

# **National Collaborative Research Infrastructure Strategy**

## **Capability 5.7: Population Health and Clinical Data Linkage**

**Update: December 2007**

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## Introduction

The purpose of this paper is to update State and Territory Government departments and agencies and other interested institutions on the development of the Investment Plan for the NCRIS Population Health and Clinical Data Linkage Capability.

The Investment Plan was originally scheduled for completion in November 2007. However, because of the need to involve Commonwealth Government agencies and accommodate the obvious pressures of the Federal Election during October and November, the NCRIS Committee decided to delay completion of the Investment Plan until February 2008.

There has been much debate about the shape of the Investment Plan and the extent to which the development of health data linkage infrastructure should be centralised. It is generally acknowledged that a focus for the coordination of nationally-significant infrastructure development is essential, and that a facility for the linkage involving national datasets is also critically important. The NCRIS emphasis is on research infrastructure. To date most NCRIS investment plans have identified a lead agency in the research sector, and the NCRIS funds have been distributed via this lead agency to research organisations throughout the States and Territories. The NCRIS Committee has expressed a clear preference for this type of model for the Health Data Linkage Capability.

While the proposed model is largely State- and Territory-based, it should also provide opportunities for involvement with Commonwealth Government agencies, notably the Department of Health and Ageing, the AIHW, the NHMRC, the CSIRO, the ABS and NeHTA. It should also provide opportunities for AHMAC input as the peak body of jurisdictional health agencies and the body that endorses health information standards. Further, linkage using national datasets, such as the Medicare datasets, would clearly make a major contribution to the national capability, provided that the governance requirements for these datasets could be met.

Discussions with Commonwealth agencies have recently been held, and will continue, to ensure that the NCRIS Health Data Linkage initiatives are consistent with activities being undertaken in the broader national context.

## Proposed NCRIS model

All State and Territory governments (through health departments and/or departments responsible for innovation) and agencies such as the CSIRO, the AIHW, the NHMRC and the ABS have expressed enthusiastic support for the development of Australia's health data linkage capability. Their enthusiasm has also been echoed by many university-based and independent health and medical research institutions.

In order to avoid cutting across other national initiatives relating to health information, the NCRIS Investment Plan will outline a model based on existing and proposed data linkage units in the States and Territories.

The main features of the model are as follows.

- NCRIS will contract with a university or a university–affiliated agency that has an interest in health data linkage to be the **lead agency**. The lead agency will receive NCRIS funding, take responsibility for the implementation of the Investment Plan in accordance with the Business Plan contained in the Investment Plan, and report to NCRIS.
- The lead agency will achieve this by **subcontracting** with other bodies based in the States and Territories to fulfil various agreed functions. These bodies may comprise universities or groups of universities, other research institutions, national agencies (located in Canberra or elsewhere), and State and Territory government agencies.
- The subcontracted functions will reflect individual States' and Territories' aspirations in data linkage.

Under this model, the NCRIS funds, supported by State and Territory co–investment, will be used for:

- The operations of the lead agency.
- Infrastructure for new data linkage units.
- Facilitating and promoting collaboration, especially in respect of data linkage methods, taking account of health information standards promulgated by AHMAC.
- Development of infrastructure to expand the capacity of existing units, including capacity for linkage with national datasets.
- Workforce development, including vocational training and professional education in linkage methods and the analysis of linked data.
- Development and/or evaluation of new data linkage technology and methods.
- Proof–of–concept activities.

It is generally acknowledged that the success of the lead agency will depend on its establishment in a close relationship with an existing health data linkage unit and a 'critical mass' of expertise in linkage systems, methods and quality assurance.

Physically, the lead agency could be located anywhere in Australia, provided that the supportive relationship could be maintained. It will be important to ensure that the lead agency fosters a national infrastructure rather than just the needs of the jurisdiction in which it is located. Conversely, it will also be important to ensure that the jurisdiction in which the lead agency resides is able to pursue its needs for data linkage, separate from national demands.

Regardless of its eventual affiliation, the lead agency should be established as a unit of an existing entity. This would give the lead agency an organisational base through which the NCRIS contract could be executed, and the means to receive and expend funds and employ staff in accordance with the contract

## Funding

The next step in the preparation of the Investment Plan is to determine the detail of the NCRIS funding distribution to the lead agency and the other organisations that will contribute to the national health data linkage effort.

The intent is for the NCRIS funds to be distributed at State and Territory level rather than at organisational level. Most States and Territories have already prepared statements outlining their intended use of monies made up of NCRIS funds plus a local jurisdictional co-investment. Their intended programs embrace a range of local initiatives involving universities, health-service institutions, other research institutions and, in some instances, State-based Commonwealth agencies.

The maximum total NCRIS investment in the Population Health and Clinical Data Linkage Capability is \$20 million over the period to 30 June 2011. In effect, this will be a three-year period, as funds are unlikely to flow until the second or third quarter of 2008. The figure of \$20 million cannot be increased.

NCRIS funding will therefore inevitably be somewhat less than the amounts described in the the States' and Territories' outlines received to date. The amounts described were, in many instances, aspirational or approximate. The following is a guide to the amounts that are likely to be available.

- The lead agency will require about 15 percent of the available NCRIS funds, i.e. about \$3.0 million.
- The jurisdictional body that takes responsibility for linkage involving national datasets will require about 30 percent, i.e. about \$6.0 million.
- About 55 percent, i.e. about \$11.0 million, will then remain for distribution to the States and Territories that are not the host(s) of the lead agency and the centre for linkage involving national datasets. This \$11.0 must stretch to cover *as many of the other intended functions as possible*.

## Invitation to jurisdictions

States and Territories are invited to revisit the funding of their plans for health data linkage development, taking account of the NCRIS investment ceiling and the three-year timetable (rather than the original four-year timetable). Setting aside the lead agency function and the centre for linkage involving national datasets, no NCRIS commitment to a single jurisdiction or collaborating group of jurisdictions is likely to exceed \$2.5 million over three years, and most NCRIS commitments will be considerably less.

On this basis, States and Territories are also invited to specify the extent of jurisdictional co-investment, both in cash and in kind. All jurisdictional funding will remain in the jurisdiction that provides the funds. For example, if NCRIS were to make a commitment of \$2.0 million to a jurisdiction and that jurisdiction's government were to co-invest \$3.0 million in cash, a total of \$5.0 million would be available for use in that jurisdiction.

Jurisdictional co-investment is one of the strengths of NCRIS, and it makes NCRIS a truly national collaboration. However, smaller jurisdictions that cannot make a substantial co-investment are not excluded from NCRIS funding. The NCRIS Committee does not seek matching funds and does not have a co-investment formula or pre-determined 'gearing ratio'. Consolidated proposals from two or more States and Territories would be greatly welcomed, and indeed are encouraged.

Australian Government agencies with an interest in participating in the NCRIS health data linkage capability are similarly invited to revisit their proposals.

Revised jurisdictional plans should be prepared during January 2008. The Facilitator, Professor Michael Frommer, will be available for discussion or clarification of options from 3 January 2008. He hopes to hold face-to-face or telephone discussions with all jurisdictional representatives during January, with a view to drafting the funding detail of the Investment Plan by 31 January 2008.