



HSRAANZ Data Availability Survey

July 2016

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**Survey conducted by the
Health Services Research Association of Australia and New Zealand**
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Acronyms

ACRONYMS	Titles/Descriptions
ABS - RADL	Australian Bureau of Statistics - Remote Access Data Laboratory
ABS NHS	ABS National Health Survey
AEDC	Australian Early Development Census
AHPRA - PIE	Australian Health Practitioner Regulation Agency - Practitioner Information Exchange
AIHW DLU	Australian Institute of Health and Welfare Data Linkage Unit
AIMS	Australian Incident Information Management System
AOANJRR	The Australian Orthopaedic Association National Joint Replacement Registry
APDC	Admitted Patient Data Collection
BEACH	Bettering the Evaluation and Care of Health - GP activity
BOS Data	Birthing Outcomes System Data
CARDIAB	Division of GPs Diabetes Register
CDIS	Child Development Information System
CHeReL	Centre for Health Record Linkage - for NSW and ACT
CINSW	Cancer Institute NSW
CU CDL	Curtin University Centre for Data Linkage
DVA	Department of Veterans' Affairs
EDDC	Emergency Department Data Collection
HILDA	Household, Income and Labour Dynamics in Australia
ICES	Institute for Clinical Evaluative Sciences - Canada
ISAAC	Integrated South Australian Activity Collection
MaCHS Data	Maternal and Child Health Services Data
MBS	Medicare Benefits Schedule
MSOD	Medical Schools Outcomes Database
NMDS	National Minimum Data Set
NSMHWB	National Survey of Mental Health and Wellbeing
PBS	Pharmaceutical Benefits Schedule
Qld RLG	Queensland Research Linkage Group
RBDM	Registry of Births, Deaths and Marriages
SA-NT Data Link	South Australia - Northern Territory DataLink
TDLU	Tasmanian Data Linkage Unit
VACIS Clinical Dataset	Ambulance specific list of clinical prompts and responses
VAED	Victorian Admitted Episodes Dataset
VDL	Victorian Data Linkages
VEMD	Victorian Emergency Minimum Dataset
WA DLS	West Australian Data Linkage System
ABS - RADL	Australian Bureau of Statistics - Remote Access Data Laboratory

1 Introduction

In June 2016, the Health Services Research Association of Australia and New Zealand (HSRAANZ) conducted a short survey to gain views from HSRAANZ mailing list recipients about their experiences with respect to accessing existing datasets that add, or could add, value to health services research. The survey was conducted to inform the HSRAANZ's submission to the Australian Productivity Commission's inquiry into data availability and use. A Productivity Commission's issues paper¹ published the terms of reference for the Commission's inquiry, which aims to:

1. Examine the benefits and costs of options for increasing availability of public sector data to other public sector agencies (including between the different levels of government), the private sector, research sector, academics and the community.
2. Examine the benefits and costs of options for increasing availability of private sector data for other private sector firms, the public sector, the research sector, academics and the community.
3. Identify options to improve individuals' access to public and private sector data about themselves and examine the benefits and costs of those options.
4. Examine the options for, and benefits and costs of, standardising the collection, sharing and release of public and private sector data.
5. Examine the ways to enhance and maintain individuals' and businesses' confidence and trust in the way data are used.

The Productivity Commission's inquiry into access and use of data arose from recurring data-related themes identified by previous reports, which are summarised in the Commission's issues paper. These recurring themes from past Productivity Commission reports include:

- Insufficient data sharing between agencies.
- Insufficient data linkage.
- Little public access to administrative data.
- Limited data access for research.
- Non-standardised datasets.
- Missed potential for stronger evidence-based policy.

In response to the Productivity Commission's invitation to make written submissions to the inquiry into data availability and use, the HSRAANZ conducted a short survey to collect data supporting the HSRAANZ's submission to the inquiry, due at the end of July 2016.

¹ Productivity Commission, (2016). Data Availability and Use: Productivity Commission Issues Paper, Australian Government Productivity Commission.

2 The survey

A short survey seeking views and experiences about access and use of existing datasets was distributed to HSRAANZ mailing list recipients in June 2016. Forty-three people responded to the survey. Core questions of the survey were:

- For which areas(s) of research have you accessed an existing dataset(s)?
- Have you accessed non-linked dataset(s)? Please list the non-linked datasets that you have accessed.
- How could the process of accessing non-linked datasets be improved?
- Have you accessed or are you trying to access linked data? If yes, which linked datasets have you accessed?
- Did you work with a data linkage facility (e.g. CHeReL, SANT Datalink etc.)? If yes, which data linkage facility(ies) have you worked with?
- How could the process of accessing linked data be improved?
- Are there existing dataset(s) that you would like to access that you have not accessed? If yes, which dataset(s) would you like to access? Why have you not accessed this dataset?
- Have you accessed existing datasets overseas? How did your experience accessing datasets overseas compare to your experience accessing Australian datasets?

