

29 July 2016

Data Availability and Use

Productivity Commission

GPO Box 1428

Canberra City ACT 2601

Dear Commissioners,

Thank you for the opportunity to make a submission to the Public Inquiry into Data Availability and Use. The Australian Longitudinal Study on Women's Health (ALSWH) is a longitudinal survey examining the health of around 60,000 Australian women in four age cohorts: women born 1921-26, 1946-51, 1973-78, and 1989-95. Since it began in 1996, ALSWH data has informed federal and state government policies across a wide range of issues. Information on ALSWH surveys, data, and research outcomes, as well as details of how to access the data can be found on the Study website <http://www.alswh.org.au/>

ALSWH strongly supports the use of linked data in health services research to provide evidence for evaluation of the use and impact of health services. Study data is currently linked with data from national administrative datasets (e.g., Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, National Death Index, and Aged Care) as well as state/territory datasets (e.g., hospital admissions, perinatal data, and cancer registries). Details of outcomes of ALSWH research using linked data are attached.

After negotiation with relevant Data Custodians and Ethics Committees, ALSWH has been able to streamline procedures required to provide data users with access to linked datasets. However, administrative management of linked datasets still requires substantial record keeping and documentation, and streamlining of application and approval process across sectors and jurisdictions would greatly increase efficiency. Increased investment in infrastructure to provide secure data

access and analysis environments, such as the Sax Institute's Secure Unified Research Environment (SURE), would also help facilitate greater use of linked data, provide consistent environments for collaborators from different institutions, ensure best practice in the management of linked data, and reduce the administrative burden of monitoring and compliance.

The capacity to capture, act as custodians of, and provide access to, linked data is an important component of ALSWH's purpose to act as a national resource for policy relevant research. We look forward to the outcomes of the Inquiry, and are happy to provide additional information if required.

Yours sincerely,

Professor Gita Mishra and Professor Julie Byles

Directors, Australian Longitudinal Study on Women's Health

ALSWH LINKED DATA PUBLICATIONS (to June 2016)

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- [Use and costs of medications and other health care resources: Findings from the Australian Longitudinal Study on Women's Health](#). Byles J, Loxton D, Berecki J, Dolja-Gore X, Gibson R, Hockey R, Robinson I, Parkinson L, Adamson L, Lucke J, Powers J, Young A & Dobson A. Report prepared for Australian Government Department of Health & Ageing, June 2008.

Other reports

- **Tooth L, Hockey R, Dobson A, Treloar S & McClintock C.** [Needs of spouse carers of World War II veterans before and after widowhood](#). Report prepared for Department of Veterans Affairs, May 2011.
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