Australian Government Statistical Forum - Agenda

9.30am-12.30pm
Wednesday 23 April 2008
Archer Board Room
ABS House, 45 Benjamin Way,
BELCONNEN ACT 2617

1 *Welcome*

a. Minutes from October 2007 Meeting
b. Statistician's update

2 *Statistical Issues arising from Government Initiatives* - briefings for information and comment -

a. Machinery of Government changes

b. National Collaborative Research Infrastructure Strategy (NCRIS) Population Health Research Network

c. Update on NatStats 08 Conference

d. Victorian Child and Adolescent Monitoring System (VCAMS)

e. Spatial Data Initiatives

3 *Around the table : Statistical matters of significance* - briefings for information and comments

MORNING TEA from 10.50 am

4 *Longitudinal Surveys Building Longitudinal Databases* for information and discussion

a. Creating a Census Longitudinal Dataset

b. The Business Longitudinal Database

5 *ABS issues of interest* - briefings for information and comments

6 *Other business*

7 *Arrangements for next meeting*

8 Close and Lunch

Actions Arising

AGSF Meeting	Review of actions	Assigned	Status
	From last meeting		
29/10/07	Include longitudinal surveys on next agenda	ABS - NSSLB	completed

AUSTRALIAN GOVERNMENT STATISTICAL FORUM

29 October 2007

Record of Discussion and Actions arising

Chair: Brian Pink (Australian Bureau of Statistics)

Present: Brian Pink, Ian Ewing, Susan Linacre, Peter Harper, Geoff Lee, Steve Matheson (Australian Bureau of Statistics), Lisa Elliston (Australian Bureau of Agricultural and Resource Economics), Julie Roediger (Australian Institute of Health and Welfare), Neil Mullenger, Naomi Hately (Department of Immigration, and Citizenship), Greg Evans (Centrelink), Andrew Whitecross (Family and Community Services), Peter Thomson (Medicare Australia), David Martin (Department of Health and Ageing), Lucio Krbavac (Department of Education, Science and Technology), Andy Turner, Gary Dolman (Department of Transport and Regional Services), Mark Neal (Australian Taxation Office), Richard Snabel (Department of Industry, Tourism and Resources), Dr Tom Karmel (National Centre for Vocational Education and Research), Lucio Krbavac (Department of Education, Science and Training), Ben Searle (Office of Spational Data Management), Barry Sandison (Department of Employment and Workplace Relations), Malcolm Thompson (Department of Environment and Water Resources)

Apologies: None

Presenters: Brian Pink, Peter Harper, Ian Ewing, Susan Linacre, Steve Matheson, Ben Symes (Australian Bureau of Statistics), Ben Searle (Office of Spatial Data Management)

Observers: Mark Lound (Australian Bureau of Statistics)

Secretariat: Lorraine Cornehls, Kettie Hewett, Sue Spearritt (Australian Bureau of Statistics)

Meeting Summary

The Australian Statistician, Brian Pink, introduced proceedings.He noted key activities within the ABS, including his discussions with senior representatives of federal government agencies, the continuing development of the National Statistical Service (NSS), the recent Census release and the release of new population estimates (Para 1-5).

In regard to statistical issues arising from government initiatives, Mr Matheson (ABS) provided an information update on Data for Science and the National Collaborative Research Infrastructure Strategy (NCRIS), while Mr Symes (ABS) gave a deonstration on the recently released Children and Youth Statistical Portal (Para 6-10).

Members reported on a range of statistical work being undertaken in their agencies (Para 11-12).

Brian Pink presented a paper on "The Impact of new Information Technology on Statistics". He noted that technology is driving an increasing demand for information and he highlighted one of the ABS responses - the National Data Network initiative, which uses collaborative approaches to promote access to and sharing of data to produce quality statistics (Para 13-17).

Mr Searle (OSDM) presented a paper on "Capturing Spatial and Statistical Data Across Government". He advised that OSDM are using GeoNetworkto manage spatial information resources and the Forum noted that metadata is fundamentally important to bringing data together from disparate sources (Para 18- 21).

