

Data Access Committee Protocol

Ethical considerations section for publications

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.

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

[Colleen Loos](mailto:c.loos@uq.edu.au), c.loos@uq.edu.au, 07 3365 5257; or
[Christine Coleman](mailto:c.coleman@uq.edu.au), c.coleman@uq.edu.au, 07 3346 4723

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):

- 1989-95 cohort <https://doi.org/10.2196/jmir.3788> and <http://www.alsw.org.au/for-researchers/dissemination#consent-1989-95>
- Other 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 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.
- State and territory collections Include Admitted Patients, Perinatal, and Emergency Department collections, as well as Cancer Registries.

- If required, specific references for all HREC Protocols are listed in the document “ALSWH Data Linkage Project: HREC approval Summary” (located on Sharepoint under Data Linkage documents).

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:

- *ALSWH Technical Report, Section 5.4.*
http://www.alsw.org.au/images/content/pdf/technical_reports/Report_41_alsw.pdf
- *ALSWH Privacy Policy* <http://www.alsw.org.au/privacy-policy>

Please also see ‘Information on requests from journals for information about data access’
(ALSWH dissemination page): <http://www.alsw.org.au/for-researchers/dissemination#data-access>