

## **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 research register that helps Australians take part in life-saving health and medical research. We match people who are willing to participate in health and medical research with studies relevant to them. The register is simple and free to join and use, with users able to withdraw at any time. We simply ask for your contact information, some brief health information, and invite you to research opportunities that may be suitable to you.

### **2. Who created Join Us?**

Join Us was created in 2020 by The George Institute for Global Health and the University of New South Wales, Sydney. We have partnered with more than 40 leading research, healthcare, and consumer organisations 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 studies 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 studies.

### **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](http://www.joinus.org.au).

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

We're asking for your contact information and some information about your health and demographics that will help us match you to appropriate research studies.

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

The privacy of your data is an absolute priority for us. After registering, your personal contact details are separated from your health details and are stored in separate, secure and encrypted databases that meet industry and Government data security standards. To maximise data security, no staff member has access to both databases. Your information will not be used outside of ethically approved studies and all your data are physically located within Australian borders. 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. Join Us participant data is not shared with researchers or any 3<sup>rd</sup> party. Join Us uses the data collected to match participants and then sends eligible participant an email invitation to join the research study. After that, it's up to you, as a potential participant to get in touch with the research 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 helps contribute to the health of the Australian community and generate new health findings in areas such as cancer treatment and chronic disease. You may also be able to take part in clinical trials investigating new treatments or let your friends and relatives know about them. Studies cover all areas of human health – everything from heart disease to mental health. Some studies may offer payment for costs such as travel. Gift vouchers or other benefits are sometimes offered when joining a study.

#### **8. What kind of studies can I get involved in?**

Getting involved in research 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

even participating in clinical trials. You will receive up to eight invitations to research projects each year. You can change the number of invitations you receive. When you receive an invitation, it is up to you to decide whether you wish to be involved with the research study.

#### **9. How do researchers use the Join Us database?**

Join Us only works with researchers who have a valid ethics approval from an Australian Human Research Ethics committee. Researchers contact the Join Us team with information about their study and we match participants and send them invitations to get involved in the research. Matched participants are sent an invitation to connect with researchers directly – Join Us never provides participant contact details directly to researchers.

#### **10. How is my information used to match me to a research study?**

The information you provide at the time of registration is used to match you to research projects. You might be matched to research studies based on information such as your age, sex and whether you do or do not have certain medical conditions. When you receive a study invitation, we will provide you with information about the research, what is involved and any further eligibility criteria. You can then decide whether the study is a good match for you and whether you would like to take part. When you sign-up to Join Us, you also have the option to sign-up to the data linkage component of Join Us (more information here).

In the future, if you opt into data linkage your de-identified electronic health record data may also be used to better match you to research studies.

Emailing Join Us at [info@joinus.org.au](mailto:info@joinus.org.au); or Calling us at (02) 8052 4798; or filling out a contact form at [www.joinus.org.au/contact](http://www.joinus.org.au/contact)

#### **11. What if I want to opt out from the register?**

You can withdraw from the register at any time and do not need to give a reason for your withdrawal by completing the electronic withdrawal form on the Join Us website or by emailing us at [info@joinus.org.au](mailto:info@joinus.org.au). You will be able to choose whether the register will destroy or retain the information it has collected about you already. It may not be possible to withdraw information already used for research or publication. You can also withdraw from the register by accessing the Join Us Participant Portal (<https://www.joinus.org.au/participants/participant-portal/>) and following the steps to update your consent or withdraw from the register entirely.

#### **12. How can I find out more about Join Us?**

To find out more about Join Us, head to [www.joinus.org.au](http://www.joinus.org.au).

You will also receive regular newsletters from Join Us team to keep you updated about the register.

### **13. Any questions or comments?**

We'd love to answer any questions you have about the Join Us Register. You can contact us by:

[www.joinus.org.au/contact](http://www.joinus.org.au/contact)

### **14. 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 it is being conducted, 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](mailto:SLHD-RPAethics@health.nsw.gov.au)

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#### **Privacy and Your Personal Information**

The privacy and security of your personal information is important to us and is protected by law. We need to collect this information so we can process and manage your applications and provide services to you. We only share your information with other parties where you have agreed, or where the law allows or requires it. Visit [servicesaustralia.gov.au/privacy](http://servicesaustralia.gov.au/privacy) for more information. For more information about the Join Us Privacy Policy, visit our website.