

NATIONAL COLLABORATIVE RESEARCH INFRASTRUCTURE STRATEGY

POPULATION HEALTH RESEARCH NETWORK - UPDATE

Summary

This paper follows from an earlier paper about the NCRIS Population Health Research Network that was considered at the Australian Government Statistical Forum at its meeting of 11 April 2008. In that earlier paper, the operational context for the PHRN was discussed, with broad descriptions of the infrastructure, privacy preserving protocols and relationship to the broader health policy agenda.

This update paper discusses the rationale for NCRIS support for the PHRN, its particular objectives, organisational functions and elements. The governance structures and community consultation processes that will align the PHRN with the wider national policy agenda are discussed.

Australian Government support for research infrastructure through the National Collaborative Research Infrastructure Strategy (NCRIS)

Through NCRIS, the Australian Government is providing over \$500 million between 2005 and 2011 to provide researchers with major research facilities, supporting infrastructure and networks necessary for world-class research. In November 2006 the former Minister for Education, Science and Training approved funding for the implementation of twelve priority NCRIS areas of investment, known as 'capabilities', under the NCRIS program. This funding included \$20 million for the Population Health and Clinical Data Linkage capability, subject to the development of a suitable investment plan and approval of this plan by the NCRIS Committee.

Appendix 1 details the NCRIS principles and planning processes, including the context for infrastructure investments in Population Health data linkage in the 2006 *NCRIS Strategic Roadmap* and the 2008 *Strategic Roadmap for Australian Research Infrastructure*.

NCRIS Investment Plan for the Population Health Research Network

The NCRIS Investment Plan for the Population Health Research Network (PHRN), facilitated by Professor Michael Frommer in consultation with the health research community, was considered by the NCRIS Committee on 28 March 2008 and has now been finalised and approved.

The Investment Plan was built on the following premises based on extensive consultation with the research community, jurisdictions and health data custodians throughout Australia:

- Like most other countries with well-developed health systems, Australia has high-quality clinical datasets at the *health service* level and important research datasets at the *project and program level*. Uniquely, however, Australia hosts numerous stable, long-standing *population-level health datasets*, such as State and Territory cancer registry and hospital inpatient activity datasets that are pooled nationally, Medical Benefits Scheme data that cover the entire resident population, and Pharmaceutical Benefits Scheme data that cover all subsidised prescriptions. Data linkage would enable the creation of information resource of unique value, both for Australia and for the world.
- Australia already has considerable experience with health data linkage; the pioneering health data linkage system in Western Australia is regarded as one of the best in the world, and the track record of research based on linked datasets speaks for its inestimable value.

- Data linkage systems and methods already developed and in use in Australia are demonstrably effective, but a continuing investment in new systems, new technology and new methods will produce greater efficiencies, coverage, breadth of knowledge, and capacity.
- The main impediments that inhibit effective use and linkage of available health data for improving health, wellbeing and health services arise from systemic factors. These include the interpretation of legislation and policy, a lack of resources to manage data access, and researchers' widespread misunderstanding of the principles of governance for datasets containing information on individuals.

Objectives of the PHRN

The purpose of the NCRIS investment in the PHRN is to provide researchers in Australia with the capability to link de-identified data from a diverse and rich range of health data sets, across sectors and jurisdictions, to carry out nationally and internationally significant population-level research, to improve health and wellbeing and to enhance the effectiveness and efficiency of health services.

The PHRN operations will not change the ownership or responsibility for the management of the health data itself, which remain with the respective data custodians. Instead, the PHRN aims to provide an effective capability for researchers to access linked health data, subject to applicable legislative, regulatory and institutional frameworks governing the uses of that data. The importance of building a strong consultative engagement with data custodians, with the key agencies that have carriage for policy in the use of health data and with the community, through organisations that advocate for consumers on issues of privacy, confidentiality and ethics, is recognised in the defined roles of the PHRN Management Council.