Mr Matheson (ABS) reported to the meeting that the ABS is planning the hosting of a statistical conference in Melbourne in November 2008. The broad theme for the conference will be "NatStat 08: Working together for a better informed and performed society" and the themes will be linked to the OECD Global Project on Measuring the Progress of Societies (Para 22-24)

An update was given on ABS issues by the three Deputy Statisticians (Para 25-27). .

Actions Arising

AGSF Meeting	Review of actions	Assigned	Status
29/10/07	**Include longitudinal surveys on agenda for next AGSF meeting**	NSSLB	Completed

Record of Discussion

Agenda Item 1. ***Welcome*** Brian Pink. ABS

1. Mr Pink welcomed members to the AGSF, and introduced the new Deputy Statistician, Ian Ewing. The minutes from the April 2007 AGSF meeting were accepted and it was noted that all the action items from the last meeting had been completed.

2. In the Statistician's update, Mr Pink informed the group that the ABS had undergone an organisational restructure in July 2007. Responses to recommendations from the ABS Strategic Review by the Allen Consulting Group and the increasing relevance and importance of developing the National Statistical Service (NSS) have contributed to the decision to have three Deputy Statisticians focussed on the Bureau's priority areas and core business.

3. In progressing the NSS, Mr Pink noted the increasing amount of contact between senior ABS staff and senior personnel from across Australian Government agencies. He added that he had recently undertaken a series of high level meetings with government agencies and received strong support for the Household Surveys Program Review and projects such as the National Data Network (NDN). The lack of coordination of statistical activity across the government sector was raised by a number of agency heads in these discussions.

4. Mr Pink informed the meeting that the work that the previous Australian Statistician undertook in developing and improving statistical education and literacy amongst secondary school, tertiary level students and the general community would continue.

5. Mr Pink noted that the second release of Census data had occurred recently and a major work challenge the Bureau is responding to is population measures. The new population estimates for states and territories that were released recently have generated significant interest. Mr Pink commented that the Bureau was looking at methods to improve the 2011 Census following on from the 2006 Census Post Enumeration Survey (PES) - the first time that a Census PES had enumerated indigenous communities.

Agenda Item 2. ***Statistical Issues Arising From Government Initiatives*** **- briefings for information and comment**

a. Update on Data for Science - Steve Matheson (ABS)

6. Mr Matheson advised the Forum that the next meeting of the Prime Ministers Science Engineering and Innovation Council (PMSEIC) is due to be held on 8 December 2007. The last meeting on 22 June 2007 focused on two new reports on "Climate Change in Australia" and "Water for our Cities" as well as an update on the Data for Science initiative. At the meeting AGIMO signalled that it is moving ahead on a National Information Sharing Initiative (NISS).

b. National Collaborative Research Infrastructure Strategy (NCRIS) - Steve Matheson (ABS)

7. Mr Matheson provided members background information about NCRIS. The "Platforms for Collaboration", which underpins all the other NCRIS capabilities, will provide operational e-Research platforms for Australian researchers. The three main elements of the capability are the Australian National Data Service (ANDS), the National Computational Infrastructure (NCI) and the Interoperation and Collaboration Infrastructure (ICI). These will be underpinned by the Australian Access Federation and AREN.

8. Mr Matheson advised that ANDS is particularly relevant to this group as it's objective is to better manage research data collections and make the use of data more effective within a federated research data management system. He commented that NCRIS was initially dominated by the physical sciences before the ABS became involved. The final draft of the ANDS paper defined NCRIS as a platform for collaboration for all statistical activity including the business and academic sectors.

c. Children and Youth Statistical Portal - Ben Symes (ABS)

9. Mr Symes (ABS) demonstrated the Children and Youth Statistical Portal (CYSP), a pilot project for the National Data Network (NDN) which was released on 8 October 2007. The objective of the Portal is to improve both the visibility and accessibility to information resources (i.e. data, tools and services) relating to the theme of children and youth. Information resources contained in the initial release are limited to those that are publicly available. However, the underlying NDN infrastructure will be used in the future to demonstrate controlled access arrangements.

10. The initial release has over 300 information resources available and a discussion forum. The ABS is working with a range of agencies across jurisdictions to increase the number of resources available via the portal. Mr Matheson welcomed feedback from users about the project.

