

## Information Statement

### Women's Health Australia

You are invited to participate in the Women's Health Australia project (also known as the Australian Longitudinal Study on Women's Health), which is conducted by researchers from the University of Queensland and University of Newcastle, and funded by the Australian Government Department of Health.

#### ***Why is the research being done?***

Women's Health Australia began in 1996 and is the longest running study of women's health in Australia. There are over 57,000 women from across the country involved in Women's Health Australia. We collect information about women's health and wellbeing via surveys and health service records, to provide findings to the Department of Health. This helps to develop women's health policies and services. The project is longitudinal - this means the study is ongoing and we follow the health of the same people over time.

#### ***Who can join the study?***

We are now recruiting females born between 1973 and 1978 who have a Medicare card to join the project! As we know many women have migrated to Australia from South, Southeast, and Northeast Asian countries since we first started this cohort in 1996, we are especially looking for women from these areas to join the WHA project. It's important to us that women from all backgrounds are given a voice in national policies that impact their health and wellbeing.

#### ***What choice do I have? Your participation is voluntary***

Your participation in this study is completely voluntary and there will be no cost to you. If you do not want to take part in this study, you do not have to. You should feel under no obligation to participate in this study. Choosing not to take part in this study will not affect your current or future medical care in any way.

#### ***What would I be asked to do?***

If you agree to participate, the first thing you will need to do is go to <https://alswh.org.au/recruit7378/> to complete questions in an online survey. You will be asked to provide your name and email address, and complete a few questions to make sure you're eligible to take part in the study (date of birth, your sex, and whether or not you have a Medicare card). If you're eligible to join the study, you will then be asked to complete survey questions about your health and wellbeing. The survey will take 15-20 minutes to complete. If you wish to view the survey, a pdf copy is available here: <https://alswh.org.au/wp-content/uploads/2022/03/SurveyPreview7378.pdf>. Surveys are conducted approximately every three years. We will email you with a link to complete the next online survey in a few years.

You will also be asked to agree to allow us to link your survey responses to other datasets and health records such as Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS). If you agree, with assistance from Services Australia, we can link your survey responses to MBS and PBS records for health information and to reduce the number of questions we need to ask you. Agreeing to this is a requirement if you wish to join Women's Health Australia. You will also be required to provide your full name, date of birth, Medicare card number, and contact details for the purpose of future correspondence, to verify your identity through Services Australia, and link your data with other datasets. For more information, see our FAQs: <https://alswh.org.au/recruit7378/faq/>.

You will also be asked to allow us to link your survey responses to other external health record collections. These include hospital admissions, emergency department presentations, and perinatal data collections; death and disease registers; and aged care datasets. National collections will be linked by the Australian Institute of Health and Welfare, and state-based collections by the responsible Data Linkage Units in each

jurisdiction. Your personal details will be securely provided to these Accredited Integrating Authorities for this purpose. You can see a list of the records we currently link to and their Data Linkage Units here: <https://alswh.org.au/for-data-users/linked-data-overview/linked-data-sources/>.

***Medicare Benefits Schedule, Pharmaceutical Benefits Scheme and other linked datasets consent form***

You will be asked to electronically sign an online consent form authorising the study to access your complete Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data as outlined in the consent form, along with other linked datasets as noted above. Medicare collects information on your doctor visits and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies. The consent form is sent securely to Services Australia who holds MBS and PBS data confidentially. MBS and PBS data will not be used in any future or unspecified research outside of Women's Health Australia. Online consent will also be sought for authorisation for the data linkages to other health records as described above.

Services Australia is not involved in the conduct of this study other than to approve the consented release of your MBS and PBS claims information. Services Australia will not release your personal information without your consent.

***What if I take part in the study and change my mind later? Your withdrawal from the study***

You are under no obligation to continue taking part in the project. You may change your mind about participating in Women's Health Australia at any time. People withdraw from studies for various reasons and you do not need to provide a reason. You can cease participating in future surveys, cease future data linkage, and/or withdraw your data from Women's Health Australia at any time.

*Ceasing participation in future surveys*

If you would like to cease participation in the Women's Health Australia surveys at any time, you can communicate that to the project team via email ([alswh@newcastle.edu.au](mailto:alswh@newcastle.edu.au)) or call 1800 068 081 (freecall).

*Withdrawing my consent to data linkage*

You can withdraw your consent for Women's Health Australia linking your survey data with Services Australia health information (i.e. linked data) at any time by completing and signing the 'Services Australia Participant Withdrawal of Data Linkage Consent Form'. If you choose to withdraw your data linkage consent, this form is to be completed by you and supplied to the research team.