The NCRIS investment in the PHRN will:

- build upon existing data linkage capacity and expertise in particular jurisdictions and in specific aspects of health data collection and management;
- establish new foci of data linkage capacity in all Australian jurisdictions;
- provide ICT support, workforce training and development, data management and custodianship, analytic capacity and coordination among data linkage centres, to support Australian researchers undertaking probabilistic linkage of datasets relevant to the health and wellbeing of the Australian population;
- facilitate research into health determinants, organisation and delivery of health services, health status and health outcomes in the population and non-health fields that impact upon health and vice versa;
- enhance collaboration across health systems, public and private health services and agencies that run health systems and provide mainstream health information; and
- consolidate the collaborations that already exist among groups in Australia already engaged in health data linkage activities.

The functions and elements of the PHRN infrastructure investment

The PHRN infrastructure will comprise a set of processes, methodologies, technologies and expertise. The infrastructure will include information and communication technology (ICT) and ICT support; acquisition and maintenance of research equipment; workforce training, development and renewal;

data management and data custodianship; analytical capacity; coordination among interested parties; and governance.

The NCRIS funding for the PHRN is to be used entirely for expanding, building and/or evaluating infrastructure for the probabilistic linkage of datasets relevant to the health and wellbeing of the Australian population. It will expand the capacity of existing units, including capacity for the future linkage of national datasets.

The PHRN infrastructure and services will enable researchers in universities, research institutes, government agencies and other organisations to access linked, de-identified data from new and existing research datasets, ad hoc survey datasets and routine administrative datasets.

The PHRN will facilitate research in the following subject-matter areas:

- health determinants;
- the organisation and delivery of health services;
- health status and health outcomes; and
- non-health fields that affect health and vice versa.

There will be no overlap between the PHRN and initiatives under development by the National e-Health Transition Authority for personal health records. The PHRN is not intended to support the core operations of health systems, public or private health services, or government agencies that run health systems or provide mainstream health information. However, where appropriate, the PHRN will enhance collaboration across all of these sectors.

The PHRN will comprise a number of nodes distributed throughout Australia which, collectively, will provide Australian researchers with state-of-the-art health data linkage facilities and services. The PHRN will comprise the following organisational elements:

Lead Agency

The University of Western Australia (UWA) has agreed to act as the lead agency for contracting purposes, disbursing NCRIS funds to the participating agencies through sub-contracts and being responsible to the Commonwealth for delivering the objectives of the Investment Plan.

A Program Office for Data Linkage

This national operational unit will be established in Perth to lead, champion and facilitate data linkage development. The Program Office will manage the contracts with other network members on behalf of UWA. The Telethon Institute of Child Health Research (TICHR), which is affiliated with both UWA and the Curtin University of Technology, has agreed to host the Program Office.

The Program Office will have the central role in leading and coordinating development and deployment of the new data linkage infrastructure. It will facilitate implementation of the PHRN Investment Plan, Access and Pricing Policy and other organisational policies and procedures.

The Program Office will provide executive support to the Management Council, monitor and report to the Management Council on performance against key performance indicators and liaise with national health information groups and agencies including the relevant Principal Committees of the Australian Health Ministers' Advisory Council (AHMAC), the Australian Health Ethics Committee of the National Health and Medical Research Council (NHMRC), the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS);

The Program Office will also provide services to researchers using the PHRN. In this role it will:

- foster standard practice and coordinate access by researchers to linked data;
- coordinate development and implementation of standards, procedures and guidelines to support national data linkage activities;
- facilitate access by researchers to linked, de-identified data for approved projects; and
- coordinate user training and professional education in linkage methods, current software, statistical and analytical methods, ethics and privacy considerations and operational processes.

PHRN Centre for Data Linkage

The Centre for Data Linkage will be established as a unit of the Faculty of Health Sciences at Curtin University, with certain services subcontracted to the Menzies Research Institute at the University of Tasmania. It will be based on the Linkage Unit in the Data Linkage Branch of the WA Department of Health and the NSW/ACT Centre for Health Record Linkage (CHeReL).

The PHRN Centre for Data Linkage will establish a secure data linkage facility and facilitate linkage between jurisdictional datasets, and between these datasets and research datasets, using demographic data. The Centre will not hold these datasets, but will link the demographic data that has been separated from the remainder of each dataset to create 'linkage keys'. Clinical or service information is not needed by the Data Linkage Centre and will not be provided to it.

Other major functions of the Centre for Data Linkage include:

- aggregation of jurisdictional linkages into a national system;
- assistance with the delivery of linkable data to researchers;
- development of data linkage systems and methods;
- evaluation and quality assurance of linkage systems and methods; and
- facilitation of geo-coding of address information.