Responses to the survey were analysed, using descriptive statistics to collate information which is presented in figures and tables. The qualitative content analysis of comments from survey respondents involved coding and categorising each comment. The comments are all provided in the appendices, with main points summarised inside the report.

3 Survey responses

The responses to the survey are summarised in following sub-sections, addressing the following topics: areas of research utilising the existing datasets; access to non-linked datasets; access to linked datasets; working with data linkage facilities; barriers to accessing existing datasets; and access to overseas based datasets.

3.1 Areas of research

Forty-one people (95% of all survey respondents) detailed areas of research for which they had accessed existing datasets. Many respondents listed more than one area of research. A summary of the twenty-eight main categories of research areas (with the number of survey respondents who had indicated these areas of research) is presented in Table 1.

Table 1: Research areas utilising the existing datasets

Research areas utilising datasets, number of respondents			
RESEARCH AREA	Number	RESEARCH AREA	Number
Health services policy, planning and research	13	Primary care	2
Hospitals - data, emergency, admissions, services and readmissions	7	Rural health	2
Epidemiology	5	Workforce research	2
Maternal and child health services research	4	Aetiology	1
Aged care & Healthy Ageing	3	Arthritis	1
Public health	3	Cancer services research	1
Aboriginal health	2	Drug and Alcohol Dependence	1
Health Data	2	Health Promotion	1
Health economics	2	Healthcare technologies	1
Health system performance	2	Incident Management (Clinical)	1
Injury services and outcomes	2	Needs assessments	1
Medications - safety and quality use	2	Refugee health	1
Mental health	2	Reproductive health	1
Population health	2	Telephone triage and health service utilisation	1

