



Australian Government
Department of Health

December 2016

**Australian Government Department of Health Submission to the
Productivity Commission Draft Report: Data Availability and Use**

The Department of Health (the Department) supports in-principle the framework proposed by the Commission. The Commission's draft report is well positioned to become a major contributor to a necessary program of work that consolidates and drives forward existing and planned data sharing activities for the benefit of all Australians. The Department of the Prime Minister and Cabinet, as the lead Commonwealth agency with responsibility for public data policy, would be well placed to lead further development of the framework through a national approach. A national approach to data sharing which includes the Commonwealth, States and Territories and public and private sectors would be highly valuable considering the fragmented nature of data collation in the health portfolio. The Department would value the opportunity to contribute to such a national solution.

The Department recognises that there still exists an enormous potential to use health data to improve health outcomes. Consultations with the research community have shown that there is not a clear consensus even among researchers how to balance the risk of potential harm from a data release, with the benefit of increased data availability. Commonwealth agencies like Health continue to work with others to build a 'social licence' from government and the public so that we may implement additional and more varied data sharing programs to maximise economic, health, and societal value. The Department welcomes any opportunity to work with other agencies to continue to exploit the value in sharing and linking health data.

The Department believes that the Commission's draft report underplays the importance of data linkage. Data linkage is a technique for creating links within and between data sources so that information that is thought to relate to the same person, family, place or event can be connected for analysis. Data linkage adds value to routinely collected data, because the information required to study complex diseases is rarely found in one dataset.

Epidemiologists, population health and health services researchers need to study many factors to make sure their research is meaningful. Linked data can be used to support approved research, develop policies and to plan and evaluate services and is a particularly valuable research tool in health. The release of data to enable linkage, and the carrying out of data linkage from multiple data sources is a more complex activity than the release of data from a single source and there would be value in the Commission discussing arrangements for this work more explicitly. There is a range of data linkage models that could be explored.

Significant work has already been done in Australia to develop data linkage infrastructure, as well as release and access protocols across all community sectors. The Department and its portfolio agencies have significant experience in data access and linkage across the health sector.

The Department, via the Australian Institute of Health and Welfare and the Commonwealth Department of Human Services, releases health data for approximately 200 projects each year. However, to realise the full potential of what can be achieved through the sharing and linking of health data a systematic national approach is required.

The Department sees value in the Productivity Commission's recommendation to establish Accredited Release Authorities (ARAs) and National Interest Datasets (NIDs). The National Interest Datasets (NIDs) concept as proposed in the draft report allows data to be held in different locations and within different sectors by different ARAs. The risk of a data breach occurring is increased when multiple copies of the same data are held in different locations. Disparate locations can, over time, lead to inadvertent variances in data management practices which can lead to disparate results from the same analyses of the same data. In addition, initial training and support for ARAs would be required from line agencies. This suggests that in principle, the number of ARAs should be kept to a minimum within any one sector, particularly when personal data are involved. This is particularly important when considering linked data, as the expertise required for data linkage, and management of the risks around managing linked data are significant. In addition, the separation principle, which separates the role of creating data linkages from that of analysing the resulting linked data also calls for a small number of agencies to be involved in the linkage and the release of such data.

The Department supports the concept of a *Data Sharing and Release Act* (the Act). The collection and dissemination of administrative and clinical health data in Australia is a shared responsibility between state and territory health departments, the Commonwealth, and the private sector. The Department supports the Commission's recommendation that the legislation and administrative arrangements be designed to support such a national approach. It should be noted, however, that the heterogeneity of existing data legalisation and governance arrangements across multiple datasets and multiple sectors could potentially require an Act that is extraordinary in detail. The draft report notes that provisions may be made for specific circumstances; however, as the Act is a critical foundation for the implementation of the framework components, it would need to be tested and developed at an early stage.

Most recommendations in the Commission's report will have either a direct or indirect effect on the Department. One of the more significant is the recommendation to change the definition of consumer data and consumer's rights. The Department believes that it is necessary to carefully consider how comprehensive rights for consumers can be accurately and sensitively communicated. There is an existing framework for releasing and using consumer data, both identified and non-identified within agencies and across agencies and with trusted research organisations, which is allowed under legislation. A public miscommunication occurring during an information campaign might impact on existing data release and linkage programs which are tied into health and medical research programs that have been, and continue to, produce results that improve health outcomes. Comprehensive rights for consumers, as featured in the Commission's proposed framework, may be one area where a long term program of culture change may be required in addition to a shorter term change in attitudes and opinions.

There would be significant initial and ongoing costs to the Department associated with implementing the Commission's framework which would need to be assessed in the context of the extent of public benefit that may be attained. Given the substantial benefits that could be gained through improved health data sharing, the Department would wish to contribute to a national solution.