

Data Access Committee Protocol

ALSWH Publishing guidelines

Preamble

This document is a guide to making statements about ethical matters, which may be required when publishing ALSWH research. The statement will depend on the requirements of the journal or publisher; which data sources were used; and in some instances, which ALSWH cohorts were involved. You may also be required to justify why your research dataset cannot be published. (If using data from the **Mothers and their Children's Health Substudy** please also refer to the MatCH publishing protocol: <https://alsw.org.au/wp-content/uploads/2021/09/MatCH-Publishing-guidelines-20210909-1.pdf>).

If you have any questions, **please contact** your ALSWH Project Liaison (listed on the project EOI) or ALSWH Data Linkage staff:

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Ethical statement guidelines

1. Survey data only

The ALSWH survey program has ongoing ethical approval from the Human Research Ethics Committees (HRECs) of the Universities of Newcastle and Queensland (approval numbers H-076-0795 and 2004000224, respectively, for the 1973-78, 1946-51 and 1921-26 cohorts; and H-2012-0256 and 2012000950, for the 1989-95 cohort).

If a consent statement is required, please use the following:

All participants consented to joining the study and are free to withdraw or suspend their participation at any time with no need to provide a reason.

Further information on recruitment (if required):

- ALSWH web site: <https://alsw.org.au/for-data-users/survey-data-overview/recruitment-methods/>
- Recruitment of the 1989-95 cohort: <https://doi.org/10.2196/jmir.3788>
- Recruitment of the three original cohorts: http://dx.doi.org/10.1300/J013V28n01_03

2. For linked data, add the following:

[insert as appropriate]

The ALSWH also maintains institutional HREC approvals for external record linkage (approval numbers H-2011-0371 and 2012000132, respectively). In addition, access to [national data collections is approved by the Australian Institute of Health and Welfare] [and the Departments of Defence and Veterans' Affairs HREC]. [Access to state and territory data collections is approved by an appropriate HREC for each jurisdiction].

Please note:

- National collections include MBS/PBS, Aged Care, National Death Index, Australian Cancer Database.
- DVA collections include Veterans' Home Care Data, Repatriation-MBS and -PBS.
- State and territory collections Include Hospital Admissions, Perinatal, and Emergency Department collections, as well as Cancer Registries.
- If required, specific references for ALSWH HREC Protocols are listed on the web site: <https://alswh.org.au/for-data-users/conditions-of-use-and-publishing/publishing-alswh-survey-data/alswh-hrec-approvals/>.

If a consent statement is required:

This statement covers all cohorts:

ALSWH participants who decline health record linkage are excluded from linked data requests. Over 80 percent of all ALSWH participants have explicitly consented to record linkage. Since 2005, the responsible HRECs have approved opt-out consent; in addition, a waiver applies to unconsented participants who were deceased or lost to follow up before 2005.

If using 1989-95 cohort data only:

All participants in the ALSWH 1989-95 cohort expressly consented to health record linkage on recruitment in 2012/13. Those who subsequently opt out of record linkage are excluded from linked data requests.

For further information about consent to health record linkage, refer to:

- The latest ALSWH Technical Report, Section 5.4. <https://alswh.org.au/for-data-users/data-documentation/technical-reports/>
- ALSWH Privacy Policy <http://www.alswh.org.au/privacy-policy>

Information on data access

Some journals request that the datasets for the paper be published. This is not possible for ALSWH datasets; if justification is required, **please see 'Information requested by journals'** on the ALSWH dissemination page: <https://www.alswh.org.au/for-data-users/conditions-of-use-and-publishing/publishing-alswh-survey-data/>

Mandatory acknowledgement

All outputs using ALSWH data must include acknowledgement of funding by the Australian Government Department of Health. The standard text, which should be the first statement in the 'Acknowledgements' section of your paper, is provided on our web site:

<https://www.alswh.org.au/for-data-users/conditions-of-use-and-publishing/publishing-alswh-survey-data/>

The sources of any linked data used in your paper must also be acknowledged. Refer to the web site for current guidelines: <https://alswh.org.au/for-data-users/conditions-of-use-and-publishing/publishing-linked-data-research/>