Agenda Item 3. ***Around the Table: Statistical Matters of Significance -***

11. Members reported on a range of statistical work being undertaken in their respective agencies. The highlights from agencies reports were:

a. DOHA reported:

- a comprehensive dataset of individual and community health records will result from the Northern Territory intervention by the Australian government;
- results from the second wave of the Longitudinal Study of Australian Children has been released;
- data from the HILDA 2006 wave will be available at the end of February 2008.

b. DITR reported that work is being undertaken to link innovation to productivity from the new ABS Innovation Survey which will improve the current measure of productivity.

c. DEWR reported that a core set of indicators for environmental statistics is being developed with consultation across government agencies.

e. DOTARS reported that the first edition of the Transport Statististics Yearbook will be released after the Federal election on 24 November.

f. DEST reported:

- they are working with the ABS to improve early childhood data through the development of a set of indicators for education and training, based on OECD standards;
- To improve Higher education data, work is being undertaken to broaden the range of data being collected and analysed To assist this, the Longitudinal Study of Australian Youth has surveyed three cohorts in the field (1998, 2003 and 2006). Each cohort is being followed yearly, with the main focus on better understanding the school to work transition.

g. OSDM advised that the report from a survey of spatial enablement of Australian government agencies has recently been released.

h. DIMA reported:

- the release of 2006 Census data relating to Migration has provided a rich dataset for the department;
- the second wave of the third Longitudinal Survey of Skilled Migrants has concentrated on skilled and family migrant statistics;
- the new ABS method of estimating Net Overseas Migration (NOM) estimated that there were approximately 160,000 migrants to Australia in 2006-07, which is the highest ever estimate on record. DIMA commented that with Australia's ageing population net overseas migration will become more important for the economy.

i. AIHW advised:

- work is being undertaken to assess the impact of diseases on labour market productivity;
- the Department is working through the issues around data linkage of health records for improving key health indicators. Whilst there has been a focus on 'person' based data linkage, another area of interest is 'geographical area' based data linkage.

12. In conclusion, Mr Pink noted that a number of agencies were undertaking longitudinal surveys and asked whether a forum exists for those agencies to share information and experiences about methodological issues for these types of surveys.

Agenda Item 4. ***The Impact of new Information Technology on Statistics*** **-** Brian Pink (ABS)

13. Mr Pink introduced this agenda item noting that new information technologies were changing the behaviour of people and organisations. The statistical community is evaluating what the impact of these new technologies will have for statistical purposes.

14. Mr Pink noted the adoption of technology is being driven by the need for

'anywhere, anytime, in a way that suits me' access to information. The ability to use the internet to easily search, discover and collaborate is driving innovation, resulting in the availability of many new tools and changes in the production model for the collection, analysis and dissemination of statistics.

15. One of the initiatives the ABS is using to meet the increased demand for information is the development of the National Data Network (NDN). The ABS has lead the NDN initiative which uses collaborative approaches to promote access to and sharing of data to produce quality statistics. As part of this initiative, the ABS is working collaboratively with the US Census Bureau to develop their new data mining and mapping tool "Data Ferrett". For the future the NDN offers many opportunities for collaboration and monitored sharing of data and frameworks, as well as challenges including ensuring data confidentiality, intellectual property issues and resourcing for the NDN.

16. An example that highlighted the potential for collaboration is the Victorian Child and Adolescent Monitoring System (VCAMS), where the Victorian Government is working with the ABS in using the NDN infrastructure to bring information from several different sources together. This arrangement is assisting delivering a solution for the Victorian Government, and demonstrating the potential use of the NDN for the ABS.

17. Mr Pink closed the discussion by observing that the success of this work would be realised when the ABS is invited to advise government agencies and non government organisations about providing support and information in the development phase of statistical collections or infrastructure.

Agenda Item 5. ***Capturing Spatial and Statistical Metadata Across Government -*** Ben Searle (OSDM)

18. Mr Ben Searle from the Office for Spatial Data Management (OSDM) , Geoscience Australia gave a presentation on 'Capturing Spatial and Statistical Metadata Across Government'. Mr Searle commented that metadata is simply a label about data and should provide a range of descriptors that assist the user to decide whether the data may be useful for the user's purposes. It should also provides details to prevent misuse of the data.