The Centre will work collaboratively with other groups that have data linkage expertise including CSIRO and ANU, and with the NCRIS Platforms for Collaboration groups.

PHRN Data Delivery System

A Data Delivery System will be developed which will provide harmonised national mechanisms for secure transfer of data between the Nodes of the PHRN and from data custodians to researchers for approved projects. Its functions will encompass:

- provision of technical assistance to enable jurisdictions to establish complementary data storage systems;
- mechanisms that enable the PHRN Data Delivery System to receive information from jurisdictional systems over secure connections in order to facilitate delivery of information that has been approved for release to researchers;
- tools to assist managing the secure exchange of data between jurisdictional systems; and
- processes for data and linkage quality review and assessment prior to release to users.

The Sax Institute (NSW) will convene a collaborative process with the research community, PHRN participants and the NCRIS Platforms for Collaboration capability to examine options, determine specifications for and develop the Data Delivery System. When fully operational, the PHRN Data Delivery System will comprise a network of data exchanges including the NSW Secure Data Exchange described below.

Proof-of-Concept

A Proof-of-Concept collaboration will be undertaken to assess the ability of the PHRN to perform cross-jurisdictional linkage of data and the feasibility of preparing and providing linked de-identified data in a form that can be used for research studies. The Collaboration will focus on an issue(s) of interest to members of the PHRN with a view to delivering research benefits.

The Department of Health WA will lead a collaborative process to solicit inputs from the community of researchers and PHRN participants to examine options, determine specifications for and develop the Proof-of-Concept.

State Nodes of the PHRN

The Investment Plan allocates NCRIS funds for further development of the Centre for Health Records Linkage (CHeReL), which incorporates data linkage capacity for NSW and the ACT. Two new units will be formed within the CHeReL: the NSW Secure Data Exchange and the NSW Data Analysis Laboratory.

- The NSW Secure Data Exchange will comprise systems and support for the fast and efficient exchange of data between custodians, researchers and the CHeReL, and will assist individual data custodians who have a large and growing workload in managing datasets, assessing requests for access to data, providing meta-data for and updates to ‘master linkage keys’ that form the backbone of data linkage processes, and preparing dataset extracts for release to researchers. The NSW Secure Data Exchange will provide a model for similar facilities that could be set up in other parts of Australia when the PHRN Data Delivery System is fully established.
- The NSW Data Analysis Laboratory will provide computing and human infrastructure for the management and statistical analysis of linked health datasets. It will also develop, use, document and promulgate a set of standardised methods and associated software tools for analysis of linked data. The Laboratory’s functions will include an evaluation of currently available analysis tools.

The Investment Plan also allocates NCRIS funds to set up new data linkage units in Queensland, Victoria, Tasmania and South Australia. These units, many of which will function as joint ventures with universities, research institutes and state government health departments, will support additional linkages within and between core population health and health services data collections, extend the capability to link to State and national data sets, provide data linkage services to researchers and facilitate local adherence to PHRN policies and protocols. The South Australian unit will operate in partnership with the Northern Territory. The individual data linkage units throughout Australia will provide data linkage capacity in their home states and territories, and will also contribute expertise in specific areas to the national endeavour. This will include training of data linkage staff. One of the state-based data linkage units will serve as a Delivery Unit for Linked Health Data, providing the interface with researchers.

Governance and Community Engagement

The governance model is broadly based. At the apex is a Management Council, which will oversee the implementation of the Investment Plan and the ongoing management and strategic direction of the Network. The composition and Terms of Reference of the Management Council are provided in [Appendix 2](#). Professor Brendon Kearney AM, Director of the Institute of Medical and Veterinary Science in South Australia has agreed to Chair the PHRN.

The Management Council will convene a PHRN Access Committee, which will include the directors of each of the PHRN units/nodes, and one of the two ‘researcher’ members of the Management Council. The PHRN Access Committee will advise the Program Office for Data Linkage on the development and implementation of the PHRN Access and Pricing Policy during the term of the NCRIS program.