When completing the form, you will be asked to choose between two options:

1. Request that the study retain the Services Australia health information (i.e. linked data) it has collected about you so far, but withdraw your consent to Women's Health Australia obtaining future linked data.
2. Request that the study destroys the linked data it has collected about you so far, and does not obtain future linked data.\*

\*Destruction of your linked data involves its deletion from the current Women's Health Australia master datasets. Withdrawal of data linkage consent prior to a round of extraction from linked datasets means your data will not be included in the resulting Women's Health Australia master datasets or analyses. Withdrawal of data linkage consent after a round of extraction from linked datasets will mean you will be excluded from any future extractions from linked datasets for the Women's Health Australia project, and your linked data will not be included in any future datasets, analyses, and publications.

You should only choose **one** of these options. Where both boxes are ticked in error or neither box is ticked, the study will destroy all information it has collected about you and will not obtain future linked data (option 2 above).

Please note that data about you that has already been analysed and/or included in a publication by the study will not be able to be destroyed. It is not possible to remove your linked data from past datasets, analyses,

and publications. In such circumstances, your information will continue to form part of the project study records and results.

***How will my data be protected? Storage, retention and destruction of your information***

All personal and survey information collected remains confidential in accordance with the National Health and Medical Research Council ethical guidelines and the Australian 1988 Privacy Act. Your personal information will be securely stored separately from your survey answers and linked data from health databases on servers, or hosted through cloud computing providers, physically located within Australian borders. These locations will be isolated from the internet by firewalls.

Access to any identifiable data (such as names and contact details) will be restricted to members of the research team and those outlined in this information statement (including those involved in verifying your data in the linkage process), unless you have consented otherwise; or disclosure is required by law in order for us to comply with our regulatory obligations. Furthermore, access to identifiable data requires user authentication for logging into the databases with a username/password combination. All database edits and data entries completed by each user are logged in the database's audit trail. Researchers conducting analyses do not have access to personal information.

The survey will be completed online through REDCap (Research Electronic Data Capture), a secure web-based database system. REDCap is a purpose-built software application for the conduct and management of medical research surveys and case report forms for clinical trials. The REDCap application is hosted within Australian borders on Hunter Medical Research Institute secure servers, which are both physically and virtually secured. User authentication is required for logging into REDCap. All database edits and data entries completed by each user (including REDCap Administrators) are logged in the project's audit trail.

The de-identified survey data captured from the online survey will be stored in the research database, separately from participant contact information. For extra privacy protection, different ID numbers will be assigned to these two databases, with the key between the two sets of IDs limited to a small number of staff. Copies of de-identified survey datasets are also archived electronically at the Australian Data Archive (a national repository for the curation of research data assets).

Due to the ongoing nature of the study, the data will be securely retained for at least five years after the study finishes, and stored in accordance with the University of Newcastle's [Research Data and Materials Management Guideline](#) or any successor Guideline, The University of Queensland Policy and Procedures (including: [1.60.02 Privacy Management](#), [4.20.06 Research Data Management](#), and [6.40.01 Information Management](#)), and applicable University of Newcastle policy provisions (as amended from time to time). After the closure of the study and the mandatory retention period, all personally identifying information (such as names, dates of birth and contact details) will be securely destroyed.

De-identified survey data will continue to be maintained in the Australian Data Archive. Arrangements will also be made at this time about the linked health record data provided to us, for the duration of the study, by national and state governments. At the discretion of the agency which provided the data, it will either be included in the non-identifiable archive, or securely destroyed.

Your personal information held by Services Australia is protected by the Privacy Act 1988 and cannot be given to a third party without your consent or where otherwise permitted by law. For more information about privacy, go to: [servicesaustralia.gov.au/privacy](https://servicesaustralia.gov.au/privacy)

***What will I get out of participating in the project?***

If you choose to take part in the project by completing the survey and allowing us to link your survey responses with other datasets, you will have a chance to win a \$1,000 Prezzy Smart eGift Card that can be used online or in-store at 100+ Australian retailers. For more details go to:

<https://www.prezzy.com.au/store/#gift-cards>. The prize will be distributed via email.

### ***What are the risks and benefits of participating?***

We cannot promise you any direct benefit from participating in this research, but we expect that the data from this study will inform health policy in the future that will benefit women living in Australia.