19. Mr Searle advised that OSDM are using Geo Network, which is a catalogue application to manage spatially referenced resources. It provides metadata editing and search functions as well as an embedded interactive web map viewer. It has been developed to connect spatial information communities and their data using Open Standards for services and protocols. The OSDM is also working with AGIMO on the National Information Sharing Startegy (NISS), which is addressing cross jurisdictional issues with the exchange of data and focussing on spatial data as a pilot.

20. Mr Searle informed the group that OSDM is using the National Address Management Framework to provide a standardised framework for the collection and storage of address information. It can extract an address, the Meshblock, and extract government records for better monitoring by agencies.

21. There was some discussion amongst participants who noted that spatial data can be used for examining a department's footprint in a region. Mr Pink observed that the key message is that if we want to bring data together from disparate sources, metadata is fundamentally important. If one agency can successfully demonstrate this data merging it will lead the way.

Agenda Item 6. ***Statistical Conference November 2008 -*** Steve Matheson

22. Steve Matheson reported to the meeting that the ABS is planning the hosting of a Conference in November 2008 in Melbourne. It's aim is to connect users and producers of statistics and provide an opportunity to discuss strategies for measuring progress in Australian society and improving statistics for the nation. The broad theme for the conference will be "NatStat 08: Working together for a better informed and performed society".

23. It is intended that NatStats 08 be linked to the OECD Global Project on Measuring the Progress of Societies . NatStats 08 could provide the opportunity for developing better measures of how societies are progressing and to ensure that statistics play a stronger role in all types of decision-making. The ABS has developed a draft set of sub themes for the conference which are outlined in the paper.

24. There was some discussion about the conference bringing together key players and the media who are an important part of relaying information from an NSS perspective. Mr Pink concluded by noting that although ABS will host the conference, other producers and users of statistics will be encouraged to participate and take leading roles.

Agenda Item 7. ***ABS Issues of Interest***

a. SSG Issues - Susan Linacre (ABS)

25. Ms Linacre outlined some key of the projects in the Social Statistics Group (SSG).

- Processing of 2006 Census has been completed. The second release of Census data was at the end of June 2007 with the next major release on 30 January 2008.
- There is preliminary work being undertaken with AIHW on the key issues in linking health data.
- A workshop was held in September 2007 to investigate the harmonising of state and federal health surveys.
- The ABS will be working with agencies from across a number of jurisdictions to develop a more comprehesive set of crime statistics broken down by state/ territory.
- An Information Paper on "Early Childhood Learning", which came from work out of the Data Gaps Workshop held in 2006, will be released later this year.
- The ABS is releasing migrant data matrices which will provide a link to a range of ABS data by country of birth.

b. PLIES Group Issues - Peter Harper (ABS)

26. Mr Harper outlined some key projects in the Population, Labour, Industry and Environment Statistics (PLIES) Group.

- In regard to results from the 2006 Census, C Data online and SEIFA 2006 are due for release in early 2008.
- The closing date for submissions for the 2011 Census is 31 March 2008. The nature of the content and procedures for the 2011 Census will be canvassed via a range of seminars ABS is conducting across Australia later this year
- Geography - A review of Australian Geographic Standards has commenced with the release of an information paper in August 2007. A number of submissions have been received and the results of the review will be published. In regard to Meshblocks, the first version of Meshblocks Digital Boundaries is expected to be released in December 2007.
- The ABS is working with the Bureau of Meteorology on the production of a National Water Account, which will examine the socioeconomic implications of water use.
- The ABS, the Australian Greenhouse Office and DITR are working on a national framework for producing gas emissions estimates.
- Data from the 2005-06 Agricultural Census has been released and estimates are available at the substate and Meshblock level.

c. MIG Issues - Ian Ewing (ABS)

