



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 project are held in trust by The University of Newcastle and the University of Queensland. The same general principle applies to research which is conducted with an affiliated institution.

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 of ALSWH. Where data are collected in collaboration with, by or for a community, community permission to use data will also be necessary. Rules relating to data relating to Aboriginal and Torres Strait Islander communities, as set out by the NHMRC, apply.

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. This acknowledgement should appear in addition to the standard acknowledgement set out in III.5 (Guidelines to Publication).

4. Where 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. A request for access to data (Expression of Interest (EoI)) must be made electronically to the Publications Substudies and Analyses Committee of ALSWH. The request should include the following information:

- ID numbers of previous related work (if this runs on from an existing EoI or previous set of analyses)
- Lead person's name and institution

- Name of liaising ALSWH Steering Committee member. It is a requirement that a member of the core ALSWH team be involved as a collaborator on every analysis.
- 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.
- Detailed scientific title of potential project
- Age cohorts and Surveys involved
- Rationale, methods, and main variables of interest.
- Expected outputs (papers, PhD, conference papers, further grant applications etc)
- Time frame
- Budget and source of funds
- Name of person who will provide the substantive expertise and input
- Name of person who will advise and/or carry out the statistical analysis

7. 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. Substantial changes to the nature of the analysis or the topic addressed require an additional request. Approval is current for 6 months and will be renewed following interim review if work is progressing reasonably.

8. Data will be provided once the collaborator has completed a Memorandum of Understanding (Document D), signed a Confidentiality Statement (see Document E: Privacy Protocol) and paid for the data (cost: \$100 – please note: student exemptions apply).

II. Guidelines to Analysis

1. Data analysis must be conducted according to recognised standards. Collaborators should familiarize themselves with the datasets, the Data Dictionary, and the Data Dictionary Supplement. Where a standard derived variable exists, or the researchers have developed a standard method of categorizing 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 the Collaborators web page www.alswh.org.au/PPA/index.html or from your WHA liason.

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:

- Use false names, if names are used
- 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.
- Indicate clearly in all written and verbal presentations that specific details have been changed to avoid recognition of individuals.

III. Guidelines to Publication

1. Where there is more than one author of a publication, one author - by agreement among the authors - should formally accept overall responsibility for the publication. Such formal acceptance must be in writing and kept on file in the department or unit of the author, together with the names and signatures of all other authors.
 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. Each co-author must acknowledge her/his co-authorship in these terms, in writing, and this must be kept in the department or unit of the responsible or executive author (see Declaration for Research Papers Form). This must be met by all authors signing an agreement that they are "authors" of a specified publication in the terms defined by the research unit or department. Such a statement must include an indication that there are no other authors of the publication, according to this definition. If one or more co-authors are unavailable or otherwise unable to sign the statement of authorship, the head of department or unit may sign on their behalf, noting the reason for their unavailability.
 5. 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.
- Additional funding agencies should also be acknowledged if this is applicable.
6. 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.
 7. 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.
 8. 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.
 9. Researchers must submit papers to the Publications Substudies and Analyses Committee for comment before submission. PSA members will check the paper to ensure that analysis appears correct and appropriate, that related work is adequately acknowledged, and that the paper does not overlap excessively with other papers published or in progress.

Document B

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10. Authors must provide copies of manuscripts and all correspondence to ALSWH when the paper is submitted, reviewed, re-submitted and finally accepted. A hard or electronic copy of the published Paper should be provided to ALSWH.