

*Public Health Information Development Unit,
Torrens University Australia – December 2015*

SUBMISSION TO THE SENATE'S SELECT COMMITTEE INTO HEALTH:

HEARING ON IMPROVING ACCESS TO AND LINKAGE BETWEEN HEALTH DATA SETS HELD BY COMMONWEALTH ENTITIES

Submission from:

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In order to assist the Committee's deliberations, the Public Health Information Development Unit (PHIDU) at Torrens University Australia offers the following submission concerning the Unit's use of and increasing difficulty in accessing health data sets held by Commonwealth entities.

The Director of PHIDU, Professor John Glover, would be interested in appearing as a witness at the hearing, to provide further detail and examples to members of the Committee.

1.0 The work of the Public Health Information Development Unit (PHIDU)

The Public Health Information Development Unit (PHIDU) was established by the (then) Australian Government Department of Health and Ageing in 1999, to assist in the development of public health data, data systems and indicators for Australia. PHIDU has recently relocated to Torrens University Australia in Adelaide, from The University of Adelaide, with funding from the Department of Health (DoH) through to June 2018.

In line with its brief from the DoH, PHIDU has led the development of a national integrated health information system that provides information on a broad range of health determinants across the life course. A major emphasis is on the development and online publication of small area statistics for monitoring differences in health and wellbeing across Australia.

PHIDU's work program for the DoH and other agencies has included:

- the publication of the *Social Health Atlas* series for Australia (now online), three Australia-wide Indigenous Social Health Atlases, and numerous Social Health Atlases with particular foci, such as avoidable mortality (with the New Zealand Ministry of Health), avoidable hospitalisations, social inclusion, mental health;
- atlases specifically prepared for Commonwealth-funded health organisations such as GP Divisions, Medicare Locals, and most recently, Primary Health Networks (PHNs) and Local Hospital Networks (LHNs);
- the development of the Business Case for a program of national health measurement surveys to provide objective health data to complement the self-reported information collected by the ABS National Health Surveys;
- an audit of international and Australian surveillance systems for monitoring chronic diseases and their risk factors (with other partners);
- arranging national symposia on health data linkage and its relevance to health policy and research; and
- the publication of a number of articles, using small area data, highlighting the extent of health inequalities in Australia, and the need for better links between policy and research in this area.

The *Social Health Atlas of Australia* series is a prime example of the benefits of sharing Government-commissioned, publicly funded data for health and related policy development. The atlas was first published by the Director, John Glover and colleagues in 1992; and is now an online atlas, updated annually. Data holdings cover population demography, social and economic indicators (including early childhood development, education, disability, income

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support, housing, and employment), health status and risk factors, life expectancy and deaths, and health service use, which are available in a range of small area geographies.

Recent advances in geographical information systems and presentation software have allowed PHIDU to develop a facility for users to map their own data, and interactive graphics packages, which highlight inequalities (both absolute and relative) in health and in the wider determinants of health. All data and the analyses of inequality are freely available via the PHIDU website at www.adelaide.edu.au/phidu¹, making this a unique national resource. For example, it provides data that show health service use for specific sub-groups of the population within small areas of Australia, such as adults who participate in the National Bowel Cancer Screening Program.

These products are consistently accessed by a wide range of people across Australia, and internationally (including policy-makers, planners, practitioners, managers, students, researchers, civil society groups, and community members), from sectors as diverse as health, welfare, education and child care, planning, disability, housing, Aboriginal community-controlled organisations, and economics, and across all levels of government. The PHIDU website currently attracts around 11,000 users per month, who access maps, tables and graphs and publications relating to the health and wellbeing of Australians. Notably, in responding to receipt of a copy of a major report on public health over the 20th century, the Parliamentary Library acknowledged the value of the social health atlases for their work.

Via this work, PHIDU has contributed to extending the Australian evidence base around:

- the factors that determine health, development and wellbeing;
- the notions of ‘inequality’, ‘inequalities in health’ and ‘inequalities in the determinants of health’;
- the relationship between socioeconomic status/position and health across the life course for populations; and
- examples of the impact of social and economic inequalities on the population’s health.

The overall aim of this work has been to direct attention to areas where we might better address our ameliorative efforts through policy and program development, service re-design, and the monitoring of population health outcomes.

¹ The website will be moved to Torrens University Australia in the near future.