Given the importance of community acceptance of the work of the PHRN in establishing future engagement and support by Commonwealth and State and Territory health agencies and data custodians, it is expected that community participation will be sought and obtained in the planning, governance and operations of the PHRN. This will be achieved through the promotion and public outreach activities of the PHRN and through consultations undertaken by the Ethics, Privacy and Consumer Engagement Advisory Group to be established by the Management Council. The composition of this Group will be determined by the Management Council and must include a nominee of the Board of the Consumers’ Health Forum of Australia

An early milestone for the Ethics, Privacy and Consumer Engagement Advisory Group will be the development of the PHRN Ethics, Privacy and Consumer Engagement Policy that will address:

- ethical clearances and privacy protocols to be adhered to in all applications and projects using the PHRN;
- adherence to the principles contained in the *National Statement on Ethical Conduct in Human Research*;
- adherence to the *Australian Code for the Responsible Conduct of Research*;
- protocols to be followed for the management of health data and linked data both during and after the research project, including:
 - data curation during the lifetime of a research project;
 - data sentencing at the end of a research project;
 - establishment of a verifiable data audit trail;
- compliance with privacy legislation and regulations both within and across jurisdictions;
- standards, templates and guidelines on the development and public release of Privacy Impact Assessments at the planning stage of projects that link or use linked health data;
- consultation with relevant privacy and consumer agencies in each jurisdiction, guided by the *Model Framework for Consumer and Community Participation in Research*, including PHRN requirements for:
 - users of the facilities – provision of evidence of community participation in the development and conduct of research projects using the PHRN;
 - operators of the facilities – provision of evidence of community participation to be included in Annual Progress Reports, Annual Business Plans and performance indicators;

Consultations and support for the PHRN

The PHRN has acceptance and buy-in from all state and territory governments and key research institutions. State and territory based consortia have developed detailed plans at the local (state and territory) level which will contribute to the national capability. Co-investments of at least \$35 million have been identified from participants in all states and territories. Research institutions and government agencies in all states and territories support the proposed model and are committed to participating.

Development of the PHRN project has involved extensive consultations with researchers, data linkage experts, consumers and jurisdictional representatives around Australia. Australian Government agencies consulted include DoHA, the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, CSIRO, the National eHealth Transition Authority, the National Health and Medical Research Council and the Office of the Privacy Commissioner. The jurisdictional representatives who were consulted include members of major Australian Health Ministers' Advisory Council information committees.

The NCRIS Committee noted the importance of working with Commonwealth Health agencies as the Network is developed to ensure that it supports and is consistent with broader health initiatives. To this end, the Committee agreed that the Secretary of the Department of Health and Ageing be invited to nominate a representative to the Management Council for the PHRN

At this stage data sets controlled by Australian Government agencies are not part of the proposed Network. However the ability to link with these data sets if and when agreements are formed with the relevant agencies is regarded as important and would be part of the responsibility of the PHRN.

The PHRN, through its nodes and key participants, encompasses a broad range of expertise and a large amount of practical experience in the area of health research and health data linkage, and is well placed to contribute to and inform the development of a broader national policy agenda for data linkage.

Appendix 1: Background – NCRIS principles and planning

The NCRIS Principles

The National Collaborative Research Infrastructure Strategy (NCRIS) was implemented to bring more strategic direction to Australia's investment in research infrastructure. The key principles underpinning NCRIS are that:

- Australia's investment in research infrastructure should be planned and developed with the aim of maximising the contributions of the R&D system to economic development, national security, social wellbeing and environmental sustainability;
- Infrastructure resources should be focussed in areas where Australia is, or has the potential to be, world-class (in both discovery and application driven research) and provide international leadership;
- Major infrastructure should be developed on a collaborative, national, non-exclusive basis.
- Infrastructure funded through NCRIS should serve the research and innovation system broadly, not just the host/funded institutions. Funding and eligibility rules should encourage collaboration and co-investment. It should not be the function of NCRIS to support institutional level (or even small-scale collaborative) infrastructure;
- Access is a critical issue in the drive to optimise Australia's research infrastructure. In terms of NCRIS funding there should be as few barriers as possible to accessing major infrastructure for those undertaking meritorious research;
- Due regard be given to the whole-of-life costs of major infrastructure, with funding available for operational costs where appropriate; and
- The Strategy should seek to enable the fuller participation of Australian researchers in the international research system.

