



Australian Government
**Australian Institute of
Health and Welfare**

*Authoritative information and statistics
to promote better health and wellbeing*

Mr Stephen Palethorpe
Committee Secretary
Standing Select Committee on Health
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr Palethorpe,

**Inquiry into improving access to and linkage between health data sets held by
Commonwealth entities**

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to make a submission to the Senate Select Committee.

The AIHW is a major national agency established under the AIHW Act (1987) as an independent body to provide reliable, regular and relevant information and statistics on Australia's health and welfare.

To support this role, we have built strong collaborative relationships with our stakeholders including Australian government agencies, the governments of the states and territories and their agencies, and a range of non-government organisations.

Our core capabilities and services relevant to this enquiry are:

- extensive practical experience in designing and undertaking complex data linkage projects as one of only three accredited Integrating Authorities in Australia.
- development of national statistical standards and classifications, and registering these in our award-winning metadata repository, METeOR.
- building and managing information clearinghouses, disease registers and similar databases
- production of innovative and insightful health and welfare reports and other web and print outputs
- advanced data modelling and analyses
- first class data management and data governance frameworks and processes

The AIHW actively supports the Commonwealth's public sector data management agenda by:

- ensuring that descriptions of projects involving access to personal data are publicly accessible on our website,
- supporting open data publishing initiatives by loading data where appropriate onto data.gov.au,
- actively engaging, sponsoring and leading initiatives such as GovHack,

- ensuring that, where appropriate, the Institute's application software contributes to the national information infrastructure and whole-of-government capabilities, and
- placing a high priority on supporting the Department of Prime Minister and Cabinet's public sector data management initiatives.

Current health data linkage infrastructure and activity

In recent years, Australian governments have made substantial investments in building data linkage infrastructure (including establishing the Population Health Research Network– a major facilitator and proponent of data linkage) resulting in the establishment of robust data linkage models that ensure the safety, privacy and security of data used in integration projects. This infrastructure includes:

- state and territory linkage nodes – the Centre for Health Record Linkage (CHeReL, NSW/ ACT), the Queensland Centre for Health Data Services (Health LinQ, Qld), SA/NT DataLink, the Tasmanian Data Linkage Unit (TDLU, Tas), Victorian Data Linkages (VDL, Vic), and the Western Australian Data Linkage Branch (WADLB, WA).
- the three current accredited Integrating Authorities (IAs) established under the Commonwealth Governance and Institutional Arrangements for Statistical Data Integration involving Commonwealth Data, are the AIHW, the Australian Institute of Family Studies and the Australian Bureau of Statistics.

Demand for data linkage services is increasing. The AIHW undertook 38 data linkage projects mostly on behalf of the medical research community during 2014-2015 and we expect to undertake over 60 projects during 2015-2016. Some of these projects are described in Attachment A.

Issues in accessing and using health data

Among national statistical agencies, quality is generally accepted as "fitness for purpose". Fitness for purpose implies an assessment of an output, with specific reference to its intended objectives or aims. Quality is therefore a multidimensional concept which does not only include the accuracy of statistics, but also stretches to include other aspects such as relevance, timeliness, accessibility and interpretability (eg the availability of metadata describing the concepts and definitions underpinning the data). The ABS Data Quality Framework is available on the ABS website - [ABS DQ Framework \(the AIHW data quality framework is based on the ABS framework\)](#).

As the custodian of a significant proportion of the nation's most valuable health and welfare data sets, the AIHW can readily access these data and make them available to others subject to privacy and confidentiality considerations and Ethics Committee approval. Some of these data sets are compiled from data provided only to the AIHW by jurisdictions, some are collected directly by the AIHW; others are national minimum data sets developed and collected collaboratively between the Commonwealth and states and territories, usually in accordance with data standards developed by the AIHW. Among other things, the standards developed by the AIHW aim to ensure that resulting data is fit for purpose.

Where data is collected and maintained by other organisations, particularly where it is collected for administrative purposes, there are often limitations which reduce its usefulness for research and/or statistical purposes. That said, administrative by-product data collected and maintained by other Commonwealth entities such as the Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) administrative data sets are highly valued. The

custodian of these data sets (the Department of Health) and the AIHW have just agreed to put in place new arrangements that will enable the AIHW to store Medicare enrolments data (identifier data) and the last 5 years MBS and PBS content data (unidentified) at the AIHW in accordance with relevant legislative and security requirements. This will result in much more efficient and faster data linkage services to the research community.

Other data sets that are of particular value to researchers are held by state and territory agencies. The absence of consistent multi-jurisdictional arrangements and protocols means that getting approvals for the release of data from these agencies and managing physical data access and transfer can be a complex and time consuming exercise. A recent data linkage project requiring data from all states and territories has taken almost two years.

‘Emerging’ data sets such as eHealth records and data collected by and in support of, Primary Health Networks will become more valuable over time and it is important that appropriate arrangements are put in place to access these data for research and statistical purposes, and to as far as possible, ensure they are fit for purpose.

From a data linkage perspective, the key issues in accessing and using health data are:

1. Variable data and metadata quality across the range of health data – particularly data produced as a by-product of administrative processes.
2. Delays in getting approvals to access data and to establish access arrangements (it is notable that access requests from the AIHW are rarely refused).
3. As noted above, cross-jurisdictional arrangements for data linkage can be cumbersome.