2.0 Evidence of increasing difficulty accessing administrative, non-identifiable health data held by Commonwealth entities

In order to continue to improve the health of all Australians, decision-makers, researchers, practitioners and communities need to be able to access public, health-relevant information through data-sharing mechanisms such as the Atlas, in order to contribute to the evidence base, which should guide policy and program development, and to monitor progress.

2.1 Lack of access to MBS and PBS data

It is disappointing that there is currently no access to the tax-payer funded MBS and PBS datasets for area-aggregated (not individual-level) data, which could underpin better health policy and program design and implementation.

For example, PHIDU published data for Medical Benefit Schedule (MBS) services at the small area level² across Australia periodically from 1992. The last data provided by the Department of Health (DoH) were for the year 2009/10, after which they declined to provide the same data, and advised that data previously provided ‘may not have met the requirements that they now have’. In addition to concerns about releasing data which might breach the confidentiality of individuals (e.g., releasing data for areas with small populations, or releasing numbers of services that were small), a concern was that the business of a general medical practitioner (GP) or group of GPs could be identified.

Since September 2012, a number of data requests have been made to the Department of Human Services, as the agent for DoH. These requests have been rejected by the External Request Evaluation Committee (EREC), on advice from Department of Health representatives on that committee. This was similarly the case for the latest request, despite it being for even larger area aggregates, whereby some areas were aggregated to a size, which PHIDU believes would not be able to reveal the business of any GP or practice, due to the extensive movement that occurs of people from their local address to the location where they visit a GP.

A request for PBS prescription data was also rejected by the EREC and, following the Director’s request for the decision to be reconsidered, was subsequently rejected on advice from the Drug Utilisation Sub-Committee of the Pharmaceutical Benefits Advisory Committee. Despite what appears to be a detailed examination of the request, the Director presumes it was not read carefully as it was for data at the ‘Population Health Area (PHA) level’, to be consistent with the remainder of the data in the Social Health Atlas, and not, as in the advice he received, a rejection of a request for data at the ‘SA2 level’. The details of the advice are shown below.

“Your request for PBS data was assessed by the External Request Evaluation Committee (EREC) on 16 April 2015.

All requests are reviewed by EREC to determine whether the provision of the information you require is consistent with relevant legislation, government policy and the Department of Human Services purpose. The committee review each request against the following criteria:

- 1. Purpose Test - Does not improve Australia's health;*
- 2. Anonymity Test - Is the data identifying Individual or Entity;*
- 3. Privacy Test - Privacy Act release of data meets the purpose for which it was collected;*
- 4. Resource Test - Does request impose unrealistic deadline and staff resources; and*

² PHIDU publishes data at the small area level, by Population Health Areas (PHAs) and Local Government Areas (LGAs). The range of data includes service use (hospital inpatients), health screening activities and outcomes, and other health outcomes, including premature and avoidable mortality, along with data describing variations at the same geographic level in the factors that influence health.

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5. Reputation and Ethics Test - Quality practices for use of information.

The Committee has carefully considered your request, evaluated it against the above criteria and advised that your request has been declined on the following basis:

Failed Test 3. Privacy Test - Privacy Act Release of data meets the purpose for which it was collected.”

Additional comments were supplied by the Committee:

“The Committee discussed this request at length and agreed that there are privacy implications as the requestor is after SA2 level, and DHS and Health have an obligation to protect the privacy of its customers. The request could be considered at a state level only, due to the potential harm and privacy issues relating to the low number of persons within the suggested age population accessing the requested medication.

This request was declined as it fails to meet Test 3, Privacy. The customer can choose to submit a new application at a later date.”

Of note is that in June 2015, in response to a Written Question on Notice, data on the number of subsidised prescriptions by patient postcode for the year 2013/14 (excluding under co-payment scripts) were released publicly. In addition to providing the data by postcode, which are geographic areas much smaller than PHAs, there were numbers of scripts as low as one. There were 2,931 postcodes provided in the response, whereas there are only 1,163 PHAs – and these were further aggregated to 884 areas for the PBS request; we did not ask for data at the SA2 level as stated in the response. This clearly makes a nonsense of the Department’s reason for refusing PHIDU’s request. Why was Senator McLucas’ purpose more in line with the ‘Privacy Test - Privacy Act Release of data meets the purpose for which it was collected’, when the PHIDU request specifically addressed the value of these data³, yet the Senator’s request did not (and was not required to).

