SUBMISSION TO PHRN REVIEW

On behalf of the Australian Longitudinal Study on Women’s Health

The Australian Longitudinal Study on Women’s Health (ALSWH), funded by the Australian Government Department of Health, has been collecting information on the health and well-being of nationally representative samples of women since 1996. The data are used for research into women’s health and to inform federal and state government policies across a wide range of issues. Further information about ALSWH can be found at www.alswh.org.au.

Since 1997, ALSWH has linked survey data to various national data sets such as those held by Medicare and the National Death Index (NDI).

The ALSWH survey data are currently linked, or are in the process of being linked, to Australian state cancer registries, perinatal datasets and hospital admission datasets:

- **New South Wales**: Cancer Registry, Perinatal Data Collection, Admitted Patient Data Collection
- **Queensland**: Cancer Registry, Perinatal Data Collection, Hospital Admitted Patient Data Collection
- **Western Australia**: Cancer Registry, Midwives Notification System, Hospital Morbidity Collection
- **Victoria**: Cancer Registry
- **South Australia**: Cancer Registry, Hospital Morbidity Collection
- **Northern Territory**: Cancer Registry, Perinatal Data Collection, Hospital Morbidity Collection (by special arrangement with the NT Top End Health Department)
- **Australian Capital Territory**: Cancer Registry, Perinatal Data Collection, Hospital Morbidity Collection

It is within this context that the ALSWH submits the following comments on the PHRN for consideration by the Review Panel.
Assess the extent to which the PHRN and its Participants have achieved the Network’s aims and objectives.

Consideration of how the PHRN has facilitated access to linked datasets for the ALSWH may highlight the actual achievements of the network. Prior to the existence of the PHRN, ALSWH had access to national data (Medicare data - MBS, PBS, DVA, RPBS; National Death Index, National Cancer Clearing House) and state data for Western Australia and NSW. Since the introduction of the PHRN, which has provided funding for state data linkage units, access to hospital data from Queensland and South Australia has been possible, but access to these data from the Northern Territory, Tasmania and Victoria remains problematic.

The accreditation of the AIHW as an Integrating Authority provides a national data linkage capacity, but achieving practical outcomes in terms of accessing linked data remains frustratingly slow. For example, in 2004, the ALSWH received ethics approval from the then Department of Health and Ageing (DoHA) Departmental Ethics Committee to link ALSWH survey data with MBS, PBS and Aged Care datasets for all women in the study on the basis of consent waiver. Despite this approval and subsequent re-endorsement in 2008 and 2012 by DoHA and AIHW ethics committees, the data remain unavailable to researchers. While some progress has been made recently, and aged care data are expected in early 2014, the full MBS and PBS datasets have still not been linked to ALSWH data. In part, the delay is compounded by restrictions on the linking of MBS and PBS data by a government agency, in this case the AIHW. These barriers limit the capacity to provide the ALSWH with departmentally-approved linked data.

Our example illustrates that the aim of functional infrastructure for national data linkage remains unachieved.

Review the extent to which the new infrastructure has met or will meet the needs of researchers and policy makers for access to linked population level data within and between jurisdictions and sectors.

Clear differentiation is required between the needs of researchers and those of policy makers and it is our belief that the PHRN’s primary focus in the development of a national infrastructure should be on providing resources which enhance the ability of researchers to utilize administrative data. In 2010, the Productivity Commission recommended that access to administrative data by academics and other researchers should be regarded as a Government priority. In its most recent report, the Commission outlined the current state of access to data linkage in Australia and warned that while the “institutional arrangements
(including the PHRN) now in place could facilitate data linkage and access for research, it is important that they do not become too onerous and ‘chill’, rather than encourage, collaboration”. The Commission has consistently stressed that the use of administrative resources to examine government policies is best performed by researchers, rather than policymakers. While a number of federal departments are custodians for large amounts of longitudinal administrative data, the expertise in analysing these data exists within Australia’s research community. This large source of untapped potential was identified by Gruen and Goldbloom who stated “Having clearly defined administrative data is all very well, but it’s next to useless if these data are not shared with those best able to build the evidence base. Our universities and research institutes are teeming with people wanting to draw lessons from agencies’ statistics”.

For the PHRN to make an enduring impact on data linkage for research in Australia, there needs to be an inclusive collaboration among all data linkage stakeholders, including data custodians, Human Research Ethics Committees (HRECs), data linkage units and integrating authorities, and researchers.

Special attention should be focussed on the data custodians who are charged with ensuring that any released data will be appropriately and securely utilised. Allen et al mentioned the difficulties experienced by custodians, including fear of becoming a scapegoat, loss of position, and loss of career prospects should ‘things go wrong’ when data are released. Releasing administrative data to researchers raises the possibility that findings will be unfavourable to bureaucracies and governments. For these reasons data custodians have little to gain by facilitating the use of data for research purposes. Conversely, members of HRECs understand many of the issues relating to administrative data linkage and can see the big picture advantage of using these data in population health research. While HRECs and custodians apply different criteria, researchers have to satisfy the requirements of both in order to access data.

The requirement to gain approval from multiple HRECs and data custodians is a significant barrier. Although the Data Linkage Units (DLUs) in NSW, WA, Queensland and SA provide assistance, in many instances, direct contact between the research team and data custodians is necessary.

In order to access national and state-based datasets for ALSWH a considerable investment of resources is required. Initial applications (many of which have required completion of a NEAF) have been submitted to 11 HRECs and, as each approved application has a finite lifespan, updated applications are also required on a regular basis for each Committee. Negotiations to access Medicare and Aged Care datasets have required approvals from the relevant section heads in the Australian Government Department of Health, Department of Human Services and the AIHW. Face to face meetings have facilitated access for ALSWH,
but this option is not necessarily available for other researchers. Approval to access the State datasets has been negotiated with 6 DLUs (or State Health Department equivalent) and 16 data custodians.

**Consider the significance of the PHRN infrastructure in the national and international context.**

The Australian health system, in which funding is split across both federal and state agencies, is unusual and provides context for the establishment of the PHRN as an overall coordinating body for data linkage in this country. Differences in state legislation and reliance on both state-based and national HRECs and data custodians for approval ensures that the process of accessing data is slow and cumbersome. The failure of some data linkage units to be functional (eg, Tasmania, Victoria and NT) after considerable time and funding highlights shortcomings in the current system.

The Scandinavian countries (Sweden, Finland and Denmark) as well as the Netherlands, New Zealand and Canada provide examples of the collection, management and dissemination of administrative data that are based on centralized models and open access for research purposes. Managing and maintaining databases so that researchers are provided with accurate, up to date information requires considerable funding and expertise. Addressing this issue as a national priority suggests that a more useful allocation of resources would be achieved if data linkages were managed within a national arena.

**Consider the role of the PHRN in the future development of a distributed national data linkage infrastructure in Australia. In particular, the role of the PHRN in the development of Australia’s data linkage infrastructure in the next 5 years.**

We believe that consideration should be given to enhancing research capacity to access and link all administrative data (not just health data) that are routinely collected in Australia by the national and state governments. This will require an institution (or institutions) that have the necessary legislated structure. It is difficult to see how this could be achieved by a university-based group. PHRN has served a valuable purpose in supporting the growth of health data linkage in the past few years. However we do not believe that it has the resources, structure or capability to achieve its national mission.
References


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