



Cross-Jurisdictional Client Services

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Prepared by PHRN Program Office

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Table of Contents

EXECUTIVE SUMMARY	4
CLIENT SERVICES AND DATA LINKAGE ORGANISATIONS	5
INTRODUCTION	5
WHAT ARE CLIENT SERVICES?	6
WHY DID WE CONDUCT THE AUDIT?	6
HOW DID WE APPROACH THE AUDIT?	6
WHAT WERE THE KEY FINDINGS?	7
STAGE 1: APPLICATION PREPARATION	8
STAGE 2: APPROVAL PROCESS	10
STAGE 3: PREPARATION OF DATA PRIOR TO RELEASE TO RESEARCHERS	10
STAGE 4: DELIVERY OF DATA EXTRACTS TO RESEARCHERS	12
STAGE 5: MONITORING OF DATA LINKAGE PROJECTS	14
OTHER CLIENT SERVICES: PROVISION OF TRAINING AND EDUCATION	16
CLIENT SERVICES FOR CROSS-JURISDICTIONAL DATA LINKAGE PROJECTS	19
WHAT IS CROSS-JURISDICTIONAL DATA LINKAGE?	19
WHO OFFERS CLIENT SERVICES FOR CROSS-JURISDICTIONAL LINKAGE PROJECTS?	19
PHRN PROOF OF CONCEPT #1: A SNAPSHOT	19
WHAT DO RESEARCHERS WANT FROM CLIENT SERVICES?	23
METADATA	23
ONLINE APPLICATION AND TRACKING SYSTEM	24
PROVISION OF OTHER GENERAL INFORMATION FOR DATA USERS	25
EDUCATION AND TRAINING	26
CONCLUSION	27
REFERENCES	29

Executive Summary

One of the primary objectives of the Population Health Research Network (PHRN) is to support research of national relevance which results in improved policy making and service delivery and demonstrates global best practice in maximising the benefits to the Australian community whilst preserving individual privacy. For the PHRN to achieve its aims, the tasks required to administer and support the delivery of data to researchers must be clearly defined and allocated between the relevant PHRN Participants. Client Services encompasses a range of processes from the study design and application for data, through to selection of study cohorts and assistance with the delivery of de-identified data extracts to researchers.

The PHRN Program Office has consulted with PHRN Participants to understand the key elements of client services provided by the Data Linkage Units (DLUs) to facilitate access to linkable data and how these services are delivered in each jurisdiction. A summary of the most pertinent findings of the consultations to date described in detail in the paper are as follows:

- Most DLUs have a client services team that is at least technologically separated from the technical linkage team and is primarily responsible for the administrative support of data linkage projects.
- The most common services provided involved supporting researchers to apply for access to linked data for research purposes including application support, assisting with project design, assisting with completing data custodian approval forms, provision of quotation estimates, review of submitted formal application to ensure completeness, publishing some online metadata and manual tracking of data linkage research projects.
- A degree of variability exists in the models of data delivery to researchers, following formal approvals, in terms of pre-delivery checking and merging and route of delivery.

The second section of this paper documents the key findings of the researcher consultation and Proof of Concept collaborations. Given that the process for access to linked data from multiple jurisdictions is more complex due to the different data custodian and Human Research Ethics Committee requirements in each jurisdiction, and the multiple linkage units involved in linking the data, there was strong support from researchers for a streamlined approach to the access and delivery of linkable data. In addition, researchers supported the development of a PHRN Metadata Framework and online application mechanisms to assist researchers formulate a cross-jurisdictional linkage project and apply for access to linked data.

Client services and Data Linkage Organisations

Introduction

The PHRN Program Office developed a cross-jurisdictional client services paper in mid-2011 that sought to capture:

1. How client services for data linkage projects are currently or will be delivered in each jurisdiction by the relevant data linkage units.
2. To define the key elements of client services required to facilitate access to linkable data for cross-jurisdictional projects.

This consultation paper was based on information received as part of a desktop audit of jurisdictional client services models by the PHRN Program Office as well as the outcomes of preliminary consultations with client services staff of all new and existing data linkage units (DLUs) and the SURE facility. Consultations with staff of the AIHW's data linkage unit also occurred in late 2011 following AIHW joining the PHRN through the EIF-SSI Investment.

The cross-jurisdictional client services paper was circulated to client services teams and management of the jurisdictional linkage units seeking feedback. All comments received were incorporated into the document which was subsequently tabled at the August 2011 Management Council meeting. Additional feedback was received following this meeting and a revised version of the paper was tabled at the February 2012 Management Council meeting including a proposed work-flow for administration of a cross-jurisdictional data linkage project. The outcome of the February 2012 Management Council meeting was that further consideration in the role of the PHRN Program Office in managing cross-jurisdictional linkage projects was required. The issue was again discussed at the August 2012 Management Council Meeting. The Council agreed that the Cross-Jurisdictional Client Services Paper should be reviewed and tabled at the November 2012 meeting.

The Cross-Jurisdictional Client Services Paper has been revised to focus on two important areas:

1. Client services and data linkage organisations: This section discusses the key elements of client services provided by data linkage organisations in Australia and overseas to facilitate access to linkable data and how these services are delivered in each jurisdiction.

2. Client services in cross-jurisdictional linkage projects: This section summarises the findings of the researcher consultation and learnings from the Proof of Concept collaborations.

What are client services?

The aim of client services is to facilitate access and delivery of linkable data for research to inform policy, planning and management to improve the health and wellbeing of all Australians. Client Services encompasses a range of undertakings from the application stage and study design, through to selection of study cohorts and assistance with the delivery of data extracts to researchers.

