



***Australian Longitudinal Study on Women's Health:
The University of Newcastle and The University of Queensland***

POLICY AND PROCEDURES FOR DATA ACCESS, ANALYSIS AND PUBLICATION

I. Ownership and Access to Data

1. Data collected by researchers associated with the Australian Longitudinal Study on Women's Health (ALSWH) are held in trust by the University of Newcastle and the University of Queensland.
2. Data may be made available to collaborating researchers where there is a formal request to make use of the material. Permission to use the data must be obtained from the Publications Substudies and Analyses Committee (PSA) of ALSWH.
3. Full acknowledgement of the source of data used must be provided in any publications that arise from access to and use of the data as set out in **III.5** (Guidelines to Publication).
4. Where substudy data have been collected by an individual researcher, or are regarded as of primary interest to that researcher, and are made available to a second scholar, the original researcher, if available, should be invited to participate in any publications that follow from use of the data. The original researcher is not bound to accept co-authorship.
5. Numerical data will be continually edited, and those who are responsible for the data (as per [1] above) are obliged to ensure that the data are regularly reviewed and edited. Publications must use the most up-to-date information available, and should include the date and source of all data used in any publication.
6. Requests may be made to ALSWH to use existing ALSWH survey data for analyses and to conduct a substudy of the ALSWH women. See point 7 for accessing data for analyses. See www.alswh.org.au/accessingdata.html for how to request permission to conduct a substudy of ALSWH women.
7. A request for access to data for analysis (Expression of Interest (EoI)) must be made electronically to the PSA Committee of ALSWH (see document F: Expressions of Interest form: www.alswh.org.au/accessingdata.html). The request should include the following information:
 - Project leader's name, institution and email

- Name of liaising ALSWH Steering Committee member. It is a requirement that a member of the core ALSWH team be involved as a Liaison person on every analysis. Collaborators must contact an ALSWH Steering Committee member to discuss their project prior to submission of the EoI. A list of current Steering Committee members is available at www.alswh.org.au/people.html
 - Names of all other people working on the project. All people working with the data must read the Privacy Protocol and sign the Confidentiality Statement Collaborators are only required to sign one Confidentiality Statement which remains current for any future projects. A MoU must be signed for each approved EoI
 - Title of potential project
 - Age cohorts and Surveys involved
 - Rationale, methods, main variables of interest and proposed analytical plan.
 - Expected outputs (papers, PhD, conference papers, further grant applications etc)
 - Time frame
 - Budget and source of funds
 - Names and addresses of all people who will have access to the raw data
 - Name of person who will provide the substantive expertise and input
 - Name of person who will advise and/or carry out the statistical analysis
 - Keywords
 - Applicable themes
 - Survey datasets required
 - Other datasets required
8. Student projects. Please follow the EoI procedure as for non-student projects – further information is available here <http://www.alswh.org.au/accessingdata.html> Students must provide updates on their project when requested every six months.
In addition, please advise ALSWH of:
- Any change of supervisor/s or course
 - Expected submission date
 - When completed please advise the date of award for thesis/degree etc
 - Upon completion ALSWH must be provided with a short summary of the student project. A lay summary is preferred, but a thesis abstract is acceptable
 - Students should check the intellectual property guidelines for their university/institution before commencing work on ALSWH projects
9. Requests for access to data are considered by the PSA. If approved, the data are provided specifically for the analysis described in the request, including any reasonable changes and additions that arise during the course of the work. Approval is current for 6 months and will be renewed following interim review if work is progressing reasonably.
- Substantial changes to the nature of the analysis, the topic addressed, or requested datasets must be notified by submitting a new EoI application form and noting the amendment/s
 - Minor changes, such as changes to the collaborators involved do not require a new EoI application form but can be advised by emailing ALSWH sph-wha@sph.ug.edu.au

10. A MoU must be signed by any person associated with the project including those who present results, or whose name appears on a publication which is associated with the project.
11. Data will be provided once the collaborator has completed a Memorandum of Understanding (Document D) and signed a Confidentiality Statement (see Document E: Privacy Protocol).
12. In signing the MoU the project leader acknowledges responsibility for ensuring adequate facilities and resources to enable the project to progress in a reasonable manner. Project leaders will be asked for 6 monthly updates to monitor progress.
13. Details of EoIs previously conducted using ALSWH data may be made available to researchers seeking access to ALSWH data. Details will only be released once the research from the previous EOI is completed or the EOI is terminated or made inactive.

