

01 December 2015

The Senate Select Committee on Health
c/-Stephen Palethorpe
Committee Secretary

Dear Mr Palethorpe

Please find attached a submission regarding the hearing on **'Improving access to and linkage between health data sets held by Commonwealth entities'** that is scheduled to occur on Friday 11 December 2015. This submission has been prepared on behalf of the Queensland Department of Health.

For inquiries about this submission, please contact Trisha Johnston on

Yours sincerely

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Within Queensland Health, as in other areas of Australia, there has been a substantial increase in recent years in the number of requests from researchers and from policy makers, planners and those engaged in service redesign and evaluation for linked administrative data. This reflects the growing recognition of the value of administrative data, particularly linked data, to inform policy and decisions.

Currently, within most jurisdictions, repositories of linked health data exist including collections such as hospital admissions, emergency department, perinatal and birth and death registrations. These data have been linked due to the recognition of the insights that can be gained by using data across collections to inform health services policy development, planning and research. Linking national data collections such as Commonwealth medical and pharmaceutical data and data collected by the Australian Bureau of Statistics such as census and survey data to Jurisdiction-based data collections, would offer further increases in the potential utility of these data. Linking Jurisdiction and Commonwealth data collections provides an increased opportunity to achieve a patient focus rather than an individual system focus which can lead to significant increases in efficiency and effectiveness of patient care. For example, insights gained through linked data can lead to improved targeting of services, improvements in allocation and recouping of funds, improved accuracy in estimation of patient needs to inform service planning, and improved monitoring of patient safety and quality of care and evaluation of the impact of models of care. Data linkage can also allow investigation of relationships between health and other areas such as education, homelessness and encounters with the justice system to provide insights into policy and research questions that cannot be addressed by existing data sources in isolation.

There are many practical issues to consider in this arena. Considerations include the need to ensure data and linkage quality are maximised and limitations are able to be clearly communicated, the need to ensure that risks involved in releasing patient identifying and clinical details to the privacy of those contributing the information are justified by the intended use of the data, the need to coordinate and plan linkage work to ensure duplication of effort is minimised and the need to ensure linked data are able to be shared reciprocally between the Commonwealth and Jurisdictions where the requirement for the information justifies such sharing.

Maximising the quality of linked data

Administrative data are generally collected for operational use in providing a health service, but there is increasing recognition of the potential for these data beyond that use, particularly when these data are able to be linked with other data collections. While use of these data provides a rich resource and represents an efficient means for providing this information, caution is required in use and interpretation of these data. Consideration is required regarding quality in not only data that are collected but in the linkage of that data. The quality of data and the linkage achieved are critical to the analysis and interpretation of these data. For example, if identifiers are poorer for private hospitals than for public this may lead to interpretation of lower readmissions or mortality for private facilities when the underlying cause may just be lower linkage rates.

The need to optimise the quality of linkage needs to be considered in decisions about how and where these data should be linked. Use of statistical linkage keys and other deterministic methods may be fit for use when data are available with few errors in identifiers or with few missing identifiers, but for the majority of administrative data collections, probabilistic linkage with clerical review of uncertain matches is required. It is important that appropriate levels of resourcing and skills are available where data are to be linked to enable high quality linked data to be created. It is also important that appropriate resources are allocated to documentation and communication of data and linkage quality issues.

Maximising privacy of information

There are currently arrangements in place to enable linkage of administrative data which are collected under government legislation behind government firewalls by accredited integrating authorities. In 2010, the Secretaries Board (i.e. heads of all Commonwealth government agencies and the Australian Public Service Commission) endorsed a set of principles to govern integration of Commonwealth data for statistical and research purposes, as well as a set of governance and institutional arrangements to support these principles. An important part of the governance and institutional arrangements is being able to hold one agency accountable for the safe implementation of a data integration project. Currently, for data integration proposals that involve Commonwealth data and that are considered 'high risk', an accredited Integrating Authority must be used.

The AIHW has obtained accreditation as an Integrating Authority, and we consider that Queensland Health data are able to be safely and effectively linked within the AIHW, which already holds National Death Index data, already has arrangements in place to receive and link Commonwealth medical and pharmaceutical data, already receives patient-level hospital, perinatal, mental health and other data from states and territories (albeit in non-identified formats), and is already authorised to perform this type of work under the AIHW Act. Provision of identifiers by custodians for specific linkage projects could enable AIHW to link data without going outside government firewalls, thus minimising risks to data integrity and security.

There is a risk to privacy and consistency involved in duplicating holdings and performing the same linkage in multiple data linkage facilities. Many national data collections are held by the AIHW, Department of Health and Department of Human Services. AIHW compiles and maintains the National Death Index (NDI) under special arrangements with state and territory Registrars-General of Births, Deaths and Marriages and services researchers' requests to link to the Index. AIHW already receives patient-level hospitalisation and other data. It would appear to be relatively uncomplicated for jurisdictions already supplying data to make arrangements to exchange identifying information with the AIHW in ways that enable linkage, within governments' own information systems. Custodians of the Commonwealth's medical and pharmaceutical benefits data have advised they will only engage in linkage with jurisdictions on a case-by-case basis via the AIHW. These are the data of most interest for linkage to hospitalisation data.

Minimising duplication of effort and sharing information across agencies to maximise efficiency and use of linked data

Duplication of the AIHW's data holdings at additional linkage facilities is inefficient and would introduce unnecessary risks in terms of duplication of data extraction and transfer, data holding, and linkage activity. Such risks are unacceptable when a lower risk alternative exists to achieve desired outcomes. We feel that it would be better to utilise and enhance the facilities developed at the AIHW to perform any national data linkage than to duplicate these data and linkage processes within any other government or non-government data linkage centre.

However, it should also be recognised that there is already a substantial amount of linked health data that has been created by Jurisdiction-based data linkage units and a substantial amount of expertise exists in these units. The Population Health Research Network (PHRN) plays a national role in coordinating liaison and skill sharing across units within each Jurisdiction and the AIHW-based linkage unit. These resources and potential efficiencies available through using linkage keys that have already been created and optimising the use of available data (e.g., current legislation does not

allow Medicare numbers to be used for linkage) should also be considered where feasible. An optimal model within Australia would involve a minimum amount of duplication of linkage in combination with a maximum amount of sharing of linked data between Commonwealth and Jurisdiction-based agencies for projects that have been approved by the appropriate data custodians to allow the value of this rich information resource to be fully realised.

In summary, in order for a national linkage capability to succeed, we believe strongly that official statistics containing personal data should be linked only within secure environments within government agencies. Advantages of this include improved security and accountability and minimised handling and storage of personal information. These factors are crucial to ensure that the necessary level of support and confidence of government agencies and the public is obtained and maintained.