Why did we conduct the audit?

The PHRN Program Office conducted an audit of client services provided by linkage organisations to understand the range of services provided to researchers to facilitate access and delivery of linkable data for the purposes of health and related research. Given that the PHRN EIF-SSI Funding Agreement stated that the Program Office will 'develop PHRN frameworks, policies and related processes required to support inter-jurisdictional linkage and access' (Australian Government 2011:45), the PHRN Program Office anticipated that the findings of the audit would inform the development of such frameworks, policies and/or processes which are necessary to support cross-jurisdictional linkage projects.

How did we approach the audit?

An audit of client services offered by a number of linkage organisations around Australia and internationally was conducted. The audit included a desktop review and consultations with staff employed by Australian DLUs who facilitate access and delivery of linkable data for the purposes of health and related research. The following organisations were included in the audit:

- Australian Institute of Health and Welfare.
- Centre for Data Linkage.
- Centre for Health Record Linkage (NSW/ACT).
- HealthlinQ/Queensland Research Linkage Group.
- SA NT Datalink.
- Sax Institute.
- Tasmanian Data Linkage Unit.
- Victorian Data Linkages.

- WA Data Linkage Branch.

Dr Felicity Flack, Manager, Policy and Client Services, who was awarded a 2011 Churchill Fellowship, consulted with client services staff at various international linkage organisations as part of the fellowship. These international linkage organisations were also included in the audit:

- Health Information Research Unit (HIRU), University of Swansea.
- Manitoba Centre for Health Policy (MCHP), University of Manitoba.
- Institute for Clinical Evaluative Sciences (ICES).
- PopulationDataBC.

What were the key findings?

Client services identified during the desktop review and consultations with staff in the national and international data linkage organisations have been collated and analysed. In Australia and internationally, it is common for linkage organisations to have a dedicated team who facilitate access and delivery of linkable data for the purposes of health and related research. In Australia this team is technologically separate from the technical linkage team; this was not found to be the case in all international linkage organisations. The most common client services provided by linkage organisations to researchers were identified and summarised in the following table:

Most common client services provided by linkage organisations	
•	Publishes online metadata for data collections available for linkage.
•	Application support including answering questions regarding the approval and application process.
•	Assistance with project design including cohort selection, control selection, variables/time periods required, power calculations.
•	Assistance with completing data custodian approval forms.
•	Provision of quotation estimates for grant applications.
•	Review of submitted formal application to ensure completeness.
•	Assistance with brokering data release agreements with data custodians.
•	Support for use of the extracted data, including answering questions about data fields and coding specifics.
•	Manual tracking of data linkage research projects.

The audit found that the client services provided differed across the DLUs in Australia. A degree of variability exists in the client services provided by linkage organisations and these were identified and summarised in the following table:

Variability in client services provided by linkage organisations

- Assistance with HREC liaison and completing HREC forms.
- Addition of derived variables to data extracts.
- Provision of privacy/security training to researchers.
- Models of data delivery to researchers following formal approvals, in terms of pre-delivery checking and merging, and route of delivery.
- Publication of lay summaries of current and completed projects and research outputs on DLU website.
- Collation of annual reports prepared by researchers.

The main client services provided by linkage organisations in Australia identified during the audit were grouped based on the general stages of administration and management of data linkage projects; these stages will form the basis of the discussion of client services and will include:

- Stage 1: Application preparation;
- Stage 2: Approval process;
- Stage 3: Preparation of data prior to release to researchers;
- Stage 4: Delivery of data extracts to researchers;
- Stage 5: Monitoring of data linkage projects; and
- Other client services: Provision of training and education.

Stage 1: Application preparation

A key client service provided by linkage organisations is the provision of support for researchers to assist them to prepare their application for data forms. A range of services are offered including:

- Publication of metadata.
- Provision of other general information for data users.
- Publication of data application forms and ethics application forms.
- Assistance with cohort and control specification including requirements of variables, time period, age ranges, number of individuals.
- Procurement of quotations for data linkage and extraction services.

These client services are discussed in more detail below.

Publication of metadata

Metadata is often called 'data about data'. More precisely, it is the underlying definition or structured description of the content, quality, condition or other characteristics of data. Data collections are held by a range of organisations and the collation and publication of

metadata is generally completed by individual data custodians or by the local DLUs in partnership with the custodians and therefore held in separate locations. The majority of client services make metadata available on their website or provide links to data custodians' publicly available metadata.

Provision of other general information for data users

Local DLUs and data custodians provide some general information about access and delivery of linkable data on their websites including an overview of the application process and information about data delivery on their website.

Publication of data application forms and ethics application forms

Data application forms: Each jurisdiction has its own application for data form. The nature and content of the data application forms for state/territory DLUs are essentially consistent and generally complement the requirements of the relevant Human Research Ethics Committee (HREC) applications. Application forms for other collections not contained within the core linkages of the state/territory DLUs can in general be sourced from the relevant custodians however their content can be highly variable.

Ethics application forms: Generally most HRECs assessing data linkage applications will accept the National Ethics Application Form (NEAF) although many states have jurisdictional-specific attachments that are required to be submitted in association. Some HRECs will not accept the NEAF and have their own forms that researchers are required to submit.

Assistance with cohort and control specifications including requirements of variables, time period, age ranges, number of individuals

All existing and new DLUs currently have or are planning to implement an Expressions of Interest (EOI) process where assistance and advice is provided by the client services staff to researchers regarding study design and feasibility. Data custodians are generally consulted during this process where required. This system has been found to function efficiently by all DLUs who use it and enables issues to be addressed before submission of formal data and ethics applications.