The 2006 NCRIS Strategic Roadmap

In 2006, the *NCRIS Strategic Roadmap* was released, identifying priorities for investment in research infrastructure based on these NCRIS principles (as opposed to a general statement of research priorities). The Roadmap provided a framework of capabilities, representing the NCRIS Committee's view as to where medium to large-scale research infrastructure investment should be focused over the next 10 years. It identified the capabilities that Australia should strive to develop, rather than specific infrastructure, and made recommendations on the appropriate means to support them.

The Roadmap drew on expert advice and consultation with the research and wider communities, and was intended to facilitate a coordinated approach to infrastructure investment across governments and agencies that:

- Concentrates effort nationally on areas of greatest strategic impact;
- Increases collaboration within the research system, and between it and the wider community; and
- Reduces the duplication and sub-optimal use of resources arising from lack of co-ordination

Rationale for investing in Population Health Data Linkage

The 2004 Investment Review of Health and Medical Research (Grant Review) *Sustaining the virtuous cycle for a healthy, competitive Australia: Investment Review of Health and Medical Research – Final Report* identified that investment in policy and practice focused research can deliver significant returns to the Australian health system, and improve the effectiveness of the \$66.6bn annual spend on health care. In the area of Population Health, the 2006 NCRIS Roadmap noted that:

- Investment in national capability for data linkage could make an important contribution to addressing this area, as data linkage has broad applications in public health and epidemiological research, health services research and clinical research.
- Linkage of population-based data sets facilitates research into policy-relevant issues spanning prevention, detection and management of disease, use and costs of health and community services, and the long- term health and societal outcomes that these achieve.

Particular opportunities for Australia in Health Data Linkage

The 2006 NCRIS Roadmap recognised that Australia is well placed to be a world leader in health research using data linkage because of its rich collection of large population databases, its favourable policy and legislative environment, and its existing foci of research excellence, including the Western Australian Data Linkage System and the Centre for Health Record Linkage (CHeReL), as well as other national and state agency research projects such as the Bio21:MMIM (now BioGrid Australia) federated data grid linking clinical and genomic data, and the CSIRO service-oriented software for linking data electronically in a secure environment.

The Roadmap identified unique opportunities for Australia to build a national capability including:

- The large number of high-quality health data sets, describing most aspects of the Australian health system in substantial detail;
- Australia's privacy laws and the privacy principles on which they are based provide a firm foundation for data linkage initiatives, and protection of individuals' privacy;
- The Australian population is relatively large, and very diverse, compared with the populations covered by other well-developed data linkage systems;
- Practices and policies for data linkage are already tested and in place in several Australia jurisdictions;
- National health data sets are endorsed by all nine Australian Governments through the Australian Health Ministers' Advisory Council's (AHMAC) National Health Information Group;
- Consistent metadata specifying these national collections is available in the National Health Data Dictionary and the Australian Institute of Health and Welfare's (AIHW) electronic repository METeOR;
- The Australian Bureau of Statistics (ABS) will allow limited linkage to census data, and thus a wide range of new social and economic variables, from the 2006 Population Census onwards.

The Roadmap acknowledged the existence of broad support from stakeholders for the development of a national data linkage capability and agreement that the principles underpinning such a capability should include:

- Linked data are to be used for research and statistical purposes only, not for the clinical care of individuals, or regulatory or enforcement purposes;
- The identity of individuals should never be disclosed;
- There should be arrangements for consumer knowledge of, and involvement in, data linkage arrangements.

Required infrastructure and support for health data linkage

The 2006 Roadmap concluded that building a national capability for research using data linkage will require investment in structures and frameworks for governance, privacy, ethics and community involvement; information technology and information management; data sets and metadata; methods and tools for data linkage and analysis of linked datasets; and human capacity.

The 2008 Strategic Roadmap for Australian Research Infrastructure

It was the Government's intention that the NCRIS Roadmap should be an evolving planning tool that is updated periodically to reflect changing priorities and the emergence of new opportunities. Accordingly, in 2008 following a structured process of consultation with stakeholders, the Australian Government released the *Strategic Roadmap for Australian Research Infrastructure*, building on the 2006 NCRIS Roadmap and presenting a renewed view of where strategic infrastructure investments should be made over the next five to ten years.