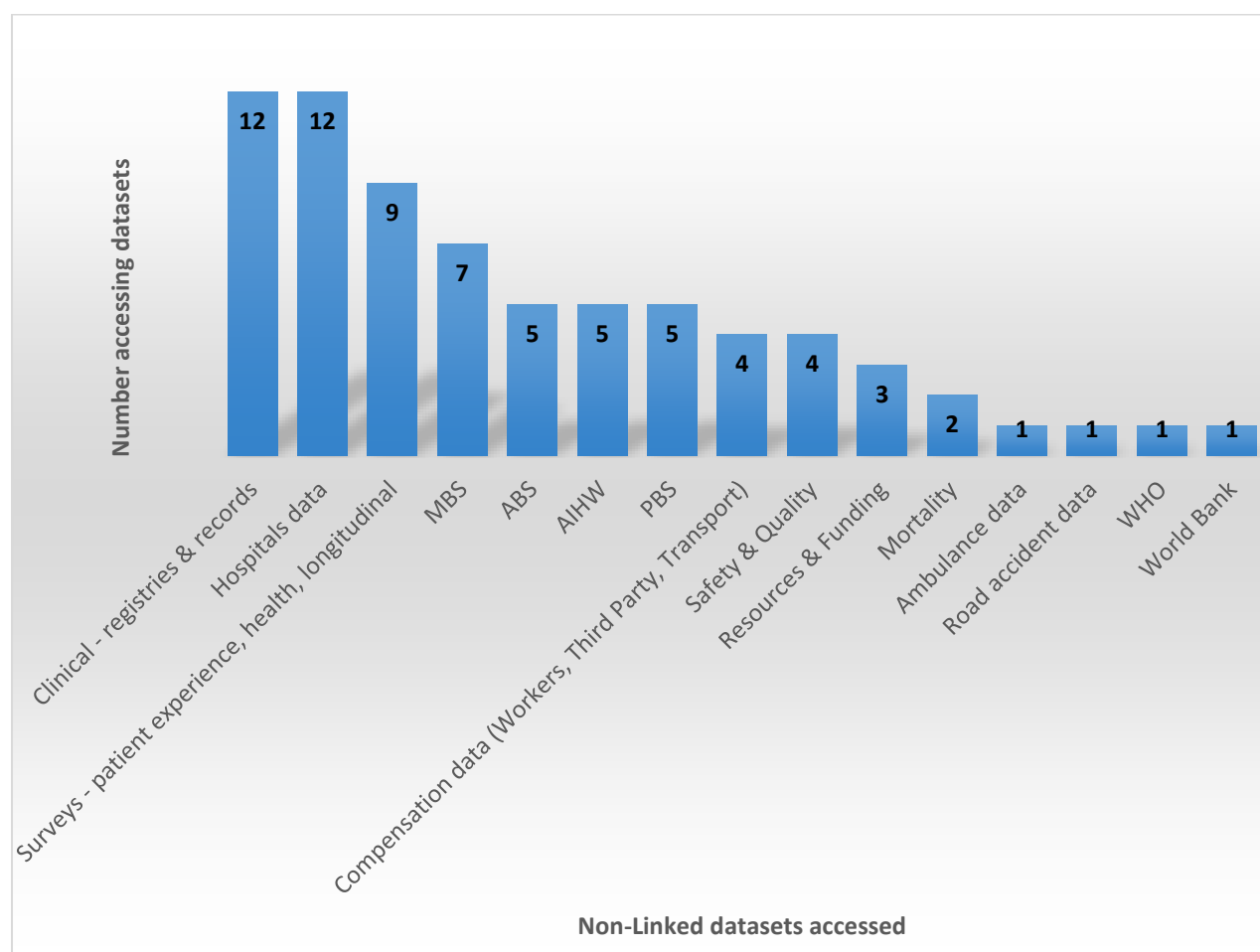
3.2 Access to non-linked datasets

Thirty-one people (72% of all survey respondents) provided information and comments about their experiences in accessing non-linked datasets. Fifteen main categories of datasets accessed by respondents are displayed in Figure 1.

Within the main categories of non-linked datasets, there was a diverse range of datasets. The set for 'Clinical – registries and records' included: Birthing Outcome System data; cancer registries; CARDIAB diabetes data for Southern Highlands Division of GP; GP clinical records; Maternal and Child Health Services data; Midwives Data Collection; Red Cross Blood Service; Royal Flying Doctor Service; Veterans' Healthcare Data; and the Victorian Lung Cancer Registry.

The set for 'Hospitals data' included data for: admitted care; non-admitted care; emergency departments (presentations and admissions); medical emergency teams; public and private hospitals.

Figure 1: Non-linked datasets accessed by survey respondents



Comments in response to the question ‘How could the process of accessing non-linked datasets be improved?’ are provided in Appendix A. Most of the comments related to issues of availability and accessibility of data, quality of information about data, and processes of approval and delivery. Experiences were mixed. For example, in relation to gaining access to data from cancer registries and longitudinal studies, several respondents had found access to be ‘very good’ and the processes to be ‘relatively easy.’

Issues in gaining access to data related to excessive periods of time involved waiting for approvals, poor transparency about data availability and processes, and lack of consistency between different data custodians in providing access to data. Several comments which typified the suggestions for improvement were:

‘The whole process of accessing datasets is not very transparent’

‘Application processing times need to be much faster’

‘Clearer processes for application to access data in most States’

‘Don’t have multiple gatekeepers’

(HSRAANZ survey respondents)

3.3 Access to linked datasets

Information about access to linked datasets was provided by 34 (79%) survey respondents. Most researchers had accessed multiple datasets and hospital datasets dominated the responses about linked data. The list of linked datasets as described by respondents is displayed in Table 2, with the number of respondents who had accessed these datasets. The set described as 'Hospitals data' includes non-specific descriptions of routine administrative and other hospital data. Other survey responses in relation to hospital data made more specific reference to the National Minimum Datasets for Emergency Department Data Collections and Admitted Patient Data Collections.

