

Data Linkage Participant Information

1. What is data linkage?

Data linkage enables researchers to look at large volumes of data from various sources and make connections and study relationships between that data. You can agree to allow Join Us to securely link your personal details with routinely collected health information to help with research. Researchers are only provided with access to deidentified data that cannot be linked to personal information you have provided like your name or email address.

The Join Us data linkage option will:

- Collect and hold one additional personal detail, your street address.
- Match your personal details to your electronic health records.
- Store your de-identified health records.

2. What databases are being linked to?

The Join Us data linkage option will connect to a variety of databases that hold a broad range of health information. Such information is routinely collected by governments and other health care providers. Data sources will include but are not limited to:

Medicare services (the Medicare Benefits Schedule); medications dispensed at a pharmacy through the Pharmaceutical Benefits Scheme; birth, deaths and marriage records; cause of death; admissions to hospitals; attendances at emergency departments; cancer registries; and pathology services.

The ability to do data linkage is expanding and we may extend future data collection to records that are not currently available. For example, it is not currently possible to link data from the electronic health record held by your general practitioner, but this might be an option in the future.

Before we link data from any additional source, we will always seek approval from a Human Research Ethics Committee.

3. Why should I agree to data linkage?

Linking routinely collected data provides a powerful way to create more detailed datasets that can help address difficult health questions across Australia. By participating in data linkage, Join Us can more precisely match you to research studies and enable researchers to use these records to answer research questions.

4. Do I have to participate in the Join Us data linkage option?

Your participation in the Join Us data linkage option is completely voluntary and there will be no cost to you. You are under no obligation to participate in data linkage; you can still help Australian researchers to improve health outcomes by signing up to the Join Us register.

5. How do I know my data will be stored securely?

The privacy of your data is an absolute priority for us. When you sign up to data linkage, you will be asked for one additional piece of information: your street address. After registering, your personal details, including your street address, 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 de-identified health information is stored in the E-Research Institutional Cloud Architecture (ERICA) Platform. ERICA has completed the full eHealth New South Wales Privacy Security Assurance Framework review and eHealth New South Wales has formally advised that ERICA is designed with adequate security to meet the requirements of New South Wales Health. The ERICA platform has comprehensive security protocols for storage, access, quality assurance, retention and destruction of data. All Join Us team members and researchers with approval to analyse linked data through ERICA will receive specific and comprehensive training. 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.

6. What if I want to opt out from the Join Us data linkage option?

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. If you withdraw from the data linkage option, 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 will need to directly contact the research coordinator or study team of the research study you participated in regarding withdrawal of your consent and/or information.

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 data linkage consent or withdraw from the register entirely

7. 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

Project Number:

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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.

For more information about data privacy in Australia, go to servicesaustralia.gov.au/privacy.

For more information about the Join Us Privacy Policy, visit our website.