II. Access to other data

1. Protocols for using Medicare Australia Data are available at <http://www.alswh.org.au/infodata.html>.

III. Guidelines to Analysis

1. Data analysis must be conducted according to recognised standards. Collaborators should familiarize themselves with the datasets, the Notes for Collaborators using ALSWH Data, the Data Dictionary, and the Data Dictionary Supplement, all of which are available from: <http://www.alswh.org.au/infodata.html>. Where a standard derived variable exists, or the researchers have developed a standard method of categorising variables and transitions, these should be used unless there are sound methodological reasons for using a different derivation. When using ALSWH qualitative data, researchers must follow the qualitative data protocols, available from <http://www.alswh.org.au/accessingdata.html>.
2. Individual comments are appropriately used in qualitative research. It is imperative that individual comments should not make it possible for a participant to be recognised. When using individual comments, researchers must:
 - a. Use false names, if names are used
 - b. Change specific details such as numbers and ages of children, and precise details of diagnosed conditions, family circumstances, employment details, or other unique characteristics. These should be altered in a way which does not substantially alter the point being made but which disguises the actual participant and her circumstances
 - c. Indicate clearly in all written and verbal presentations that specific details have been changed to avoid recognition of individuals

IV. Guidelines to Publication and Conference Presentations

1. Researchers should follow their institutions guides as well as NHMRC guidelines pertaining to publications and conference presentations. The current NHMRC Australian Code for the Responsible Conduct of Research can be found at <http://www.nhmrc.gov.au/publications/synopses/r39syn.htm>
2. There will be no honorary or courtesy authorship; ie. no person may be listed as author when he/she has not participated in a substantial way in conceiving and/or executing and/or interpreting at least part of the work described in the publication.

3. Minimum requirement for authorship is participation in conceiving and/or executing and/or interpreting at least part of the publication in a co-author's field of expertise, sufficient for him or her to take public responsibility for it.
4. All publications must include the following acknowledgement:

The research on which this paper (book, monograph, abstract, or report) is based was conducted as part of the Australian Longitudinal Study on Women's Health, the University of Newcastle and the University of Queensland. We are grateful to the Australian Government Department of Health and Ageing for funding and to the women who provided the survey data.
5. Where Medicare or Pharmaceutical Benefits Scheme (PBS) data are used, 'Medicare Australia' must be acknowledged with the statement 'We acknowledge Medicare Australia for providing the PBS and MBS data'.
6. Additional funding agencies should also be acknowledged if this is applicable.
7. The acknowledgement may refer to any other persons who have provided comments, advice, support or other input into the paper, who are not already listed as authors. Permission should be sought from these persons before including their names.
8. Due recognition of all participants is part of the proper research process. Authors should ensure that research assistants, technical officers, and other 'non-authors' who contribute, including community members involved in supporting the project, are properly acknowledged.
9. Publication of multiple papers based on the same set(s) or subset (s) of data is improper unless full cross-referencing occurs within the papers, for example, by reference to a preliminary publication at the time of publication of the complete work which grew from it.
10. Project leaders must take overall responsibility for publications. Publications and journal submissions must be reviewed by the ALSWH liaison person before submission to a journal or editor. The ALSWH liaison person reserves the right to refer publications to the PSA Committee.
11. Authors must provide copies of manuscripts or reports and all correspondence to ALSWH when the paper/report is submitted, reviewed, re-submitted and finally accepted. A hard or electronic copy of the published Paper should be provided to ALSWH.
12. Authors must provide all details of conference presentations to ALSWH. This correspondence should occur as soon as the abstract has been accepted.