27. Mr Ewing outlined key projects in the Macroeconomics Integration Group (MIG).
- Standard Business Reporting (SBR) project, an initiative that seeks to reduce the reporting burden by the business community in their dealings with government, has been accepted by Cabinet. The key departments in this project are the ABS, ATO, APRA and ASIC. The ABS's role is to develop a Data Definition Repository.
- The ABS has been working on the development of a business longitudinal database. The purpose of the database will be to provide information for the analysis of business microdata to understand the key drivers of productivity.
- An information paper was released in September 2007 on revised international standards for National Accounts and the impact this will have on Australia's national accounts, balance of payments and related statistics.
- The labour force survey has been published using the ANZSIC 2006 coding. ANZSIC 2006 aligns with the upcoming revision of the International Standard Industrial Classification of All Economic Activities (SIC, Revision 4).

Agenda Item 8. Other Business

28. There was no other business.

Agenda Item 9. Arrangements for next meeting

29. The next meeting date will be confirmed out of session. Mr Pink noted that delegates had requested that the meeting be held at a time which avoided budget preparation and Senate Estimates time commitments.

Agenda Item 10. Close and Lunch

30. Mr Pink thanked members for their attendance and contributions and closed the meeting at 12.45pm.

Agenda Item 2(b)
NATIONAL COLLABORATIVE RESEARCH INFRASTRUCTURE STRATEGY
POPULATION HEALTH RESEARCH NETWORK

Overview

1. The NCRIS Committee has endorsed the investment of $20 million of NCRIS funding for the establishment of the Population Health Research Network. This funding will be used to implement a nation-wide health data linkage structure modelled on the existing state-based units in Western Australia and New South Wales and assist the establishment of similar capacity in the other states along with national coordination mechanisms.

2. 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.

3. The PHRN has acceptance and buy-in from all state and territory governments and key research institutions, with the University of Western Australia agreeing to be the lead agency for contracting purposes and the Telethon Institute of Child Health Research agreeing to host the national coordinating unit. State and territory based consortia have developed detailed plans at the local (state and territory) level which will contribute to the national capability.

4. The PHRN will provide researchers with access to Australia-wide health data and a resource that is world-leading in scope and quality.

5. 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.

Background

6. Australia s extensive range of population-based health and health-service datasets have been described as the envy of the world . Data linkage provides the means to multiply the utility of these datasets in population health and clinical research and related areas of policy development. By means of data linkage, expense and intrusion of additional data collection can be avoided and the evidence base for decision making greatly enhanced.

7. Australia has a strong track record in data linkage, and has created data linkage systems that are very secure. These systems are explicitly designed to preserve the privacy of individuals by completely separating individuals personal health and service data from identifying data.

8. The development of a data linkage capacity will in no way dilute existing protections on data collections, and will not affect existing or planned controls on access to datasets.

9. 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 the Department of Health and Ageing, the AIHW, the CSIRO, the ABS, NeHTA, the NHMRC and the Office of the Privacy Commissioner. The jurisdictional representatives who were consulted include members of major AHMAC information committees.

10. The PHRN is based on existing and proposed data linkage units in the states and territories, embracing universities, other research institutions and government agencies. States and territories have indicated an intention to boost local initiatives by co-investing

with NCRIS. The Network structure provides opportunities for engagement with Australian Government health and related agencies.

NCRIS and the health data linkage capability

11. NCRIS has earmarked $20 million to 30 June 2011 for the implementation of a collaborative Investment Plan to develop a national PHRN.

12. The broad objective of this Network is to provide a collaborative Australia-wide infrastructure that facilitates population health data linkage. This will enable researchers in universities, research institutes, government agencies and other organisations to new and existing research datasets, *ad hoc* survey datasets and routine administrative datasets. The ultimate purpose is to improve health and wellbeing and enhance the effectiveness and efficiency of health services.

13. A crucial aspect of the capability is to address existing barriers that impede health data linkage. The main difficulties stem from systemic factors that inhibit the use of available health data for applied research. These systemic factors are universally recognised by (a) agencies that hold data, (b) agencies that pursue information for effective health policy and health services delivery, and (c) researchers keen to provide such information through research using data linkage. Yet to date there has been no concerted effort and no allocation of resources to address the systemic deficiencies through infrastructure provision. The PHRN therefore represents a great opportunity. It has been greeted with enormous enthusiasm by researchers, individuals in positions of health policy and health services leadership, service providers and consumers.