Procurement of quotations for data linkage and extraction services

In general there are charges associated with the linkage and extraction services provided for each linkage project. Quotation estimates are usually provided to the research team upon submission of an EOI. These can be passed on to the research team from the linkage units involved or directly from the custodians. Each agency has their own pricing structure and the final quotation is dependent on a number of variables including number of records

required and degree of project complexity. The Sax Institute will also recover costs associated with the use of the SURE facility based on a specific pricing algorithm.

Stage 2: Approval process

A key client service provided by linkage organisations is to manage the approval process which includes the coordination of application submission, negotiation of formal contracts with data custodians following approvals and negotiation of SURE approvals (where required). These client services are discussed in more detail below.

Coordination of application submission

Each HREC, data linkage unit and data custodian has its own procedures and timelines for submission of applications which can be a complex path to navigate. Client services review submitted formal applications for data forms to ensure completeness and coordinate the approval process. Some DLUs also provide assistance with HREC liaison.

Negotiation of formal contracts with data custodians following approvals

Following receipt of approval from the relevant HREC and submission of an acceptable data application form where all components have been answered satisfactorily, data custodians require legally-binding contracts to be negotiated and executed in general between the agency responsible for disclosing the approved data extract(s) and the host institution of the Chief Investigator listed on the project. Some DLU's assist to coordinate this process.

Negotiation of SURE approvals (where required)

The SURE facility that has been developed by the Sax Institute requires researchers wishing to use the facility to obtain separate approval from the SURE administrators following undertaking of prescribed training. An agreement for the project signed by the lead organisation for the study will need to be signed prior to gaining access. All new users will also need to sign an Agreement agreeing to the terms and conditions of SURE access. Approved investigators would be directed to work directly with the Sax team to negotiate and execute SURE approvals and associated agreements as required.

Stage 3: Preparation of data prior to release to researchers

A key client service provided by linkage organisations is to prepare data prior to release to researchers. The tasks associated with this service include preparation of a data extraction plan including cohort/control selection, pre-merge checking of data extracts, addition of derived variables to data extracts and merging of data extracts and post-merge checking prior to making data available to researchers. These client services are discussed in more detail below.

Preparation of data extraction plan including cohort/control selection

In all jurisdictional DLUs, preparation of the data extraction plan is a process facilitated by the data linkers, client services team and data custodians, depending on the complexity of the project and the variables available to the linkers. The experience of the existing DLUs in WA and NSW has demonstrated that some projects can require multiple iterations to determine cohort selection prior to the extraction process commencing.

The checking of data extracts prior to release to researchers for merging can be useful in order to detect errors such as missing variables, incomplete/inaccurate cohort selection or release of variables outside the scope of the HREC or data custodian approval. As the ultimate responsibility for the release of data to researchers rests with the data custodians, the general feeling expressed in previous consultations with data linkage unit staff is that the responsibility should rest with the data custodians to perform this task. However, it has been reported by a number of the more mature DLUs that pre-merge checking by data custodians does not occur consistently, in most instances due to lack of resourcing, and as a result researchers frequently report errors in the data they receive.

At the WADLB, data analysts employed by the WA Department of Health and housed within the DLU's client services unit receive the data extracts from the relevant custodians within the Department and check them prior to delivery to researchers for merging. In keeping with the best practice 'separation principle', the data analysts are physically, technologically and logistically separated from the data linkers and therefore do not have access to identifying variables including names and addresses. If errors in the extracts are detected, they are referred back to the custodians and resolved prior to their release to researchers. QLD Health does some pre-merge checking of the data extracts but intends to employ data analysts to perform this task. In contrast, the other state/territory DLUs do not currently offer this service.

Addition of derived variables to data extracts

This function concerns the addition of variables such as age, Socio-Economic Indexes for Area (SEIFA) or Accessibility/Remoteness Index of Australia (ARIA) codes or the geocoding of addresses. Generally this requires access to identifying variables that are not routinely made available to the researcher. Currently the responsibility for performing this task differs between states/territories. At WADLB, derived variables are generated and added to the project linkage keys by the data linkers that are then sent to the custodians. QLD Health engages staff within the Research Linkage Group (RLG) to perform this task whereas in NSW this is the responsibility of the data custodians. SANT DataLink does not currently offer this service. VDL are looking into creating minimum datasets for their core collections which will contain value-add variables such as SEIFA and ARIA codes.

Other derived variables may require access to content data that is not available to linkage staff. Responsibility would then rest on data custodians, data analysts within local DLUs who have access to content data or the researchers themselves (if access to sufficient variables is permitted) to apply.

Merging of data extracts and post-merge checking prior to making data available to researchers

The merging or the bringing together of data extracts from different sources using project-specific linkage keys is currently performed by researchers across the country with the exception of Queensland data, which is merged and post-merge checked by the QLD Health RLG staff prior to release. For the other jurisdictions, researchers merge the data due to either the mode of data extract delivery (i.e. directly to researchers from individual custodians) or a lack of adequate resourcing within linkage units who do have access to the extracts.