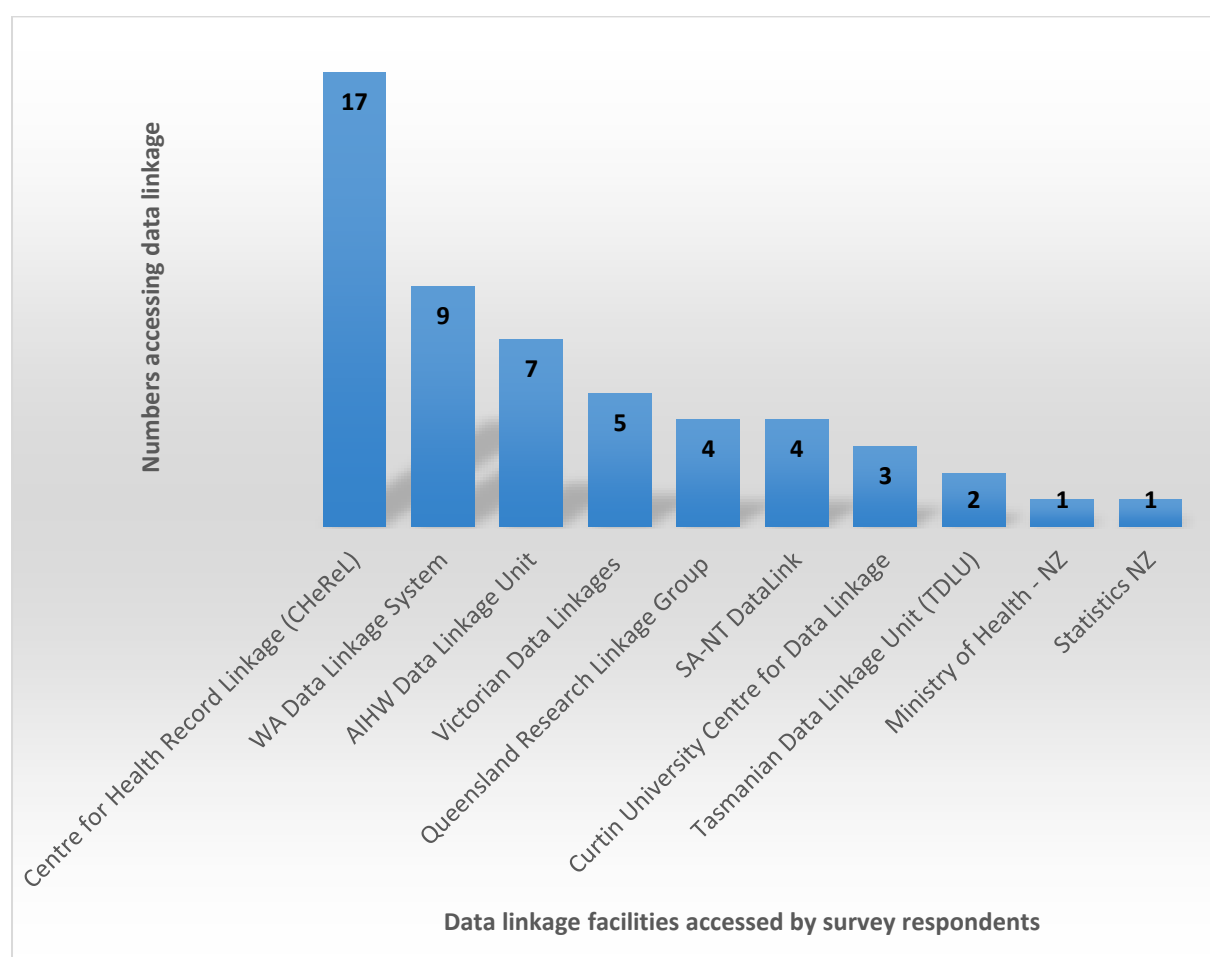
Table 2: Linked datasets accessed by survey respondents

Linked datasets accessed by respondents, number of respondents			
LINKED DATASET	Number	LINKED DATASET	Number
Hospitals - Emergency Department Data Collections (presentations, admissions)	17	Child protection data	2
Hospitals - Admitted Patient Data Collections	16	Education and school enrolments	2
Medicare Benefits Schedule (MBS)	13	Mental health	2
Mortality - State and national death registries, ABS data	13	Notifiable conditions	2
Hospitals data (admissions, episodes, separations, morbidity, public and private)	12	Australian Early Development Census (childhood development)	1
Pharmaceutical Benefits Schedule (PBS)	11	Breast Screen SA	1
Cancer registries - NSW, SA, or not specified	7	Corrective services	1
Perinatal Data Collections	7	Electoral roll	1
Health services - State, community, rehabilitation	5	Herceptin Program data	1
Registries of Births, Deaths and Marriages	5	Infections Database - Qld	1
Survey - 45 and Up	4	Midwives data	1
Ambulance data	3	NZ Census	1
Ambulatory care data	3	Pharmaceutical Information system (opioid maintenance prescribing data)	1
Congenital conditions	3	Service use costs	1
Road accident and trauma registries	3	Survey - Australian Longitudinal Survey of Women's health	1

3.4 Working with data linkage facilities

Twenty-nine (67%) survey respondents had worked with data linkage facilities based in Australia and New Zealand. Data linkage facilities accessed by survey respondents and the numbers respondents who described working with these facilities are displayed in Figure 2.

Figure 2: Data linkage facilities accessed by survey respondents



The most utilised Australian data linkage facility was the Centre for Health Record Linkage (CHeReL), which maintains record linkage systems for health and human services in NSW and the ACT.² One person listed facilities based in New Zealand (the Ministry of Health and Statistics NZ).

² Bureau of Health Information, (2015). Data Matters – Linking data to unlock information: The use of linked data in healthcare performance assessment. Bureau of Health Information, Sydney, NSW.