The 2008 Roadmap reaffirms that the 12 capabilities progressed from the 2006 Roadmap continue to represent priority areas for investment, and places increased emphasis on eResearch, in recognition of the pervasive and underpinning relevance of Information and Communications Technologies to research. Subject to the availability of further funding, the implementation of the 2008 Roadmap will involve consultation with the research community and other stakeholders to agree the detailed needs for each capability area.

Opportunities to develop a Population and Biological Health Data Network

The 2008 Roadmap reaffirms the importance of health data linkage by recommending investment in a Population and Biological Health Data Network. The capacity for researchers to access an integrated, national resource of population health and biological data will contribute to identifying the causes of disease in individuals and populations, and to developing new diagnostic, preventive and therapeutic interventions.

Similarly, the Roadmap notes that successful clinical development of new therapeutic agents and drugs require improved capacity to perform and interpret clinical trials and participate in large-scale studies of drug efficacy, safety and other properties. Successful translation of Australian drug discoveries into effective medicines and clinical application requires knowledge and skills in translational sciences, network infrastructure, access to defined clinical populations and access to unique clinical and non-clinical biological samples.

These capacities will require access to biological specimens and the biochemical, genetic and other information obtained from these specimens, detailed information about health and lifestyle factors derived from cohort studies and clinical research, and information from key administrative health datasets including those relating to Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) services, hospital inpatient episodes, diseases and deaths.

Required infrastructure and support for population and biological health data linkage

The 2008 Roadmap notes that linkage of key administrative health datasets, data on hospital inpatient episodes, diseases and deaths, and exchanging and delivering these data to researchers in a secure manner (as planned in the Population Health Research Network) are important first steps in harnessing Australia's major population-based collections of health data for research and creating the most comprehensive national health data linkage system in the world.

The Roadmap recommends that, to maximise the value of the national data linkage system and significantly increase its potential for "discovery" research, research infrastructure investments should build on this 'first step' linkage capability in the longer term. It proposes expanding the national resource of health data beyond those collected routinely in administrative systems and in a relatively small number of statutory registers (cancer, deaths), to incorporate two additional types of data:

- Detailed data about socio-demographic factors, lifestyle and health from cohort studies and clinical research. Large volumes of data from these studies already exist, distributed across institutions; and
- Biological specimens and the information derived from them. This would entail the development of large scale biobanks to house collections of samples such as cells, tissues, blood or DNA, that are associated with personal and health information of their donors and can play an important role in determining the role of genetic factors in the causation of diseases.

The following infrastructure and support would be required:

- Dedicated ICT infrastructure to support the access, analysis, management and storage of large, complex datasets;
- Infrastructure to support the ongoing maintenance of key cohort and clinical studies of national significance (participant tracking and follow-up, ongoing data collection, data management);
- A coordinated network of physical facilities for secure storage, retrieval, management and use of biological samples of various types (blood, cells, tissues, organs). This might take the form of networked facilities specialising in specific types of sample, and/or several more general facilities at strategic locations around the country.
- Research workforce capacity building and training initiatives;
- Linkages with other health capabilities; and
- eResearch infrastructure that provides the critical links to other enabling technologies, which in turn feed into datasets across all biological systems, population health databases, imaging and other phenotypic screens databases.

The Roadmap recognises that these advances would present challenges, including the cost and complexity of setting up facilities for storage and retrieval of biological specimens, creating cohesion from existing diverse arrangements, and reshaping behaviours around data sharing.

The 2008 Roadmap also acknowledges the necessity to address community concerns about privacy and ethics, and integrating and coordinating with eHealth strategies under development by Commonwealth, state and territory health departments across Australia.

Enabling factors

The 2008 Roadmap reiterates that the critical enablers for the Population Health Research Network are also crucial to the proposed Population and Biological Health Data Network, namely:

- Robust ethical frameworks and mechanisms for community engagement;
- Robust mechanisms for protection of privacy and confidentiality;
- Appropriate arrangements regarding intellectual property and its commercialisation;
- Cooperative and constructive participation of data custodians, including government departments, universities and research institutes;
- Secure and reliable ICT infrastructure; and
- Availability of research and technical staff with the relevant range of skills.