Merging and post-merge checking of data extracts prior to making data available to researchers is also relevant in light of the Commonwealth's requirement for an Integrating Authority (IA) to manage each data integration project (*High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes; endorsed by Portfolio Secretaries, February 2010*). The Department of Health and Ageing articulated the proposed role of the IA in the draft *National Policy Framework for Statistical Integration in the Health Sector (September 2010)* to include merging prior to provision of access to approved researchers. This requirement will mean that all custodians including those in the states and territories will have to consent to their content data variables being sent to the nominated IA (in addition to the identifying variables required for linkage) prior to release to the research team. This process is as yet untested however preliminary discussions have commenced in light of the approval of the fourth PHRN Proof of Concept Collaboration which will involve the AIHW as an Integrating Authority.

Another important issue to consider is the merging strategy to be used – researchers do not generally merge all extracts on a once-off basis. Depending on the research question, they may choose to merge parts of extracts or recode data in certain ways prior to merging so there are often endless permutations of this process. The feasibility of conducting and checking all of these merged datasets by a third party such as an IA or other is an issue that needs further consideration. More practical alternatives may be for the pre-merged extracts or the analysis results to be checked.

Stage 4: Delivery of data extracts to researchers

For single jurisdiction linkage projects, data extracts with attached project linkage keys are currently provided to researchers via encrypted disc. The responsibility for delivery of data extracts to researchers varies and is dependent on the operational model of each of the

DLUs as well as independent custodian preferences. For example, in WA the custodians based at the Department of Health provide the extracts to the data analysts within the WADLB who check the data and create a metadata file about the extracts before providing them to researchers. However, WA custodians external to the Department of Health, as well as those in NSW and SA/NT provide the data extracts to researchers on encrypted disc directly without involving the DLU. In the other states there appears to be a hybrid model for data provision i.e. directly from custodians or via DLUs dependent on the collection.

The Secure Unified Research Environment (SURE) facility

The Sax Institute's SURE facility will provide custodians with an alternative to supplying data directly to researchers. Provision of access in a centralised secure virtual environment would also be consistent with the Commonwealth's IA model under its *High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes* which, according to DOHA's draft *National Policy Framework for Statistical Integration in the Health Sector*, would see the IA deliver the data to a secure data laboratory instead of to the researcher. The SURE by its design is fully auditable and SURE administrators will also be able to manually monitor incoming and outgoing data files.

There are cost implications associated with researchers using the SURE for storage and analysis of their data so it is initially expected that there will be mix of projects using the SURE or receiving data in the 'conventional' manner, dependent on HREC and custodian requirements and project budgets.

The PHRN Data Delivery System (DDS)

Under the current NCRIS Funding Agreement, the Sax Institute and now the CDL have received funding to co-develop a secure Data Delivery System (DDS) for the PHRN. The DDS is an ensemble of technology and standards, agreed operational procedures, software and supporting IT infrastructure that will provide harmonised national mechanisms for secure and efficient transfer of data between nodes of the PHRN and from data custodians to linkage units and researchers for approved projects.

The project to develop DDS functionality for secure transfer of data among PHRN participants has to date proceeded in two phases. Phase 1 has been completed by the Sax Institute and involved definition of standards, metadata and data file formats for data being exchanged between PHRN parties, evaluation of approaches to secure data exchange and related documentation. Phase 2 is being undertaken by the CDL to provide a generalised operational production DDS system for the PHRN for file encryption, transfer and decryption between data linkage units and data custodians and researchers, and for metadata file authoring by users of the system. Phase 3 has now also been approved and will be managed by the CDL with a focus on integration of the DDS with the CDL's National Linkage System and other PHRN deployments as well as the establishment of business processes,

documentation (e.g. access agreements) and administrative support for the DDS. The CDL are funded to provide DDS administrative/user support including set-up/site implementation assistance and procurement of licenses through until 30 June 2013, after which time continuance measures will need to be in place.

Stage 5: Monitoring of data linkage projects

A key client service provided by linkage organisations is to monitor data linkage projects. The tasks associated with this service provision include monitoring of researcher compliance and outputs, monitoring of timely data provision to researchers and records management and reporting. These client services are discussed in more detail below.

Monitoring of researcher compliance

Researchers conducting projects using linked data are required to comply with:

- The approved proposal and any conditions applied by the approving HREC.
- The terms and conditions outlined in their contractual arrangements with data custodians.
- The terms and conditions outlined in their contractual arrangements with funding bodies.

According to the *National Statement on Ethical Conduct in Human Research* chapter 5.5, the institution under which the research is conducted is responsible for monitoring compliance with the proposal approved by the HREC/s. Researchers are responsible for reporting regularly, at least annually, to the HREC about:

- The progress to date, or outcome in the case of completed research.
- Maintenance and security of records.
- Compliance with the approved proposal.
- Compliance with any conditions of approval.

The data custodians are responsible for monitoring compliance with the terms and conditions of their agreements with research institutions and researchers. However, they have the ability to include the requirement for independent monitoring of compliance in their agreements should they require it.

Similarly funding bodies are responsible for monitoring compliance with the terms and conditions of their agreements with research institutions and researchers.

In general most jurisdictional DLUs do not require annual reports or reporting of project amendments, this responsibility rests with the approving HRECs. As an exception, WADLB do require researchers to complete separate annual reports and amendment request forms if required. A few of the DLUs also require formal notification that all data files involved in a

linkage project have been securely archived or disposed of at the end of the project in accordance with the retention and disposal plan submitted with their application for data.