The question ‘How could the process of accessing linked data be improved’ was responded to by 37 (86%) survey participants, including several people who had not listed specific facilities, but had attempted to access linked data. Responses in full are provided in Appendix B. The majority of suggestions for improvement related to timeliness of approvals and delivery, and for streamlining and standardisation of processes across all the facilities. There were also several comments about quality of information for accessing linked data.

In relation to process improvement, many researchers saw a need for standardisation in processes for approvals to access data, across multiple jurisdictions, between different States and the Commonwealth. Lengthy delays for approval and lack of clarity about the requirements to gain access to data had been experienced. Numerous participants commented on a need for improved efficiency and streamlining of processes. Several people suggested centralisation for the initial process of gaining approvals from a single ‘gatekeeper’, instead of duplicating the same process with multiple facilities. Examples of comments were:

‘We need to speed this up and reduce the number of individual approvals needed – different research groups are all using exactly the same data so not only is the process slow, it is multiplied many times’

‘Streamlined ethics approval and data custodian sign-off process’

‘One national HREC approval for ethics for multi-stage data linkage studies’

(HSRAANZ survey respondents)

One person highlighted the implications of delays, observing that ‘Delays can negatively impact on the policy relevance of study findings (e.g., policy has changed, or funding for a particular initiative ceased, before data has been sufficiently analysed and results reported). Several respondents also saw the need for better information about data availability, and clearer guidelines on what can be accessed and how. Several of these comments were:

‘A more streamlined process, with information upfront about the necessary steps, would be useful’

‘Better information about the datasets (e.g. data dictionaries). Greater promotion/awareness of their availability. Clearer guidelines on what can be accessed’

3.5 Barriers to accessing the existing datasets

In response to the questions ‘Are there existing dataset(s) that you would like to access that you have not accessed?’ and ‘Why have you not accessed this dataset?’, the majority of comments related to: lack of availability of data (for example, not being able to gain access to health insurance claims data); difficulties in gaining access and approval for national datasets (in particular the PBS and MBS); and prohibitive cost. One respondent summarised the situation succinctly, stating *‘Too expensive, request takes too long.’* The full set of comments from 29 (67%) survey respondents about why they have not accessed the existing datasets is provided in Appendix C.

3.6 Access to overseas based datasets

Twelve survey participants (28%) responded to the question 'How did your experiences accessing datasets overseas compare to your experience accessing Australian datasets?' Participants provided examples of their experiences in accessing data from: United Kingdom, Scotland, Wales, New Zealand, USA and Canada.

Overall, the comments were favourable about experiences in accessing overseas based datasets. Several examples were provided from the USA of being able to download data online, following simple and efficient processes of approval, agreements and training. One respondent found the processes overseas to be *'Much the same'*, but most comments indicated that researchers' experiences in accessing datasets overseas had been faster and easier than experienced in Australia. The responses in full are provided in Appendix D.

One participant had observed greater investment in data in the UK (in comparison to Australia) with *'more of a drive for data for performance monitoring, benchmarking and to build cases for funding...'* A question from this respondent which is pertinent to further discussions about data use and accessibility was:

'What do health services in Australia do with the data they collect?'

4 Key messages from HSRAANZ survey respondents

Although only 43 survey respondents participated in this short survey, the responses indicated deep and extensive experience across a wide spectrum of research areas (Table 1). Also, the researchers had accessed many datasets (Table 2). Overall, key messages from HSRAANZ survey respondents were:

- Imperative to improve the speed and ease in accessing data, to provide more up-to-date and relevant information for policy and practice to improve health and wellbeing.
- Need to improve timeliness for approval and delivery of data, both for non-linked and linked datasets.
- Potential to improve streamlining of processes to reduce delays and prevent duplication of effort, by researchers and data custodians.
- Suggestions to improve standardisation and centralisation for cross-jurisdictional data linkage, to reduce duplication of same requirements with multiple gatekeepers.
- Acknowledgment that access to linked data has been steadily improving.
- Many examples provided by HSRAANZ survey participants of research projects with high impact and benefits, which highlights why access and use of data is important.

Appendix A: Responses to ‘How could the process of accessing non-linked datasets be improved?’