Should you find any of the questions upsetting, you can skip them or stop the survey at any time. You can contact the following support services should you wish to seek support regarding any of the issues raised within the survey:

- Lifeline provides 24-hour crisis support by calling 13 11 14. Lifeline online chat is available from 7pm to midnight AEST through the following website: <https://www.lifeline.org.au/crisis-chat/>
- Beyond Blue provides mental health support through calling 1300 224 636. They also offer an online chat on the following website: <https://online.beyondblue.org.au/#/chat/start>
- 1800RESPECT provides 24-hour confidential information, counselling and support services for people impacted by sexual assault, domestic or family violence and abuse, by calling 1800 737 732. An online chat can be accessed at any time through the following website: <https://chat.1800respect.org.au/#/welcome>

### ***How will the information collected be used?***

If you choose to participate, you will be joining an existing cohort of participants providing data as part of Women's Health Australia.

Your Medicare card number will only be needed for the first survey. By providing the number, you will help us verify your details and ensure that the person who completed the survey is the appropriate sex and age for the survey. Your Medicare number also allows us to link information like health services you use (not results of tests) with your survey responses. Your completed consent form and required personal details will be provided to Services Australia confidentially so that they can verify your identity and provide a list of identifiers to the Australian Institute of Health and Welfare, who will extract the MBS and PBS data for this Study. Your personal details will be securely provided to the Australian Institute of Health and Welfare to link your national collections, and the responsible Data Linkage Units for each state-based collection as listed here: <https://alswh.org.au/for-data-users/linked-data-overview/linked-data-sources/>

It is expected that the de-identified study results will be used in journal articles, reports, conference presentations and seminars. All published data will be de-identified, and there will be no possibility of re-identification of your data within publications. Non-identifiable data may be made available for future research. All researchers who wish to use Women's Health Australia data, including linked data, will need to apply to the Australian Longitudinal Study on Women's Health (ALSWH) Data Access Committee, adhere to all ethical requirements and guidelines, and agree to the ALSWH terms and conditions for use of the data as outlined here: <https://alswh.org.au/for-data-users/applying-for-data>

We will keep you informed of study results via an annual newsletter. You will also be able to view updates on the project website: [www.alswh.org.au](http://www.alswh.org.au)

### ***What do I need to do to participate?***

Please read this information statement and the accompanying consent preview documents before you commence the survey. Commencement of the survey will be taken as implied consent to participate. If there is anything you do not understand, or you have questions, please contact the researchers (see details below). At the beginning of the survey, you will be required to provide your preferred name, email address, date of birth, sex, and whether or not you have a Medicare card. After the survey health questions, you will be required to provide consent to data linkage and additional personal details including your title, full name, permanent address, postal address, and Medicare card number. If you would like to participate, please click on the survey link below to commence the online survey (please have your Medicare Card number ready).

[Start the online survey here.](#)

**Where can I get more information?**

If you would like further information, please see our FAQs (<https://alswh.org.au/recruit7378/faq/>) or contact the Women’s Health Australia team via email ([alswh@newcastle.edu.au](mailto:alswh@newcastle.edu.au)) or phone (1800 068 081).

Thank you for considering this invitation.

Professor Gita Mishra  
Co-Investigator

Professor Julie Byles  
Co-Investigator

A/Professor Leigh Tooth  
Co-Investigator

Professor Deborah Loxton  
Co-Investigator

**The Research Team**

Prof Gita Mishra University of Queensland	Prof Julie Byles University of Newcastle	A/Prof Leigh Tooth University of Queensland	Prof Deborah Loxton University of Newcastle
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**Complaints about this research**

This project has been approved by the University of Newcastle and University of Queensland Human Research Ethics Committees, Approval No. H-076-0795 and 2004000224 respectively.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to Co-Investigator Prof Loxton: (02) 4042 0690 or [deborah.loxton@newcastle.edu.au](mailto:deborah.loxton@newcastle.edu.au), or, if an independent person is preferred, to the Ethics Officer, Research and Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333 or email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).

Prize draw runs 21/03/22 – 05/12/22, drawn 07/12/22. Winners randomly drawn from a ballot box and will be informed via email. For prize draw terms and conditions see <https://alswh.org.au/wp-content/uploads/2022/03/Cohort-Refresh-197378-TCs-1.pdf>.

If you have a privacy complaint in relation to the use of your Services Australia information, you should contact the Office of the Australian Information Commissioner. You will be able to lodge a complaint with them.

Website: [www.oaic.gov.au](http://www.oaic.gov.au)

Telephone: 1300 363 992

Email: [enquiries@oaic.gov.au](mailto:enquiries@oaic.gov.au)

Mail: GPO Box 5218, Sydney NSW 2001

**Please keep this information sheet for your information.**