

Recommendations

Recommendation 1

2.36 The committee recommends that Australia forms partnerships with other countries engaged in data linking to ensure that Australian data access and linkage policies and regulations are developed to world's best practice.

Recommendation 2

3.37 The committee recommends that the Department of Health, as a high priority, actively explore and then implement measures to advance cost-effective, evidence-based policy development through the use of data linkage.

Recommendation 3

3.38 The committee recommends that relevant government departments should include information in their annual reports which describes the processes and projects being undertaken to establish evidence-based policy based on data linkage as well as strategies they have adopted to contribute to the government's public data policy.

Recommendation 4

4.40 The committee recommends that given the changes in technology, and mindful of the capacity and moral obligation for governments to hold and strongly secure personal data and privacy, the government review the operation of section 135AA of the *National Health Act 1953*, with the aim of improving access to de-identified MBS and PBS data for the purpose of health policy evaluation and development as well as research undertaken in the public interest.

Recommendation 5

4.41 The committee recommends that the Australian Information Commissioner, in consultation with privacy advocates, data custodians, academics and healthcare consumers, review the *Privacy Guidelines for the Medicare Benefits and Pharmaceutical Benefits Programs* in order to ensure that the government:

- retains ownership and management of Australian MBS and PBS data and improves technological capacity to ensure the privacy of all Australians health data; and

- **develops a strategy to improve access to de-identified MBS and PBS data for the purpose of health policy evaluation and development as well as research undertaken in the public interest, in ways that don't decrease privacy.**

Recommendation 6

5.75 The committee recommends that each Australian Government agency develop and maintain on its website a list of datasets held by the agency along with the contact details of the data custodian. This list should be updated at least twice annually.

Recommendation 7

5.76 The committee recommends that all datasets held by the Commonwealth be listed on www.data.gov.au, identifying which agency is the data custodian.

Recommendation 8

5.77 The committee recommends that each Australian Government agency that is a data custodian develop and publish on its website guidance for researchers detailing its process for data requests and approvals.

Recommendation 9

5.80 The committee recommends that the government take a whole-of-government approach to streamlining the ethics approval process and the authorising environment in consultation with the Privacy Commissioner, privacy advocates, the NHMRC, data custodians, academics, consumers and the States and Territories. The government should also work with the States and Territories to establish a national accreditation system so that ethics approvals from accredited jurisdictions are recognised by the Commonwealth.

Recommendation 10

5.87 The committee recommends that relevant government agencies give greater priority to, and adequately resource, their data custodians.

Recommendation 11

5.88 The committee recommends that relevant government agencies provide guidance to data custodians to assist them in their decision-making, with a view to making more de-identified data available on an enduring basis.

Recommendation 12

5.89 The committee recommends that the government adopt the Productivity Commission's proposed principle that open access to de-identified datasets should be the default position.

Recommendation 13

5.90 The committee recommends that the government should direct relevant agencies to release de-identified datasets on an enduring basis as the default position.

Recommendation 14

5.91 The committee recommends that departments that have data custodianship responsibilities must establish and publish realistic Key Performance Indicators for the timely consideration and approval of datasets requests. These departments must publicly report on their KPIs in their annual reports.

If after 5 years departments continue to delay the release of datasets, then the committee recommends that the government establish binding timeframes for processing applications for data. Failure to comply with the timeframe should trigger appeal rights similar to those found in other information access regimes.

Recommendation 15

5.93 The committee recommends that Government encourage collaboration on data linkage projects between government agencies, as well as academia and industry to provide for evidence-based policy development and facilitate research that is undertaken in the public interest.

Recommendation 16

5.98 The committee recommends that government consider accrediting State data linkage units to link Commonwealth data with State data collections, subject to comprehensive privacy and security protocols.

Recommendation 17

5.99 The committee recommends that the Government review the cost of data access and linkage work undertaken by Commonwealth entities with a view to facilitating research and innovation in the national interest.