Technological and methodological initiatives

The AIHW is collaborating with researchers and other experts to improve data linkage accuracy and performance. However, in our assessment, technological, IT capacity, or methodological constraints will not be the main factor limiting the delivery of benefits from data linkage. Direct experience as well as evidence from overseas suggests that unwarranted fear of disclosure and the cultural barriers to sharing data will continue to be key issues. That said, some investment may be necessary to improve IT infrastructure as more data becomes available and more linkages are undertaken.

International policy developments

It is notable that the OECD has acknowledged Australia’s leadership position in some areas of best practice for health data access – see the [OECD paper on strengthening health information infrastructure](#). Other infrastructure of note includes Statistics New Zealand’s [Integrated Data Infrastructure](#) and the Scottish Government’s [data linkage framework](#). The AIHW continues to learn from best practice experiences internationally recognising that these approaches must be adapted for the Australian environment.

Initiatives to address issues

What the AIHW is doing now

Substantial investment in developing Australia’s flexible and varied data linkage infrastructure has already occurred and further work is now extending this into a fully realised national system. Some examples of initiatives currently underway at AIHW include:

- a pilot of a national enduring linkage key methodology to complement existing state and territory infrastructure and enable efficient re-use of linkages is being negotiated with

NSW and Victoria. This has been endorsed as valuable health data infrastructure by the National Health Information and Performance Principal Committee (NHIPPC),

- a request for expressions of interest to redevelop the AIHW's metadata online registry (METeOR) has been issued. METeOR should be more widely used to create and store health metadata in order to reduce the chance of error and to enable more efficient and effective use of health data. A redeveloped, more easy to use METeOR will facilitate this,
- arrangements that allow AIHW to store MBS and PBS data and use this for approved linkage projects are now being established as an efficient model which future health data linkage processes can follow, and
- the AIHW continues to invest in developing technological and methodological improvements to meet increasing demand for linkage services.

What still needs to be done

Given the substantial benefits to be gained from data linkage Senators may wish to consider the following as potential recommendations:

- recognising that security, privacy and confidentiality considerations are satisfied by the enduring national linkage key methodology, encourage all governments to actively support the rapid introduction of the methodology in order to satisfy data linkage requests more quickly and efficiently,
- all health data (including the 'emerging' data such as eHealth records) should be assessed as a potential resource for data linkage purposes and processes be put in place to ensure that high value data is made 'fit for purpose' where possible,
- that appropriate metadata is developed and maintained on METeOR as a matter of course for health data, and
- consistent approvals processes and performance standards, should be adopted by all governments.

Should the committee have any queries about the information I have provided or wish to seek additional information from the AIHW after 24 December 2015 please contact Dr Nick von Sanden, the Head of the AIHW's Statistics and Analytics Support Unit.

Dr von Sanden and I will attend the public hearing you have scheduled in Sydney on Friday 11 December 2015.

Yours sincerely 

Warren Richter
Chief Information Officer
7 December 2015

Attachment A

Examples of data linkage projects under way or completed at AIHW include:

- Pathways in Aged Care – this linked dataset covers aged care assessments and use of 7 different Commonwealth aged care service programs from 2002 to 2011, as well as deaths. The study showed that even where people are eligible for residential aged care they prefer to remain in their homes for as long as they can.
- Cancer risk in people exposed to computed tomography scans – Medical Benefits Schedule data on 680,000 CT scans were linked to the Australian Cancer Database to examine if there was increased incidence of cancer after CT scan exposure. The study showed exposure to CT scans in childhood increased the incidence of cancer.
- Impact of a population-based HPV vaccination program on cervical abnormalities – this collaborative study between the Australian Institute of Health and Welfare (AIHW) and the Victorian Cytology Service (VCS) linked the National HPV Vaccination Program Register with Victoria's Pap test Register. The study was the first in the world to show a population-based HPV vaccination program resulting in a fall in cervical abnormalities within 5 years of implementation.
- Dementia care in hospitals – this study, commissioned by Alzheimer's Australia, used linked data to investigate the experience of people with dementia in the New South Wales hospital system. It showed that people with dementia stay in hospital longer than other patients and have higher costs of care, and that the condition is often not recorded in patient records.
- Diabetes Care Project – this 3-year pilot study was conducted by McKinsey and Company, with AIHW being contracted to coordinate the data linkage components across a range of health data sources. The study evaluated whether new models of care deliver better-quality outcomes for people with diabetes.
- Homelessness, income support and employment pathways – AIHW are undertaking a project funded by the Department of Social Services to link Specialist Homelessness Services client data with income support and employment services data from the Commonwealth Departments of Human Services and Employment. The study will to identify the service delivery patterns and pathways used by clients.
- Child Protection data and educational achievement – this project involves linking Child Protection data with educational achievement data as measured by NAPLAN (National Assessment Program – Literacy and Numeracy) testing.
- Child immunisation and health – the AIHW linked a large birth cohort from NSW and WA to the Australian Childhood Immunisation Register (ACIR) to evaluate the effectiveness of childhood vaccinations in reducing rates of vaccination preventable and other diseases. In 2016 the AIHW will undertake data linkages of ACIR to hospital and other data to assess the safety of childhood vaccinations.

