

NCRIS: National linkage in Australia

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Background

There is considerable experience in health data linkage in Australia, including in national information and statistical agencies and in states and territories. Western Australia has had a statewide health data linkage capability since 1994-95. New South Wales has recently established a similar capability.

In 2006 the Australian Government allocated \$20 million over three years from 2008-09 through the National Collaborative Research Infrastructure Strategy (NCRIS) to further develop Australia's population health and clinical data linkage capability.

Population Health Research Network (PHRN)

An Investment Plan to support the capability was approved by the NCRIS Steering Committee in April 2008. The Plan for the PHRN provides for the establishment of data linkage nodes in all Australian states. A Network Program Office will be established at the Telethon Institute for Child Health Research in Perth to co-ordinate the program. A Network Linkage Centre will be established by Curtin University to develop linkages between data held in the state data linkage nodes.

There is strong support from all Australian states and territories for the development program. States, territories and related tertiary institutions have agreed to provide an additional \$31 million in cash and in-kind contributions to develop the infrastructure over the three year period.

Linked data from the PHRN will be provided for approved research projects. This will support important new health and health service research. In some nodes, linkages will also be established between health and other human services data. This is already happening in Western Australia.

The Australian Government Department of Innovation, Industry, Science and Research (DIISR) is responsible for the NCRIS program. DIISR are currently finalising a funding agreement for the program with The University of Western Australia (UWA) in consultation with the proposed nodes.

The PHRN will be governed by a Management Council that will include nominees from Australian Government, state and territory health departments. The Council will have an independent chairperson. Health consumers will be involved in governance processes for the PHRN and the state-based nodes.

Linkage protocols will be based on the best-practice models used in Western Australia and New South Wales. These models involve probabilistic linkage based on demographic data. Deidentified, linkable service data can then be provided by the data custodian(s) to the researcher for an approved project.

Conclusion

The PHRN will enable access to linked deidentified data from the Australian population for approved research projects and programs. The new infrastructure will support a range of

research that will result in improved health outcomes. It will also provide exciting opportunities for international collaboration.