Data custodians have the ultimate responsibility for the data they provide and hence the contract for data release exists between them and the researcher, not the DLU. It is therefore each data custodian's obligation to ensure that their data is handled in the manner stipulated in the data release contract. However, in reality custodians often do not have the time to perform rigorous monitoring of each project for which they supply data. In this case, DLUs may be able to offer a monitoring service on behalf of the custodians, if requested, which could be formally reflected in the contracts between the DLU and the custodian, and the custodian and the researcher. For example, SANT DataLink have included in their template Deed of Confidentiality signed by the researcher and custodians, a clause that binds the researcher to provide information to and allow auditing by the DLU if requested, on behalf of the custodians.

Monitoring of timely data provision to researchers

The PHRN Access Committee which is responsible for the development and review of the PHRN Access and Pricing Policy, agreed at its meeting in October 2010 that 'monitoring the timeliness of provision of data for PHRN projects was the most important thing the PHRN could do to ensure fair access to the infrastructure' and furthermore that 'the timeliness of access could be monitored by reporting in the Key Performance Indicators section of annual reports'. Based on this recommendation, it is important that the Client Services Models governing the administration of jurisdictional projects by local DLUs incorporates a mechanism for monitoring data extract provision as part of the project management process. This exercise is also essential agencies involved in single- and cross-jurisdictional linkage projects to provide estimations of project timelines to prospective researchers interested in conducting data linkage projects.

For the new and existing DLUs, monitoring of data provision to researchers is currently undertaken in general by their client services team. This occurs by default in those DLUs whose operational models have the client services staff supplying the data extracts to researchers on behalf of the custodians. In the other jurisdictions where custodians supply the data directly to researchers, the DLU client services team is frequently contacted by researchers who have experienced a delay in data provision and in these instances the DLU can assist in liaising with the custodian to negotiate the release of the data in a timely fashion.

Monitoring of research outputs

Monitoring of research outputs from data linkage studies is a priority for the PHRN and its Participants on two levels: 1) reporting to funding bodies to justify their investment and lobby for continued investment; and 2) reporting on the critical role of data linkage research

in improving the health and wellbeing of the people whose data is used in order to maintain community support.

Monitoring of research outputs by the WADLB relies on the researchers informing the unit of any report, journal article, other publication, conference presentation or media interest generated from data supplied. This seems to be a method commonly employed by other linkage units around the country.

Records management and reporting

For linkage projects administered by the jurisdictional DLUs, a secure electronic repository of documentation required for the administration and support of these projects is generally curated by the client services teams in the DLUs. This generally includes completed project applications and supporting documentation such as research protocols and copies of HREC approval letters and enables the client services teams to maintain oversight of all projects and ensure all requirements of a project are met prior to provision of data access to the research team. In addition, the DLUs can produce summary statistics regarding linkage projects in order to meet reporting requirements of its senior governance and funding bodies.

A detailed summary of the findings of the audit can be found at Appendix 1 and Appendix 2 of this report.

Other client services: Provision of training and education

Training and education are important services to facilitate the successful use of the PHRN linkage infrastructure. The PHRN Program Office, under its NCRIS contractual obligations, is involved in the co-ordination and implementation of a national training program covering key aspects of data linkage relevant to technical data linkers, researchers, funding bodies and ethics committees. The Training and Development Coordinator located in the Program Office is responsible for the coordination of training, including programs for vocational training and continuing professional education as appropriate through the development of a National Training Program.

The Training and Development Coordinator undertook a national scoping exercise to identify the training and education requirements by consulting with the staff of each PHRN Participant. The final report of the scoping exercise was presented to the Management Council at its May 2011 meeting and identified the following priority areas:

1. Researchers – privacy training, understanding administrative data, training on applying for HREC approval and data, and training on conflicts of interest.
2. Data custodians – development of an information booklet covering general data linkage.

3. HREC members – general data linkage information and key ethical considerations pertaining to data linkage.
4. PHRN Participant staff – Consumer and community member participation and communications training for key staff members and training for new technical staff.

From the above list, training for HREC members and training for PHRN Participant staff around consumer and community participation were initially selected for focus. Through consultation with the key stakeholders including members of HRECs and national ethics bodies, consumer groups and individual representatives and current trainers in consumer and community participation, the following two training packages have been developed through the Program Office:

Human Research Ethics for Data Linkage

Target group – members of accredited HRECs who examine data linkage applications

Facilitated by – A/Prof Judy Allen, Dr Felicity Flack and Ms Kate Tan

This training workshop examines the particular ethical issues raised by data linkage and research.

This one-day workshop provides participants with a range of skills and knowledge that improve their ability and confidence to assess research applications proposing the use of linked data. The training covers the following topics:

- What is data linkage?
- Overview of data linkage in Australia.
- Risks and benefits of data linkage.
- Best practice protocol.
- Minimising and managing risk.
- Considering a waiver of consent.
- Legal framework and legislative requirements.

The training was successfully piloted with HREC members in WA and has since been delivered to HREC members in SA, NSW and QLD with dates planned for the ACT in the near future.

Consumer and Community Participation: A training workshop on implementing participation

Target group – technical, administrative and managerial staff of the PHRN Participants

Facilitated by – Ms Anne McKenzie (Consumer Advocate/ consumer member of the PHRN Ethics, Privacy and Consumer Engagement Advisory Group/ Chair of the Health Consumers' Council of WA)

This one day workshop provides participants with a range of skills and knowledge that aims to improve their ability and confidence to work with consumers and community members. Primarily, participants will learn:

- To understand the principles of consumer and community participation in organisational development.
- How to begin planning and implementing consumer and community participation in all aspects of your nodes activities.

The training has now been conducted with staff from data linkage units in SA, NSW, Victoria and the ACT and evaluation feedback has been positive.

Client services for cross-jurisdictional data linkage projects

What is cross-jurisdictional data linkage?