From the website of the Office of the Australian Information Commissioner:

“In certain circumstances, the Commonwealth *Privacy Act 1988* permits the handling of health information, including personal information, for health and medical research purposes, especially where it is impracticable for researchers to obtain individuals’ consent. This recognises:

- the need to protect health information from unexpected uses beyond individual healthcare; and
- the important role of health and medical research in advancing public health.

To promote these ends, the Privacy Commissioner has approved two sets of legally binding guidelines, issued by the National Health and Medical Research Council (NHMRC). Researchers must follow these guidelines when handling health information for research purposes without individuals’ consent. The guidelines also assist Human Research Ethics Committees (HRECs) in deciding whether to approve research applications. The guidelines are produced under sections 95 and 95A of the *Privacy Act*. The guidelines are:

- Guidelines under Section 95 of the *Privacy Act 1988*, which set out procedures that HRECs and researchers must follow when personal information is disclosed from a Commonwealth agency for medical research purposes.
- Guidelines under Section 95A of the *Privacy Act 1988*, which provide a framework for HRECs to assess proposals to handle health information held by organisations for health research (without individuals’ consent). They ensure that the public interest in

³ Our request for the release of these data stated: The dataset includes many social indicators, to set the context in which users view details of disease prevalence, disability, health service use (data for hospital inpatient separations and Emergency Department presentations), preventive health actions (screening for bowel, breast and cervical cancer) and premature mortality.

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the research activities substantially outweighs the public interest in the protection of privacy.”

“To be relevant to public health or public safety, the outcome of the research or the compilation or analysis of statistics should have an impact on, or provide information about, public health or public safety. ‘Public health or public safety’ is not defined in the *Privacy Act*. Examples that could fall into this category are research and statistics on communicable diseases, cancer, heart disease, mental health, injury control, diabetes and the prevention of childhood diseases.” (See <https://www.oaic.gov.au/privacy-law/privacy-act/health-and-medical-research#medical-research>)

The work of PHIDU over more than 16 years fulfils this category of public health research, and does not use identifiable data. PHIDU has contributed to the public benefit of such research given the extensive citations of its publications in the medical and public health peer-reviewed literature. It therefore remains unclear why the EREC has determined that PHIDU’s use of the data does not comply with the provisions of the *Privacy Act 1988*.

I understand that the DoH could be prepared to allow for release of the MBS data at a larger statistical area level (SA3 areas, which are aggregations of SA2s). Although these larger areas show sufficient geographic variation for the capital cities of Sydney, Melbourne and Brisbane, this is not so in relation to Perth, Adelaide, Hobart, Darwin or Canberra. In these smaller capital cities, there is a great deal of averaging at the SA3 level and important variations between areas are lost.

2.2 Inconsistent Departmental approaches to data release within the DoH

It is evident to PHIDU that there are inconsistent and opposing views to the release of de-identified aggregated health data across the Department. For example, the Director’s recollection of a conversation in May 2014 with Dr Paul Madden, who was Chief Information Officer in the DoH at that time, was that Dr Madden could not see that the MBS data requested at the PHA level could be seen as breaching privacy. He also commented that the inconsistency in response from various areas of the DoH, or from different agencies for the same data, was what he was hoping to re-dress with a policy paper he expected to take to the Department’s Executive ‘in the next short while’. As the Director understands, no such Department-wide information strategy has been introduced to date.

Furthermore, the Departmental Secretary, Martin Bowles, is reportedly encouraging information-sharing and has firmly stated that he did not want “a department that crucifies people when they make mistakes” but one that listened to views from staff and stakeholders, whether positive or negative, and made use of new technologies, particularly in the area of big data analytics.

“We should not be constrained in our thinking — and I think we have been largely constrained on a lot of fronts,” said the Secretary, who briefly referred to the very difficult challenge of supporting the government through its Medicare co-payment crisis. But, he said, the rapid policy change also allowed Health to “push the boundaries and get some real change-thinking around Medicare and primary healthcare.” (See “Be stewards of the system you’re dealing with; don’t try to be the owner,” – at <http://www.themandarin.com.au/42988-innovation-month-summit-2015-martin-bowles/?pgnc=1>).

On the other hand, researchers and others are blocked from access to datasets of use to many agencies and the community. In this respect, we have in the past received many requests from Medicare Locals (MLs) to provide data for MBS services by geographic areas within

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their ML: such demands will continue with PHNs now a major focus for local area planning and service delivery.

3.0 Conclusion

We appreciate the opportunity to raise these matters, and the possibility of Professor Glover attending the Committee's meeting in Sydney.