

A national research register of one million people directly supporting Australian research

Privacy policy

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 aims to give 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.

This website is not 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, date of birth, sex, address, postcode, Medicare number (optional), telephone number and/ or email address. You will also be invited to complete an optional survey after you register providing health and demographic information.

We collect this information to:

- match the information you provide to your healthrelated records
- contact you about research projects that you might be interested in joining
- provide you with information and updates about the Join Us register
- enable us to use your de-identified health data to try and answer future research questions

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, you will be given the option to deal with us without identifying yourself or by using a pseudonym (e.g. when inquiring about the Join Us register).

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 in order 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.

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 disclose your personal information to authorised register staff and external service providers who are performing services in relation to the register and responsible to us.

Our register staff and external service providers must comply with privacy and confidentiality terms as part of their employment or enagement with us.

We may also disclose your personal information as directed or permitted by law or court order.



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Data Security

We have put in place measures to protect the security of your information. We limit access (by physical and technical safeguards) to your personal information to those staff and trusted 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.

Marketing

You 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 and to satisfy any legal, regulatory, or reporting requirements.

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 Chair of the Join Us Steering Committee:

Address:

Level 5 1 King Street Newtown

NSW 2042 Australia; or

Email: Info@JoinUs.org.au

Typically, we will respond to your request within 10 - 20 business days, but sometimes we may require more time depending on the 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 or the Chair of the Join Us Steering Committee:

Address:

Level 5 1 King Street Newtown

NSW 2042 Australia; or

Email: privacy@georgeinstitute.org or Info@JoinUs.org.au

Please provide sufficient information, so that the 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.

How are changes to this privacy policy made?

This Policy was created in July 2020. We may amend this Privacy Policy from time to time. Please refer to this website for the latest copy.