Non-linked datasets accessed	COMMENTS – Availability and accessibility
AHPRA	PIE not easy to navigate in terms of implications for the university (building a web interface)
AHPRA	Cost
AIHW datacare	more intuitive interface
AIHW, ABS, NHPA, St John Ambulance	Limitations as to what can be accessed prior to request
AIHW, NACDCH	by being linked
Birthing outcome system data (BOS), Maternal and Child Health services data (MaCHS), hopefully CDIS when it is up and running	Has always been relatively straight-forward with the exception of CDIS. BOS and MaCHS were held with the organisations directly so to access it was going direct through the organisation. For CDIS this will be different as it is held by MAV. Not sure how this will work.
CARDIAB data for Southern Highlands Division of GP	the process is adequate
MBS data, ABS data	The whole process of accessing datasets is not very transparent. You need to be in the know in terms of what is available, who to contact and what information do they need. As a result, accessing this data has been restricted to only a select group of researchers.
Medicare	Longer data periods for data extraction (e.g., for Medicare, ability to extract data from say last 10-20years, rather than last 5 years)
Medicare MBS and AIHW Aged care funding instrument data	It was fairly easy to undertake. I did not have problems with accessing the data I needed
National coroners’ information system	I was provided access to fully identified data (including names and addresses). For security, I would have preferred non identifiable data.
SA Cancer Registry; SA public & private hospitals; public emergency department	Access was very good
SA clinical and administrative public hospital data; national public hospital data; PBS and MBS data; Veteran's healthcare data; longitudinal studies (e.g. Ausdiab, ALSWH and DYNOPTA)	Gaining access to data from longitudinal research studies has been relatively straightforward.

Non-linked datasets accessed	COMMENTS – Information about data
Admitted patient data collection, Emergency Department data collection, Midwives Data collection, patient experience survey and population health survey data	Data dictionaries freely available (which they generally are); streamlined access requirements.

AIHW datasets, population projections from ABS, WHO and world bank	...getting updates when more recent data becomes available.
Australian Incident Information Management System	AIIMS id maps with APC NMDS id so they can be mapped.
Clinical cancer registry	...better data quality, investment in data collection.
NSW Admitted patient data, NSW Health Survey data	Data custodians should provide clear, accessible, information about what datasets are available and how these can be accessed for research.
State and territory workers' compensation and transport injury compensation data	Better information about datasets (e.g., data dictionaries). Greater promotion / awareness of their availability.

Non-linked datasets accessed	COMMENTS - Processes
AIHW datasets, population projections from ABS, WHO and world bank	... an established mapping process to map the data with previous years.
AIHW National Hospital Morbidity Database	More timely access (timeframe from initial request to data was 15 months), clearer guidance on format required for data requests, single point of contact for request so information doesn't get repeated/lost.
CARDIAB data for Southern Highlands Division of GP	Getting approvals takes an inordinate amount of time.
Clinical cancer registry	Access, smoother ethics.
HILDA	The process was extremely easy and fast.
Hospital Admitted Data Collection, Medical Emergency Team database, PBS dataset, MBS dataset, 45&Up Survey, NSW Health Survey	A single-central repository where skilled data managers can understand a request and download the subset for users.
Hospital separation data in each state and territory; mortality data; workers' compensation data, road crash data; third party compensation claims data	Central repository of data collections; don't have multiple gate keepers.
Medicare data, NHS 2011/12, NSMHWB 2007, NSMHWB 1997	Using the RADL (at ABS) is very slow - suggest datasets be available to approved researchers.
National Non-admitted Patient ED Care database	A speedier jurisdictional approval process, especially if requesting the equivalent data annually.
PBS	Timeliness.
SA clinical and administrative public hospital data; national public hospital data; PBS and MBS data; Veteran's healthcare data; longitudinal studies (e.g. Ausdiab, ALSWH and DYNOPTA)	Reducing the risk aversion of the data custodians of routinely collected data, which results in excessive delays and demands regarding aggregation and storage of data.
State and territory workers' compensation and transport injury compensation data	Clearer processes for application to access data in most states.
Unit record mortality data from state/territory deaths registrars	Application processing times need to be much faster. Access agreements are too restrictive.

Appendix B: Responses to 'How could the process of accessing linked data be improved?'

Data linkage facilities experienced	COMMENTS – Availability, accessibility and quality of information
CHeReL	Data about registrants on the PBS and MBS for NSW and ACT residents could be released to the CHeReL for inclusion in the MLK. This would be enormously more efficient and would enable far more robust science than is currently possible for case-control studies based on linked health records.
SANT Datalink	Ideally, one or two linkage facilities would be able to link data from the Commonwealth and all States and Territories.
CHeReL; WADLS; AIHW	I think WADLB have good processes in place for 'standard' projects, but it would make approval processes much more efficient if the decisions being made at the EOI stage were more transparent - as a researcher from NSW planning to conduct a cross-jurisdictional data linkage project, I experienced a lot of reluctance from the WA data custodians to release their data. As result, I experienced long delays in gaining approval for my research, and only after reducing the scope of my project substantially.
CHeReL	More freely available linked data
SA NT DataLink	SA private hospitals MUST become available; temporal depth is limiting (e.g. 1990's records for SACR and ISAAC would have been very helpful
Qld RLG	Private hospitals could be more engaged with and understand research more - they're quite suspicious.
Centre of Data Linkage (CDL) Curtin University	Stipulate the restrictions upfront. Iron out consent from patients
Victorian Data linkages	"a/a" copied: Better information about datasets (eg, data dictionaries). Greater promotion / awareness of their availability. clearer guidelines on what can be accessed.