In addition, the expansion of the capability to incorporate biobanks, exchange of biological samples and linking of biological data will require different and additional infrastructure support including:

- A framework and sound business model for biobanking infrastructure that also addresses how it will be accessed and costed; and
- Research and technical staff with skills in biostatistics, genetic epidemiology and bioinformatics.

Appendix 2:

PHRN Management Council Composition and Terms of Reference

The Management Council will oversee the implementation of the NCRIS Investment Plan, as its primary responsibility. It will achieve this by:

- Providing advice to the Director of the PHRN Program Office for Data Linkage, who will formulate and give effect to a strategic plan and three-year and annual business plans for the implementation of the Investment Plan, in consultation with members of the data linkage network throughout Australia;
- Providing advice on the strategic directions and management of capacity-building for national data linkage;
- Facilitating the development and maintenance of relationships with government and other agencies holding datasets that would add value to or be enhanced by data linkage;
- Facilitating the development and maintenance of relationships with government and other agencies and consumer organisations with regard to information privacy, confidentiality and ethics;
- Promoting and supporting data linkage collaborations throughout Australia and internationally;
- Monitoring progress in the implementation of the Investment Plan through the review of reports compiled by the Program Office, and providing advice on any necessary variations to the Investment Plan or modifications to the implementation process;
- Reviewing the performance of the PHRN against the agreed performance indicators;
- Monitoring and reporting on research outcomes from the PHRN;
- Overseeing and reporting the outcomes of an independent review of the implementation of the PHRN and the extent to which it has met the Objectives of the Project; and
- Formulating a plan for the continued development and maintenance of data linkage systems and activities beyond the life of the current Investment Plan.

The Management Council will have an Independent Chair, appointed by the NCRIS Committee. The Chair will be an eminent figure with a knowledge of the Australian health system and related health information systems and a knowledge of the laws relating to health information privacy at Commonwealth and State/Territory levels.

Membership of the Management Council will comprise the following individuals in addition to the Chair:

- One nominee of the Director General, Department of Health WA, being a person with expertise in linkage of health databases
- One nominee of the Board of the CHeReL, being a person with expertise in linkage of health databases
- One nominee of the Management Committee of QCHDS, being a person with expertise in linkage of health databases
- One nominee of the Victorian Department of Human Services, being a person with expertise in linkage of health databases

- One nominee of Steering Committee of the South Australia/Northern Territory Data Linkage System, being a person with expertise in linkage of health databases
- One nominee of The University of Western Australia
- One nominee of the Secretary of the Department of Health and Ageing; and
- Two researchers with a knowledge of health data linkage systems and methods and the analysis of linked datasets, selected by the Chair in consultation with other members of the Management Council

The Council may be expanded to include individuals nominated by other agencies who are custodians of population health data as appropriate. Inclusion of any such agencies will be by agreement of the Management Council.

With the concurrence of the members, the Chair may appoint a Deputy Chair from among the members.

A quorum will be five people including the Chair or Deputy Chair and four other members. When chairing, the Deputy Chair will be ex officio from his or her usual role.

The Chair and members will be appointed for terms ending on 30 June 2011. With the exception of the Chair and the two researchers, the appointments of Management Council members will be reviewed and may be terminated if the professional responsibilities that formed the basis of their appointments change.

The Program Office for Data Linkage will serve as secretariat for the Management Council and its Director will serve as the Secretary.

The Management Council may establish Committees, Working Groups and Advisory Groups. Given the importance of consumer and community engagement, it is expected that the Management Council will establish an Ethics, Privacy and Consumer Engagement Advisory Group. This will include a nominee of the Board of the Consumers' Health Forum of Australia.

The Management Council will establish a process to ensure that advice is sought from the National Health and Medical Research Council Aboriginal and Torres Strait Islander Health and Research Advisory Committee on issues relating to Indigenous health.

The Management Council will establish a consultation process with the Platforms for Collaboration capability, in particular the Australian Research Collaboration Service.

The Management Council will also develop and maintain formal consultation processes with the Australian Health Ministers' Advisory Council (AHMAC) and its committees and other bodies and agencies as appropriate. It will investigate and where appropriate develop processes to support the participation of the private health sector in the PHRN.