A cross-jurisdictional data linkage project involves the linking of two or more Commonwealth, state and/or territory datasets for research purposes using national linkage keys.

Who offers client services for cross-jurisdictional linkage projects?

Currently there is no single organisation with client services that facilitate researchers' access to cross-jurisdictional linkable data for the purposes of health and related research. Researchers who wish to apply for access to linked data held within Australian states and territories are currently directed to the local data linkage units in each jurisdiction. Within each unit there is generally a dedicated client services team that can assist researchers with various aspects of projects involving linked data including design and cohort selection, provision of quotations, completion of data applications, advice on HREC process and applications, negotiation of contracts with custodians and in some instances, archiving of data extracts at the completion of the study. Compared with single-jurisdiction projects, the process for access to linked data from multiple jurisdictions is more complex due to the different data custodian and HREC requirements in each jurisdiction. There is also multiple linkage units involved in linking the data.

A snapshot of PHRN Proof of Concept #1 project illustrates the complexity of accessing cross-jurisdictional linkable data.

PHRN Proof of Concept #1: A snapshot

Title of Collaboration:

In-hospital and post-discharge mortality: learning about quality of care using data linkages from Australian states.

Study design:

The project involves provision of linkage variables (name, address, DOB and sex) from state and territory hospital inpatient and death (mortality) data collections to the Centre for Data Linkage and provision by data custodians of linkable de-identified content information to the approved researchers. The cohort is defined as every person who had an inpatient

admission from 2004/05 to 2008/09, and their linked mortality record if death occurred within 30 days of their last hospitalisation during this period. Additionally, for each cohort member, diagnosis data is needed from at least 2003/04 (preferably from 1999/00) to establish a 12-month (ideally five-year) co-morbidity profile.

Cohort selection:

Undertaken by the Centre for Data Linkage

Lead Analyst:

Dr Katrina Spilsbury, a highly qualified analyst with experience investigating quality and safety issues with linked hospital and death data, is currently contracted to analyse research data for PoC #1 (NB Dr Spilsbury assumed the role from Dr Janine Calver in October 2010).

Funding contracts:

1. WA Department of Commerce and TICHR: Financial Assistance Agreement for provision of co-funding
2. TICHR and WA Department of Health: contract for undertaking of coordination and analysis activities

Project commenced:

October 2009.

PoC Coordinators:

Janine Calver: October 2009 – October 2010

Emma Fuller: August 2010 – January 2012

Angela Rate: February 2012 – October 2012

Summary:

Summary of key project elements	No.
States involved	4
Data collections involved	9
Linkage units involved (state and national)	4
Data custodians involved	8
Data application forms required	5
HREC application forms required	5
Data transfer agreements required	8

Summary of key project elements	No.
Reports to funders required	3

Applications and Approvals in detail:

	NSW	WA	QLD	SA
Collections	NSW Admitted Patient Data Collection (APDC) NSW Death Registration Data ABS Mortality Data	Hospital Morbidity Data Collection (HMDC) WA Mortality Dataset	Queensland Hospital Admitted Patient Data Collection (QHAPDC) QLD Mortality Dataset	Integrated South Australian Activity Collection (ISAAC) SA Death Registration Data
Metadata available	Provided by CHeReL on CD to the CI (now transitioned to online system through CHeReL website)	WADLB website	QHAPDC manual published on QLD Health and HealthlinQ website; QLD mortality metadata not published	SANT DataLink website
# of data Custodians	Two	Two	Two	Two
# of data applications required	One: CHeReL data application form	One: WADLB data application form	Two: QLD Health PHA application form QLD RBDM Application Form	One: SANT Statistical Integration Project Application Form
Central point of submission?	Yes – CHeReL	Yes – WADLB	No – applications submitted to QLD Health (morbidity data) and QLD Registry of Births, Deaths & Marriages Research and Statistics Unit	Yes – SANT DataLink

	NSW	WA	QLD	SA
			(mortality data)	
HRECs involved	NSW Population and Health Services Research HREC	WA Department of Health HREC Curtin University HREC (for use of CDL to perform national linkage)	QLD Health HREC	SA Health HREC
Data transfer agreements involved	Two: Confidentiality Undertaking between NSW Ministry of Health and linkers Confidentiality Undertaking between NSW Ministry of Health and researchers	Two: MOU between WA Department of Health/ WA RBDM and Curtin University for linkage variables Confidentiality acknowledgement as part of the WADLB data application signed by the research personnel for content variables	Two: MOU between QLD Health, Curtin University and Sax Institute (covering potential use of SURE) for QLD morbidity data MOU between PHRN convenor (Di Rosman) and QLD RBDM)	Two: SA Health Confidentiality Deed for SA morbidity data (separate deeds for linkers and researchers) SANT DataLink Researcher Deed Of Confidentiality and Compliance for SA RBDM death data
Data linkage units involved	CHeReL	WADLB and CDL	N/A (QLD RLG/ HealthlinQ not involved in PoC #1)	SANT DataLink

Roles of PoC Coordinator for PoC #1:

- Negotiation of funding contracts
- Preparation of Progress Reports
- Drafting and submission of data and ethics applications including obtaining data variable lists
- Negotiation of data transfer agreements
- Management of documentation around project

What do researchers want from client services?

The PHRN Program Office consulted with researchers with an interest or experience in data linkage between April and August 2012. A total of 100 researchers participated in the consultation, including 40 researchers who completed the PHRN linked data researcher survey and 60 researchers who participated in nine face-to-face meetings held in Perth, Sydney, Canberra, Adelaide, Hobart, Melbourne and Brisbane.

