



Privacy and Information Management Protocol for Australian Longitudinal Study on Women's Health – Researchers (Opt-in consent for MBS and PBS linkage)

Background

The Australian Longitudinal Study on Women's Health (**ALSWH**), managed by research teams at The University of Queensland and The University of Newcastle has previously collected data on the health of Australian women in three age cohorts. Around 40 000 women agreed to participate in the project and provided personal and health information on survey forms (**ALSWH survey data**). Data for participants who previously consented to data linkage to MBS and PBS data are available, this is the opt-in consent. This information is currently held in hard copy and electronic form at the University of Newcastle. De-identified health information is held in electronic form at the University of Queensland. The longitudinal project utilises identifiable survey data and is ongoing.

This document is pertinent to those collaborators and investigators who are seeking to access ALSWH data linked with Medicare Australia data (MBS and PBS) for the data where consent was obtained as part of this **opt-in procedure**.

A further project has now commenced to link ALSWH survey data in a de-identified form with other data sets including de-identified data from the Medicare Benefits Scheme (MBS), Pharmaceutical Benefits Scheme (PBS), Aged Care Assessment Program and Home and Community Care Program. The linked data will provide a unique resource for the evaluation of current policy and the development of future policy initiatives to improve health services to women throughout Australia. This form is not for people seeking to access linked data under the opt-out procedure currently being developed.

Approval of projects requesting use of MBS and PBS linked ALSWH data using the opt-in procedure

Requests to use ALSWH (+ MBS and/or PBS) data must be made on the standard ALSWH expression of interest (EOI) form to be considered for approval by the ALSWH Publications, Substudies and Analyses (PSA) committee.

General Privacy Obligations

Once approved by the PSA, the linked ALSWH (+ MBS and/or PBS) data you receive will be in a de-identified form. This means that you will not be able to determine the original study identification number or access any personally identifying information about individual participants. Further, where you have requested information in relation to rural or remote regions, the data you receive will only include area or other demographic information which

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is at a level where re-identification is highly unlikely. For example, the data you receive will not include postcode information and dates of birth.

Data will be released by ALSWH for requested variables only. To minimise the impact of this on ALSWH resources and staff time, you are asked to provide a clear list of variables from the requested datasets as an appendix to your EOI. A brief justification for the inclusion of each variable should be provided.

Although you will only receive de-identified information, you must treat this data as though it is 'personal information' for the purpose of the Commonwealth *Privacy Act 1988* (**Privacy Act**) and comply with the Information Privacy Principles (**IPPs**). The IPPs govern the collection, solicitation, security, use and disclosure of personal information.

Data you receive for this project must only be used for those purposes specified in your research application and must not be used for any other purpose. You must not provide the data to any third party unless that third party has been identified in your application for access to data (your EOI). These individuals will be required to sign a Privacy Protocol, a Memorandum of Understanding and this document and to agree to be subject to the requirements of these documents.

Re-identification of individuals

As indicated above, where you have requested information in relation to rural or remote regions, the data you receive will only include age and area information which is at a level where re-identification is highly unlikely. In order to ensure that re-identification of individuals does not occur, you must not make any attempt to identify any individual whose data is contained in the material you have received. Further, any publications you produce must not contain tables or other information that might allow readers to identify any individual whose data have been used in this project.

Privacy and publications

The publication of any papers, conference abstracts or reports must be in accordance with the ALSWH policies detailed on the ALSWH website: [<http://www.alswh.org.au/>].

Access to data

Access to the data will initially be for 12 months unless a longer term is specifically requested and approved.

At the conclusion of the analyses all copies of the data files will be returned to the ALSWH or destroyed with written notification to this effect to the ALSWH PSA.

Medicare Australia must be acknowledged in publications using this wording:

We acknowledge Medicare Australia for providing the PBS and MBS data.

Breaches

You have a responsibility to monitor your project to ensure that all privacy and data security requirements are complied with. You must report any breaches of privacy to the Chief

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Investigator of the ALWSH who will inform the ALSWH PSA and other relevant bodies as appropriate. You will also need to notify the relevant approving ethical review body/s.

Secrecy obligations

In some circumstances, the data you receive may have been initially divulged relying on the secrecy provisions under subsection 135A(3) of the *National Health Act 1953 (NHA)*, subsection 130(3) of the *Health Insurance Act 1973 (HIA)* or subsection 86(3) of the *Aged Care Act 1997 (ACA)*. Under other provisions of those Acts, you are required to treat the data in accordance with the requirements set out in section 135A of the NHA, s130 of the HIA and section 86 of the ACA. These provisions essentially prevent you from divulging this data to any third parties. Failure to comply with those provisions, where applicable, is a criminal offence.

SIGNED:

.....
(Printed name of Researcher)

.....
(Signature of Researcher)

.....
(Date)

in the presence of:

.....
(Printed name of witness)

.....
(Signature of witness)

.....
(Date)