Data linkage facilities experienced	COMMENTS – Processes for timeliness, streamlining, and standardisation
CHeReL, AIHW DISC	The processes via AIHW are lengthy and challenging to navigate.
Victorian Data Linkages	was a relatively smooth process
All of them - national study.	One national HREC approval for ethics for multi-state data linkage studies
CHeReL	Requests for access to data should NOT be submitted to individual custodians and then requests to CHeReL for linkage. CHeReL should have ability to represent the interests of custodians and process data requests from the various custodians.
CHeReL	Approval process could be streamlined: a concurrent process with the different approvers would be more efficient.
CHeReL	Ethics approval was quick (approx. 2 months from submission) but governance approvals took 15 months. We need to speed this up and reduce the number of individual approvals needed - different research

	groups are all using exactly the same data so not only is the process slow, it is multiplied many times.
CHeReL	Timeliness
CHeReL	more timely approvals
CHeReL and the AIHW for national datasets	Streamlined ethics approval and data custodian signoff process.
CHeReL and WADLS	Increase efficiency of data (and concurrent ethics) application process
CHeReL, AIHW DISC	More standard processes for working with data custodians, particularly new data custodians, would improve the process greatly.
CHeReL, AIHW DISC	The processes at CHeReL are generally efficient and have continuously improved over time...
CHeReL, WADLS, AIHW	A standard set of de-identified linked datasets including hospital inpatient, death, MBS and PBS data should be made freely available to bona fide researchers
CHeReL;	Simplify access requirements
Cherel; Qld Health RLG and WA Health DLU	to have a national/statewide Data linked System
CHeReL; WADLS	Is it a time consuming process (HREC in particular). Delays can negatively impact on the policy relevance of study findings (e.g., policy has changed, or funding for a particular initiative ceased, before data has been sufficiently analysed and results reported.
CHeReL; WADLS; AIHW	I think the process of accessing linked data through the CHeReL works really well.
CHeReL; WADLS; AIHW	The process of accessing Commonwealth data for linkage projects could be improved substantially, mainly through better and more regular communication from the AIHW linkage unit, better systems to ensure progress on each project does not stall, and more accurate advice regarding likely timelines.
Government Health statistics division	Not the linking but the time constraints on departments to deliver data for research rather than government reporting to the commonwealth and ethics requirements- all a bit of a merry go round.
SA NT DataLink	Timeliness of delivery;
SANT Datalink	I use linked data to evaluate healthcare services, for which access to contemporary data is key. Quicker access to data and linkage by linkage facilities would be useful.
Statistics NZ and Ministry of Health	The model being used is world leading.
Victorian Data Linkage	A quicker process...
Victorian Data Linkages	A more streamlined process, with information upfront about the necessary steps, would be useful.
Victorian Data Linkages	a/a" Copied from Q2: Clearer processes for application to access data in most states.
WA DLB, CHeReL, SANT, TDLU, AIHW, Queensland Health	Too many approvals with no consistency (Commonwealth access is not Transparent)
WA Health data linkage branch, Curtin	Consistency in willingness to share data between custodians at different levels, centralised approval process where data required from different levels (state and Commonwealth)

University Centre for data linkage	
WADLS and also Centre from Data Linkage (Curtin University) AIHW	Shorter time frames from approvals to actually receiving data (esp. WADLS)
(Facility not specified)	Uniformity of platforms
(Facility not specified)	Less cost, better ethics approval system
(Facility not specified)	Clear data owner, consistent data collection methods, unique identifiers, low cost
(Facility not specified)	Reduce the red tape.

Appendix C: Responses to ‘Why have you not accessed this dataset?’