The aim of the consultation was three-fold. First, the PHRN Program Office wanted to provide current and future users of linked data with an overview of the PHRN and its initiatives. Second, the PHRN Program Office wanted to obtain information about access and usage practices around current client services for data linkage research available around Australia. Third, PHRN Program Office wanted to understand the gaps or areas for improvement with a particular emphasis on three elements of client services that the Program Office is currently funded to investigate for the PHRN: a) metadata; b) online application mechanisms for cross-jurisdictional projects; and c) training for users of linked data.

The key finding from the consultation was that researchers were supportive of a streamlined approach to the access and delivery of linkable data, including the development of a national metadata resource, an online application and tracking system and provision of general information for data users. Researchers also identified their education and training needs.

Metadata

Participants were provided with a definition of the term 'metadata'. Given that the PHRN Program Office is contractually obliged to develop a PHRN Metadata framework, participants were advised that the PHRN is considering ways to provide information about data collections across Australia that are potentially available to be linked. It was made clear that the intention would be that links will be provided back to the source metadata wherever it is available rather than the PHRN developing its own metadata per se.

Participants supported the development of a PHRN Metadata Framework. Currently metadata is not automatically used by all researchers to prepare application for data forms because many researchers are not aware of its availability and usefulness or are concerned about its quality, including reliability and accuracy. Steps towards increasing the availability and visibility of metadata were overwhelmingly supported.

Survey participants (40) were provided with a list of suggested metadata items and were asked to nominate whether they agreed with their inclusion in a PHRN Framework. The following table summarises their responses:

Metadata Item	% Agreement
Which data collections are available	100.0%
Where the data collections are held	97.4%
Custodian contact details	95.0%
Approvals required for access to the data collections	95.0%
Quality of the data (including reliability, accuracy, completeness)	95.0%
Detailed descriptions of the variables in the data collections (including mode and method of collection, changes over time)	95.0%
Links to any validation studies of the data available	92.5%
Legislation covering the collection, use and disclosure of each data collection	87.2%
Glossary of commonly used data linkage terms	82.1%
Researcher forum for exchange of information/ experiences with using specific data collections	81.1%

In addition to those listed above, the following metadata items were suggested to be included:

- Classification and re-coding methods applied to data.
- Publication of data collection instruments.
- Publication of completed and current data linkage projects, collections involved and contact details of primary researcher (upon consent) available.
- Publication of concept dictionaries similar to that produced by the Manitoba Centre for Health Policy Research.

Online application and tracking system

Access to data from multiple jurisdictions currently requires the completion of individual data applications for each data collection as well as multiple HREC applications. The PHRN Program Office is contractually obliged to develop an online application and tracking system that will serve as a central point for researchers to electronically complete and submit data applications for cross-jurisdictional projects. The key findings from the researcher consultation about the application and tracking system are as follows:

- General support received for an online application submission system for cross-jurisdictional projects.
- Tracking thought to be a good idea however concern expressed as to how this may be effective for a cross-jurisdictional project involving multiple application forms to be reviewed by multiple custodians and ethics committees.

- All supportive of the development of a single data application form that would be acceptable across the jurisdictions.
- Variable use of currently available online NEAF application submission websites but positive feedback from those who had used these services.

Forty (40) survey participants also provided feedback on the desired functions of an online application system which are summarised in the following table.

Online application feature	% Agreement
Web interface to allow access from any computer	100.0%
Individual user accounts for each researcher that can hold multiple applications for different projects	100.0%
Automated project tracking to provide information on the progress of project applications	100.0%
Electronic applications specific for each data collection/jurisdiction that can be updated and saved on a periodic basis	97.3%
Ability to invite other registered users to view/edit applications	86.5%
Ability to import and export information in XML format	71.4%

Provision of other general information for data users

In addition to metadata about specific data collections, the consultation with researchers has shown that availability of other information is extremely important in the design of projects involving linked data and the drafting of data and ethics applications. Beyond the general metadata information requested, researchers at face-to-face consultations indicated they wanted more information provided on:

- How to access to Commonwealth data (common request from all face-to-face consultations).
- Links to local data linkage units.
- Ethical/privacy aspects of linkage (although many of the researchers who had completed the SURE training said that this was covered in the training).
- Geocoding.
- Pricing for data linkage projects.

The responses from survey participants (40) related to suggested information elements can be found below.

Information Portal Item	% Agreement
Ethical issues including considerations for HREC applications involving	94.9%

Information Portal Item	% Agreement
linked data	
Standard FAQs for researchers	94.9%
Other useful resources e.g. training opportunities	91.7%
Security aspects of data linkage projects	90.0%
Information about pricing of data linkage projects	87.5%
Linked data application process and approximate timelines	85.0%
Statistical disclosure risk assessment and control	85.0%
Approximate timelines for applications	82.5%
Legal framework governing data linkage projects	82.5%
Data linkage methodology – how data linkage works	81.6%
Links to data linkage publications	75.7%
Design of data linkage projects	62.2%

Education and training

The PHRN Program Office has now conducted consultations with the linked data user community to determine their past training history and current/future additional training requirements in order to feed in to the development of a training program for this target group. Based on the face-to-face consultations with 100 linked data users and additional feedback provided from 40 users through an online survey, a number of key issues emerged:

