



Participant Information Sheet and Consent Form

Participant Information

The **Join Us Research Register** would like to invite you to help save lives and improve health outcomes for all Australians by joining our medical research register.

1. What is the Join Us Research Register?

Join Us is an online medical research register that helps Australians take part in life-saving health and medical research. Join Us helps match people who are willing to participate in health and medical research with research projects relevant to them. The register is simple and free to join and use, with users able to withdraw at any time.

2. Who is Join Us?

Join Us was created in 2020 by The George Institute for Global Health and the University of New South Wales, Sydney.

The register is managed by The George Institute for Global Health, with the assistance of the University of New South Wales.

Join Us has collaborated with more than 40 leading research, healthcare, and consumer organisations (<https://www.joinus.org.au/collaborators>) from across Australia.

3. Why should I join?

Australia's world-class health and medical researchers make many discoveries to improve health and save lives of people here and around the world. But this relies on people like you volunteering to be involved. Many Australian-led research projects fail every year because researchers cannot find enough volunteers to get involved. When asked, most people say they are interested in getting involved in research projects that are relevant to them - but in practice very few get the opportunity. Join Us helps connect people interested in research and match them with relevant research projects. Your participation in the Join Us Register is not conditional on your acceptance of any invitation and/or your participation in any research.

4. What do I need to do?

To sign up to Join Us, all you need to do is complete the online registration form, at www.joinus.org.au.

5. What sort of information do you need from me?

To join the register, you will need to provide your contact information and some information about your health and demographics that will help match you to appropriate research projects. If you do not provide this information, you will not be able to join the register and participate in the Join Us initiative.

6. How do I know my personal information will be secure?

The privacy of your data is an absolute priority. After registering, your personal contact details are manually separated from your health-related details. Your personal details are held in a database managed by The George Institute for Global Health and your health-related information is transferred to and stored in a separate database managed by the University of New South Wales. Both databases are secure and encrypted, meet industry and Government data security standards and are located in



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Australia. To maximise data security, once separated, no staff member has access to the separated datasets. Both The George Institute for Global Health and the University of New South Wales have also put in place procedures to deal with any suspected data breach; you and any applicable regulator will be notified of a suspected breach where we are legally required to do so. Join Us participant data is not shared with researchers or any 3rd party. Join Us uses data collected to match participants to research projects and then sends eligible participants an email invitation to join that research project. After that it's up to a potential participant to get in touch with the research project team and there is no obligation to do so if it's not right for you at that time.

7. How will joining Join Us help me and others?

Taking part in the Join Us register and participating in health research projects helps contribute to the health of the Australian community and generate new health findings in areas such as cancer treatment and chronic disease. Where relevant, you may also be able to participate in clinical trials investigating new treatments and you can even let your friends and relatives know about the research projects and trials. Some research projects may offer payment for costs such as travel. Gift vouchers or other benefits are sometimes offered when joining a research project.

Whether you do participate in any suggested research project or not will have no bearing on your Join Us registration and we will continue to match you to appropriate research projects and send you invitations to join them.

8. What kind of research projects can I get involved in?

"Join Us" facilitates recruitment to healthcare and medical research projects aimed at advancing treatments, health programs, policies, and services to enhance population-level health outcomes. The initiative supports recruitment efforts across a wide range of public health issues, with research projects spanning all areas of human health—from heart disease to mental health. For more information on the specific studies supported by "Join Us," please visit [URL link to research studies supported].

Getting involved in a research project can range from something as simple as answering an online survey, through to having your blood tested, testing new medical devices and phone apps, and sometimes participating in clinical trials. You will receive up to 16 invitations to research projects each year. You can change the number of invitations you receive and also update your health conditions in the participant portal (URL link). When you receive an invitation, it is up to you to decide whether you wish to be involved with the research project.

The conduct and/or outcome of any research project you chose to participate in is not the responsibility or within the control of either The George Institute for Global Health and/or the University of New South Wales.

9. How do researchers use the Join Us database?

Join Us will only suggest and invite you to participate in research projects which have received a valid ethics approval from an Australian Human Research Ethics committee. Researchers contact the Join Us team with information about their research project and, if appropriate, we match and send participants invitations to get involved in that research project. Matched participants are sent an



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invitation to connect with researchers directly themselves – Join Us never provides participant contact details to researchers.

Researchers may also request to use your de-identified health data to try and answer future research questions. (de-identified means that the information cannot be linked to you personally). Use of this de-identified health data in this way will be subject to the researchers obtaining ethics approval from an Australian Human Research Ethics committee.

10. How is my information used to match me to a research project?

The information you provide at the time of registration is used to match you to research projects. You might be matched to research projects based on information such as your age, sex recorded at birth and whether you do or do not have certain medical conditions. When you receive a research project invitation, you will be provided with information about the research, what is involved and any further eligibility criteria. You can then decide whether the research project is a good match for you and whether you would like to take part.

11. How long will you keep my 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 (or someone requests for your removal on your behalf).

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. For more information, please read the Privacy Policy (text linked).

12. What if I want to opt out from Join Us?

You can withdraw from Join Us at any time, without having to give a reason for your withdrawal, by completing the electronic withdrawal form (text linked). You can also withdraw from the register by accessing the Join Us Participant Portal (text linked) and following the steps to update your consent or withdraw from Join Us entirely. If you withdraw, you will be able to choose to destroy all information about you OR retain only the de-identified health information the register has collected. (De-identified means that the information cannot be linked to you personally).

13. Will Join Us cost me anything?

It doesn't cost anything to sign up to Join Us and there is no cost associated with being a participant in the register.

14. How can I find out more about Join Us?

To find out more about Join Us, head to www.joinus.org.au. Once you have signed up to Join Us, you will receive regular newsletters from the Join Us team to keep you updated.

15. Any questions or comments?

You can contact the Join Us team by phone or email:



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Telephone: (02) 8052 4798

Email: info@joinus.org.au

16. What if I have a complaint or any concerns about Join Us?

If you have a complaint regarding any aspect of the Join Us register or the way your data is being handled, please contact the Sydney Local Health District Human Research Office:

Complaints Contact

Position: Research Executive Officer

T: 02 9515 6766 E: SLHD-RPAethics@health.nsw.gov.au

Join Us Register approval number: 2021/ETH12277

For more information about the Join Us Privacy Policy, visit our website www.joinus.org.au. -



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Consent

☐ By ticking the box, you confirm that you:

1. have **read and understood the Participant Information Sheet** and the **Privacy Notice; consent** to the collection, use and disclosure of your personal information as set out in this Privacy Notice and the Privacy Policy; and
2. understand that:
 - (a) the information you provide will be used to **match you to research projects**,
 - (b) you may be **contacted about participating** in research projects you have been matched to;
 - (c) if you are invited to participate in a research project, it is up to you to **decide whether you want to participate** in that research project;
 - (d) your information could be **held indefinitely** unless you withdraw from the Join Us Register and **ask for it to be deleted**.

Signature

Date (DD/MM/YY)

Print Name