Existing datasets you would like to access	COMMENTS – Availability and accessibility
PBS and MBS	Currently there are issues with cross jurisdictional linkages to Commonwealth data from WA - we are hoping to resolve this using a privacy protecting protocol developed by the CDL (Curtin). Currently WA Health will not send identifiable data to the AIHW to facilitate linkage- this has meant that commonwealth data cannot be linked with WA health data - I have access these data under the old MOU that existed in WA.
Hospital-specific death review data	Despite having hospital-specific ethics approval to access death review data, the custodian refused to release it to my research team.
Centrelink income assistance and family payment data	It has taken a few years to negotiate accessing this data but now the project funding is running out and we probably can't access unless more project funding is obtained
childhood immunisation data	Not sure how it could be linked with MaCHS and now CDIS. Not sure where to start!
Department of defence, DVA, Ambulance Victoria	Access issues
Full nation-wide Medicare data with postcodes	Applied but was rejected
health insurance claims data	Lack of availability
I would like to link data across all Australian public hospitals with PBS and MBS and mortality data.	Cross-border linkage has only been attempted as part of demonstration project and linkage of PBS/MBS data is still at a very early stage.
MBS and PBS	Unable to get approval for linkage.
MBS and PBS should be available to state linkage unit for linkage	unfathomable Commonwealth red tape and access rules
Medicare and CINSW registry	Too hard on rems if access

National admitted patient data, internally linked and linked to mortality data and ideally MBS and PBS data	It is almost impossible to obtain national linked hospital admitted patient data, because approval is required from each jurisdiction, and some jurisdictions (e.g. Victoria) are lagging behind in getting their datasets linked up
other states data and ambulance data	Not available/ beyond the scope of the project
PBS	Generally, not released in combination with MBS
PBS and MBS	Currently data is provided only to the Department of Health. Also, PBS and MBS only link to one another and don't want to be linked to external data sets
Taxation records and social security (benefits) data	It is not made available for research
The Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) and the 10% PBS sample	10% PBS sample - the project has been simply delayed. Orthopaedic registry - No idea about how to go about it.
The Health Roundtables Healthcare Evaluation Dataset	Organisation I work for is not a healthcare provider
(Dataset not specified)	quality, time and access issues
(Dataset not specified)	They are not linked and easily available

Existing datasets you would like to access	COMMENTS – Processes
MSOD	Don't know who owns its now, changes to the dataset when management changed.
ABS causes of death;	ABS cause of death data was not available for several years;
Death registry data for recent year	Long waiting times for death data with unaffordable fees if we request several small chunks;
MBS and PBS records for non-consented randomly selected sample	The requirement for consent. The cumbersome, expensive and lengthy data custodian process added to by the very lengthy linkage queue at AIHW. These requirements are impacting the health of Australians without clear or reasonable justification.
National Medicare (MBS), PBS data and the immunisation register	Approval process not considered feasible as yet.
Recent ISAAC data	Prolonged waiting time for delivery of data

Existing datasets you would like to access	COMMENTS – Costs
45 and up	Cost
45&Up Study data;	The 45&Up Study data access fee is prohibitive; we had to discontinue a project because the fees went up by several thousand% in the 2nd phase of data request;
BEACH study data	High fee

local health service data e.g. community nurses	Resources - we may try to do this later this year when linked data linkage completed
National non-admitted patient emergency department care database (AIHW)	Too expensive, request takes too long

Appendix D: Responses to ‘How did your experience accessing datasets overseas compare to your experience accessing Australian datasets?’

COMMENTS – Availability and accessibility of overseas datasets

Road crash and behavioural risk survey data is available online for researchers to download free of charge

These are NZ data sets. We have not used OZ data sets. It is very powerful.

In the US you can download unit record mortality data from the web

pharmaceutical companies have set up decent processes to allow public access to individual level data from their clinical trials, which might provide an exemplar for accessing routinely collected data in Australia.

COMMENTS – Processes in accessing overseas datasets

More streamlined approval process and quicker data extraction for overseas (Welsh) data

Fantastic. ICES in Toronto Canada are an excellent model. I worked at ICES and found using their linked-data to be straightforward and ethical.

Much easier. I had to present an ethics approval letter for the project, a copy of my CV, signed a simple research agreement, and did a 1-hour online registration course and then I was able to access a data subset from teaching hospitals in USA via a drop box and in Denmark & Ireland via a web-based interface.

Much easier!

About the same

The process in Scotland is clear, straightforward, relatively inexpensive and timeframes are predictable. The whims of individual data custodians do not come into play.

I worked for a data analytics company in the UK and found accessing health datasets from the NHS very straight forward. Each organisation had sophisticated data intelligence and analytical teams and invested in this area. There was more of a drive for data for performance monitoring, benchmarking and to build cases for funding in the UK so data was more heavily invested in. In Australia, there seems to be less requirement for this or perhaps this is just in the maternity and maternal and child health sector; however, I feel that it is a very long way behind the UK in using data to make everyday business decisions as aside for research purposes. My query is, what do health services in Australia do with the data they collect? Do they use it aside from research purposes? Data for research purposes only seems like a very limited use of the data that is being collected.