14. 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 support for the development of Australia s data linkage capability. The states and territories endorse the strengthening of both a national capability covering national datasets and compatibility of policies, processes and metadata and jurisdictionally-based capability. State governments have indicated a readiness to co-invest in shared capability, and the states and territories are keen to collaborate with each other. Major institutions, including universities in all states, wish to collaborate and may also co-invest.

15. At this stage data sets controlled by DoHA, Medicare Australia and other Australian Government agencies are not part of the proposed PHRN. However the ability to link with these data sets if and when agreements are formed with the relevant agencies is important and will be part of the responsibility of this capability.

16. In order to avoid cutting across other national initiatives relating to health information, such as those led by NeHTA, the AIHW and the AHMAC National e-Health Information Principal Committee, the PHRN will be based on existing and proposed data linkage units in the states and territories. There will also be formal processes for consultation with and regular provision of information to relevant bodies to ensure that the implementation of the Population Health Research Network is consistent with and supports activities being undertaken in the broader national context.

17. The Secretary of DoHA will be invited to nominate a member of the Management Council of the PHRN.

Implementing the Population Health Research Network

18. The process for implementing the PHRN is as follows:

i. The Department of Innovation, Industry, Science and Research (DIISR) will contract with the University of Western Australia (UWA) as lead agency. UWA will receive and disburse NCRIS funding, take responsibility for the implementation of the Network in accordance with the business plan approved by the NCRIS Committee, and report to DIISR.

ii. UWA will subcontract with other bodies based in the states and territories to fulfil various agreed functions. These bodies comprise universities or groups of universities, other research institutions and state and territory government agencies.

iii. A Management Council will be established to oversee the implementation of the Investment Plan, promote and support data linkage collaborations, and provide advice on the strategic directions and management of capacity-building for national data linkage.

iv. In anticipation of NCRIS funding, states and territories have already formed consortia of universities and government departments, and a strong spirit of inter-jurisdictional collaboration has formed. State and territory governments have indicated an intention to co-invest with NCRIS, thus providing additional resources for their local initiatives.

v. A Network Program Office and a Network Data Linkage Centre undertaking nation-wide coordination and data linkage functions respectively will be located in Western Australia, based on the existing capability there.

vi. States that do not already have a data linkage unit, such as Queensland, South Australia and Victoria, will establish one. South Australia and the Northern Territory are committed to a joint development which will include an intersectoral data linkage capacity and a particular emphasis on Indigenous data.

19. The NCRIS funds, supported by state and territory co-investment, will be used for:

i. infrastructure for new data linkage units;

ii. facilitating collaboration;

iii. development of infrastructure to expand the capacity of existing units, including capacity for the future linkage of national datasets;

iv. workforce development, including vocational training and professional education in linkage methods and the analysis of linked data; and

v. a proof of concept collaboration to test data linkage processes across several jurisdictions.

The Research Infrastructure

20. The infrastructure for this capability comprises a set of processes, methodologies, technologies and expertise. The proposal is for a national capability based on the structures and methodologies employed by the existing state-based units in Western Australia (Data Linkage WA (DLWA)) and New South Wales (Centre for Health Record

Linkage (CHeReL)). Funding will also be directed to a major proof-of-concept collaboration of the data linkage infrastructure established through the NCRIS investment. This will assess the ability of the new systems and methods to perform cross-jurisdictional linkage of data and provide linked de-identified data in a form that can be used for research studies.

21. The location and scope of the research infrastructure have been agreed in principle by the capability participants in all of the states and territories. The Network Program Office for Data Linkage in Perth, to be hosted by the Telethon Institute of Child Health Research, builds on existing infrastructure and expertise. The Network Centre for Data Linkage to be established under the auspices of Curtin University in Perth and in conjunction with the Menzies Research Institute in Hobart similarly recognises the location of existing capability. The CHeReL in NSW will lead a process, in collaboration with other participants, to recommend a model for the proposed Data Delivery System.

