

# AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

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## Australian Commission on Safety and Quality in Health Care submission to the senate inquiry into health policy, administration and expenditure

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The Australian Commission on Safety and Quality in Health Care (the Commission) is pleased to provide this submission on improving access to and linkage between health data sets to the Select Committee on Health.

Data linkage is the act of matching records that relate to distinct entities within and between datasets. As these records often relate to personal information, there are significant privacy and confidentiality considerations in linking health data.

The Commission is a strong advocate of linking datasets to monitor and identify areas for improvement in the safety and quality of Australian health care. Data that could be readily linked include data from the Medical Benefits Scheme (MBS), the Pharmaceutical Benefits Scheme (PBS), admitted patient datasets (ICD coded data), the National Death Index and a number of national surveys and registries. These data are already collected and linkage would expand on current use to provide opportunities for improvements in the safety, quality and efficiency of health care and for health research.

### Why data linkage is important

Data linkage provides opportunities for monitoring care across facilities (public, private, acute and primary care) and state and territory borders and also provides opportunities to triangulate different data sources to provide a more complete picture of the care patients receive. By linking the available data highly granular indicators that can be precisely risk adjusted can be developed and used at healthcare facility or jurisdictional level to support monitoring of quality of care and improvement strategies. Some examples of indicators that could be developed if linkage were available are provided below, however this list is not exhaustive and there are many other potential uses for these data.

**True readmission rates for specific conditions or procedures:** Currently readmission is used as a safety and quality indicator but is limited to readmissions to the same hospital or readmissions to a public hospital within the same jurisdiction. In reality, patients may be readmitted from a private hospital to a public hospital or in another state entirely, hence a large number of patients are not included in the current indicators. Lack of linkage also limits the ability to correctly include patients who receive care in more than one hospital or jurisdiction. True readmission rates that include private-public and cross-border readmissions and can accurately track patients who are transferred would provide a more accurate indicator of readmission rates increasing the utility of the indicator monitoring safety and quality.

**30-day mortality rates following admission to hospital for a specific condition or procedure:** Measuring mortality in the 30 days following a procedure or hospitalisation for a specific condition as an indicator has been used for some time in the UK, USA and Canada. In Australia, this measure is also limited due to the lack of data linkage. 30 day in-hospital mortality is used as a proxy and some states have the capacity to link data to provide 30 day mortality within the jurisdiction for public hospitals however private hospitals are excluded. Capturing out-of-hospital mortality at a national level requires linkage of state and territory admitted patient datasets and the national death index. This indicator would be more robust than current indicators used as patients would not be excluded from the analysis.

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## **Generating actual patterns of usage of health services for specific patient cohorts:**

Linked data between the admitted patient datasets, PBS and MBS would allow for mapping of hospital admissions, GP and specialist encounters, surgical procedures, non-admitted diagnostic services, and medicines dispensed to provide information on actual patterns of care. Currently these patterns are analysed using limited, manual “patterns of care studies” examples of which include surgery, chemotherapy and radiotherapy – including timeliness of therapies - for colon or breast cancer patients; diabetic or asthmatic patients use of acute and GP services, and medicines.

The following scenario is provided as an **example** of how linked data can efficiently monitor actual care and inform safety and quality improvement. This type of analysis is what future editions of the Commission’s Atlas of Variation in Health Care<sup>1</sup> would seek to describe.

National guidelines for the management of acute coronary syndrome (ACS) specify that patients admitted to hospital for management of ACS be discharged on five medications:

1. Beta blocker
2. Aspirin
3. Anti-platelet agents
4. Cholesterol lowering medicines (‘statins’)
5. ACE inhibitors.

However, studies show compliance with this guideline has been shown to vary across hospitals and hospital types highlighting this as an area for potential improvement.<sup>2</sup>

Linking admitted national patient datasets (to identify ACS patients using ICD10AM Principal Diagnosis codes for ACS) to PBS datasets using anatomic therapeutical chemical codes would allow analysis of adherence to national guidelines and variation from best practice, and provide valuable information for improving care of patients with ACS. Similar analyses could be conducted to monitor guideline compliance by healthcare facilities for a range of other conditions including recommended stroke discharge medicines.

Linking data would also provide opportunities for research that could contribute to increased safety and quality of the health system. The Commonwealth conducts a number of surveys that are rich sources of health related data. There are many potential opportunities for this data to be linked to explore relationships between health behaviours and the social determinants of health and outcomes such as hospitalisation, GP attendance, medication use or mortality. While linkage studies currently take place they are limited due to the lengthy ethics approvals required to get approval for linked data. Streamlining this process could lead to advancements in the prevention of illness as well as improvements in care.

## **Barriers to data linkage**

One of the main issues is the variation in privacy legislation and complicated ethics approvals systems in the various jurisdictions. In Australia, projects using linked data must be approved by the data linkage unit; the data custodian responsible for each data set; and one or more Human Research Ethics Committee(s). Alignment and streamlining of these systems is required to ensure that personal data is properly protected at the same time as decreasing the burden

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<sup>1</sup> The Australian Commission on Safety and Quality in Health Care has released the first *Australian Atlas of Healthcare Variation*. The atlas presents a clear picture of substantial variation in healthcare use across Australia, across areas such as antibiotic prescribing, surgical, mental health and diagnostic services. See: <http://www.safetyandquality.gov.au/atlas/>

<sup>2</sup> Briffa T et al, Should fee-for-service be for all guideline-advocated acute coronary syndrome (ACS) care? Observations from the Snapshot ACS study, *Australian Health Review*, 2015, 39, 379–386

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required to use this data. The practical issues of where the data will be stored, who will be able access it and how it will be protected need to be addressed.

Existing infrastructure to support the linkage of national population datasets exists in the Population Health Research Network. While the information technology and methodologies exist to link data from multiple data sets, timeliness of data provision is an issue due to the aforementioned approval requirements. In order for data on safety and quality to be most effective in driving improvement, regular and timely review is required.

## **An example of data linkage**

Secure data linkage using the conventional data linkage methodology is a proven research and analysis methodology. NSW Health has established one of the most mature and complete systems built around the *Information Privacy Code of Practice*, the *Health Records Information Privacy Act* (2004), dedicated statutory guidelines, a population and health services research ethics committee with state-wide coverage, and the Centre for Health Record Linkage (CHeReL) which uses configurable probabilistic data linkage.

Identifiers are linked by a dedicated data linkage unit as a “trusted third party” with no patient clinical information. Statistical linkage keys are provided to the researchers, who then use these to provide a linked, de-identified clinical dataset for analysis. Once an analysis is complete, the linkage keys and analytic dataset are deleted.

This example outlines the complexity of successful data linkage and the various structures required to achieve data linkage within a state. National data linkage requires this as well as alignment between jurisdictions to streamline the process.

## **Next steps**

The advances in information technology and the current interest in using data to improve the health system provide opportunities for the issues that currently limit the capacity for data linkage to be progressed. Further national collaborative work is needed to identify, firstly the optimum sources of data to be linked (what are the most useful products that we want) and secondly, ways to streamline the linking of large confidential datasets within the national and jurisdictional privacy and confidentiality constraints. The Commission is interested in this work and will continue to be an active participant in this discussion going forward.