



1.6 What is missing from the picture?

The AIHW manages many important national health and welfare data collections and ensures that the information it reports is comprehensive, accurate and timely. Other government and non-government agencies also collect and report health information based on surveys, registries and administrative data collections. This information is used to inform research findings and policy decisions that improve the health and wellbeing of Australians. Despite efforts by policy, service delivery and statistical agencies, both individually and collaboratively, to develop and improve national health data, there remain opportunities to make better use of existing data and fill gaps in our knowledge.

A key issue for all data users is ensuring that information collected is used in the most effective manner; that is, turning 'big data' into 'smart data'. Information may be collected in 'silos' and may not be readily accessible or integrated or even comparable from one jurisdiction to another. Improving access to and use of existing data (see Chapter 2.5 'Secondary use of health information') would benefit Australians both through health research and through enhanced policy and service delivery. Additionally, it will allow real data gaps to be identified. This will be important for future National Healthcare Agreements, and is timely in the context of Australia's Digital Health Strategy (see Chapter 2.4 'Digital health') and, more broadly, the Australian Government's public data agenda (PM&C 2018).

However, there is currently no overarching strategic approach implemented to manage and address these gaps nationally. A strategy, with associated action plan, could improve health information assets and would be guided by policy, service delivery and research needs. This requires an understanding of the health information environment and health priority areas. The 'enhanced health data' priority associated with the current national health reform agenda (COAG 2018) provides an ideal opportunity to initiate development of a strategy and a work plan.

Individual chapters in this report describe data gaps under the 'What is missing from the picture?' headings. Some articles and snapshots list gaps that are unique to the topic or data collection. Data gaps exist where no national data are currently available or where data collected are not comprehensive. The 'What is missing from the picture?' sections may also describe analysis or research gaps that may be addressed by making better use of existing data.

This snapshot lists some of the major gaps, both data and analysis gaps, in health data and considers how they can be filled.





Major data gaps

A number of health data gaps are identified throughout this report. These gaps include:

- primary health care data (see Box 1.6.1)
- incidence and prevalence data for certain health conditions (for example, dementia and mental health)
- the ability to measure patient pathways through the health system, including across different service types and different jurisdictions
- longitudinal data to measure outcomes related to health determinants, health conditions or health interventions
- the ability to identify some populations of interest in health data (for example, people with disability)
- geospatial information to look at locational variation in health and the effects of population growth and demographic change.

Box 1.6.1: Gaps in primary health care data

Primary health care and hospital services each account for more than one-third of health expenditure in Australia but compared with the volume of hospital information that exists, there is a surprising lack of primary health care data.

Medicare services data provide some insight into variation in use of primary health care (mostly general practice) across Australia, but do not include information about why patients visit health professionals, their diagnosis, the treatment or care they received, test results or referrals for further care. There is currently no national data that allows assessment of the appropriateness, cost-effectiveness, safety, quality and accessibility of primary health care. The cessation of the Bettering the Evaluation and Care of Health survey (which collected data on general practice visits including patient demographics, types of problems being managed and the type of care provided from 1998 to 2015–16) has enlarged the primary health care data gap. Additionally, there are no comprehensive, national data for ambulance, aeromedical, allied health or state-funded community health services.

There have been developments to improve the completeness and utility of primary health care data, including a commitment to develop a national primary care data set. Making electronic health information available for secondary use will support improved primary health care data but is not a total solution.

Filling data gaps

The goal of filling these major health data gaps is to achieve stronger evidence for better decisions and improved health for Australians. The AIHW is working with government and non-government agencies to fill some of these gaps and make better use of existing data, including through data linkage.





Data linkage, also called data integration, is a process that combines information from multiple databases, while preserving privacy, to tell a much more powerful story than would be possible from a single source. The Productivity Commission's (2017) *Data Availability and Use, Inquiry Report* highlighted the substantial value of data linkage because it enabled 'more insights to be derived from information already collected'. Data linkage is cost-effective because it re-uses existing data, and is non-intrusive because it avoids the need to re-contact people whose information has already been collected. Data linkage is most commonly used to measure health outcomes; for example, showing that the human papillomavirus vaccination is effective in reducing cervical cancer (Gertig et al. 2013). However, it is also valuable for patient pathways—for example, hospital re-admission following a heart attack (Lopez et al. 2017)—and for identifying populations within an existing data collection.

Data linkage is increasingly being used to link across health and welfare; for example, the National Integrated Health Services Information Analysis Asset brings together aged cared with health services data (AIHW 2018). The volume and complexity of linkage projects undertaken by the AIHW continues to increase.

Much of this work centres on achieving valid and valuable person-centred data while ensuring that individual privacy is protected. Person-centred data are beneficial for insight on an individual's health situation, their treatment pathways, interactions and experiences with health care and their health outcomes, potentially leading to improved coordination and quality of care. However, individuals need to trust how their data will be handled, feel they have control over how and who will use it and see the value and benefits in its use.

A national direction for filling data gaps

Australia's health information and data environment is changing rapidly, with increasing demands made on the collection, reporting and use of health data. There is a strong need for a strategic approach to how we manage national health data assets in Australia—a strategy that provides a desirable vision for the future of Australia's national information resources. The overall aim would be that future developments in national health data assets are more coordinated, cost-effective and tailored to current health priority areas.

This rapid change and current technological developments mean that now is the time to build on current health information work and existing infrastructure to improve how we use and share data. The AIHW is well placed to work with Australian and state and territory agencies to provide strategic direction and improve coordination. This would ensure investments are well targeted, and that new and improved data collections match national priorities.

Improved coordination and planning of health information work could assist in creating a more comprehensive list of current and future national information gaps and overlaps, as well as identifying priorities—as determined by policy and policymakers, strengthening the links between policy and outcomes. A structured, strategic approach to data and evidence is critical to support continuous improvement, innovation and progress in health—strengthening it as a 'learning system'.





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