroo Avenue  
Sydney, NSW 2000 Australia  
Or

**Email:** [privacy@georgeinstitute.org](mailto:privacy@georgeinstitute.org)

Typically, we will respond to your request within 10 - 20 business days, but sometimes we may require more time depending on the circumstances.

We will generally not charge a fee for such requests, but we may charge a reasonable fee if your request is clearly unfounded or excessive.

Alternatively, we may refuse to comply with the request in such circumstances. In your request, please ensure that you provide a reply address, so that we can contact you if we are unable to locate your personal information, if we need to verify your identity, or if we cannot carry out your request (in which case, we generally tell you why).

### What should you do if you have a complaint about the handling of your personal information?

Please set out your complaint in writing to the Privacy Officer:

**Address:**

Level 18, International Tower 3  
300 Barangaroo Avenue  
Sydney, NSW 2000 Australia  
or

**Email:**

[privacy@georgeinstitute.org](mailto:privacy@georgeinstitute.org) or [info@joinus.org.au](mailto:info@joinus.org.au)

Please provide sufficient information, so that we can consider your concerns and contact you. Typically, we will respond to your complaint within 10 - 20 business days.

If you are not satisfied with our response, or you consider that we may have breached the Australian Privacy Principles or the Privacy Act 1988 (Cth), you are entitled to make a complaint to the Office of the Australian Information Commissioner. The Office of the Australia Privacy Commissioner can be contacted by telephone on 1300 363 992 or full contact details can be found online at [www.oaic.gov.au](http://www.oaic.gov.au).

### How are changes to this privacy policy made?

This Policy was created in July 2020 amended in January 2024. We may update this Privacy Policy from time to time, with or without notice to you.

When we do update this Privacy Policy, we will take appropriate measures to inform you, consistent with the significance of the changes we make. We will obtain your consent to any material changes if and where this is required by applicable privacy laws. Please refer to the [Join Us website for the latest copy of this Privacy Policy](#).

The latest copy of The George Institute's Privacy Policy can be accessed [here](#).