22. New health data linkage units will be established in Victoria, Queensland, South Australia and Tasmania with the participation of state health departments, universities and research institutions, including the CSIRO. The Northern Territory will collaborate with the proposed South Australian unit and the ACT will continue its existing collaboration with the NSW CHeReL. The physical location of the facilities is not a major factor in this capability as access to the infrastructure will generally be electronic.

23. There is strong consensus across the health and research communities that nation-wide health data linkage infrastructure will benefit Australian researchers and also policy makers. The proof of concept collaboration will demonstrate how the infrastructure works on a multi-jurisdictional basis.

24. The proposed model builds on the successful WA and NSW models which have a record of high quality research outcomes and publications. The PHRN has the support of all of the state and territory governments and leading research institutions in all jurisdictions. The involvement of all of the state and territory health administrations will facilitate access for researchers to comprehensive, high quality, population-wide data sets covering many aspects of health and health care.

25. The PHRN will position Australia at the leading edge of health data linkage. While Australian researchers currently engage in some international data linkage activity, the nature of the data to be accessed through the proposed infrastructure will be primarily relevant to Australia. There are existing international collaborations between researchers in Australia and in Canada these will be strengthened by increased linkages and improved access to the distributed Australian health data sets.

26. The likely demand for use of the Network is estimated to be around 250-300 linkage projects during the three-year funding period. This figure is extrapolated from current demand for the services of Data Linkage WA and the NSW CHeReL. The NHMRC currently funds many of the research projects which use data linkage. It is noted that the level of complexity of requests is expected to increase as multiple data sources become part of the Network. In view of the level of interest from the health and research sectors observed during the facilitation of this capability, this would appear to be a reasonable estimate of demand.

27. The PHRN is based on the principles for this capability set out in the NCRIS Roadmap. These are that linked data be used solely for research and statistical purposes, that the identity of individuals whose health data are being linked should never be discoverable by users of the facility, and that there should be scope for consumer knowledge of and

involvement in data linkage arrangements.

Privacy Preserving Protocols

28. The essential features of the current protocol used for cross-jurisdictional data linkage between WA and the Commonwealth are:

i. Named data are only provided to a small, isolated linkage group which generates the links in the form of pointers to unit records in the various data sets.

ii. Linkage unit staff are barred from any access to the actual clinical or service data held in the data sets.

iii. De-identified linked data sets are provided only to the analysts involved in the project, all of whom sign strict confidentiality agreements. The analysts are the only people with access to linked information across the various contributing data sets.

iv. Analysts are not given access to the names and other identifying data.

v. Custodians do not have access to any of the data supplied by other custodians to either the linkage unit or to analysts.

vi. Custodians sign off each project on an individual basis, so have the power to veto a project as far as their particular data are concerned.

29. The fact that the data have been linked does not imply that they can automatically be used in projects. This separation of linkage and analysis has proven to be invaluable in gaining the confidence of many data custodians, as well as privacy and consumer advocates.

30. The ideal situation is for the named data to be located, together with the technical staff linking the information, quite separately from those people involved in the extraction and supply of de-identified, linked data files to researchers. It is not sufficient to just tell the world that the named data are being held in as secure a manner as possible; this must be seen to be the case.

31. The NCRIS Roadmap envisaged a national health data linkage system supported by a range of actions from the health sector, including high level support from Australian Health Ministers, cooperation of data custodians nationally, and simplification of ethics approvals processes. It is not feasible or appropriate for NCRIS to address all of these matters. The PHRN is a catalytic initiative, stimulating the establishment, coordination and interoperability of health data linkage services to researchers across the jurisdictions, with a view to a fully national health data linkage capability in the longer term.

32. It is vital, therefore, that the PHRN is implemented and operated so that it is consistent with and supports national health data linkage policies and initiatives developed by the peak bodies responsible for this area. To this end, formal processes will be established for the PHRN to engage with AHMAC and its committees, DoHA, Medicare Australia, AIHW, NHMRC, ABS, the Office of the Privacy Commissioner and other key bodies.

NCRIS Secretariat

Department of Innovation, Industry, Science and Research

15 April 2008