- Current levels of undergraduate training were not deemed sufficient for conducting research using linked data and a lot of learning was done via on-the-job training and through supervisors.
- Many of the researchers surveyed had completed the Introductory Analysis of Linked Data course offered by Prof D’Arcy Holman from UWA or the adapted version of this offered by the University of Sydney and had found it to be extremely useful.
- A smaller number had completed Prof Holman’s Advanced Analysis of Linked Data.
- Some researchers in states outside of WA and NSW said that they would be interested in completing the Introductory Analysis of Linked Data course but limited availability and costs associated with travel to Perth had so far prevented them from attending.
- A growing number of researchers had or were intending to complete the SURE training.
- A small number of other training modules had been undertaken by a few of the data users including a Biostatistics Collaboration of Australia (BCA) traineeship (1 person),

a 5-day course on multilevel modelling (3 people), Prof D'Arcy Holman's Data and Biospecimen Law for Epidemiologists (1 person) and vendor-run courses on the use of IBM, SAS and COBOL (1 person).

- There was general support for provision of basic information such as how linkage is conducted, how to merge data, limitations of administrative data, legal/ethical aspects of linkage and access to Commonwealth data but it was felt by a number of data users that this could be provided through an information portal rather than training *per se*.
- Some data users felt that the PHRN should be less focused on delivering linkage-specific training but should instead be supporting training aimed at data analysis in general such as the units and traineeships offered by the Biostatistics Collaboration of Australia.

Conclusion

This paper has documented the range of services that data linkage organisations offer to facilitate access and delivery of linkable data for the purposes of health and related research. The audit of client services provided by linkage organisations in Australia and internationally found that the most common services provided to researchers involved supporting researchers to apply for access to linked data for research purposes including application support, assisting with project design, assisting with completing data custodian approval forms, provision of quotation estimates, review of submitted formal application to ensure completeness, assistance with brokering data release agreements with data custodians, support for use of the extracted data, publishing online metadata and manual tracking of data linkage research projects.

This paper also summarised the learnings to date from the Proof of Concept Collaborations. The Proof of Concept Collaborations have highlighted the complexity and cumbersome nature of cross-jurisdictional linkage projects as they require the cooperation and collaboration of large numbers of organisations compared with single jurisdictional linkage projects. In particular, researchers wanting to conduct a cross-jurisdictional linkage project must submit multiple application for data forms and ethics applications for approval from DLUs, data custodians and HRECs in each jurisdiction. This is a time-intensive and frustrating process for researchers in the current environment because there is no one organisation or website that a researcher can access that can provide them with all the information they require (including information about data collections available for linkage, application and approval requirements for each data collection) to assist them design and conduct a cross-jurisdictional linkage project. The Proof of Concept Collaborations have also highlighted the need for continuity in administrative support to facilitate access and delivery of linkable data in a timely manner.

This paper has outlined the needs of current and future population researchers based on the findings from the researcher consultation. Given the number of gaps in the services available to researchers wishing to conduct cross-jurisdictional linkage projects, i.e. in the application preparation and approval stages as identified in the Proof of Concept Collaborations, it is not surprising then that a key finding of the researcher consultation was that researchers strongly supported a streamlined and coordinated approach to the access and delivery of cross-jurisdictional linkable data including the development of a PHRN Metadata Framework and an online application mechanism.

The PHRN Metadata Framework and online application mechanisms have been identified as “priority elements” of national data linkage infrastructure for researchers and funded under the EIF-SSI Funding Agreement:

The first element is development of on-line application mechanisms that will enable researchers who wish to access cross-jurisdictional linked research datasets to apply via a web link and monitor the progress of their request. The second element will involve development of a framework for a national metadata repository that will enable researchers to identify the availability of linked or linkable data across Australia (Australian Government 2011: 51).

These elements will enable researchers to efficiently determine the availability and quality of linked or linkable data and its suitability for specific research purposes as well as lodge and track the status of their application. Work on these elements has commenced.

References

Australian Government 2011 *Funding Agreement between the Commonwealth of Australia as represented by the Department of Innovation, Industry, Science and Research and The University of Western Australia regarding funding for Population Health Research Network Education Investment Fund Super Science Initiative.*

Australian Government 2009 *Funding Agreement between the Commonwealth of Australia as represented by the Department of Innovation, Industry, Science and Research and The University of Western Australia regarding funding for Implementing an Investment Plan for the National Collaborative Research Infrastructure Strategy's Research Capability known as Population Health Research Network.*

Appendix 1: Summary of PHRN nodes' client services

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
Services							
Same organisation as linkage unit?	Yes	Yes	No. Health LinQ provides consultation services and facilitates access to linked data. The RLG (i.e. DLU) will operationalise the linkage of datasets, both within the state and nationally. Health LinQ is located at University of Queensland and RLG is located at QLD Health. (See http://www.healthlinq.org.au/queensland-node)	Yes	Yes	(See http://www.menzies.utas.edu.au/article.php?Doo=ContentView&id=1055)	Yes.
Staffing capacity for researcher services	Client services manages linkage projects and assists research applicants obtain linked data. Senior Data Linkage Consultant (role addresses strategies to address emerging development issues) Project Manager (role coordinates the approvals and linkage and extraction work for	Research Project Manager and Research Project Support Officer (half time in client service role).	Staff at Health LinQ includes 1 x Director, 1 x Research Officer, 1 x Project Coordinator	Manager, Research Data Services and Linkages 0.5FTE	1 x Director (0.6FTE) 1 x Associate Director (1.0 FTE) 3 x Business and Data Analysts (2.5 FTE) 1 x Administration Officer	Manager TDLU responsible for client liaison.	There is no dedicated client services team - this is undertaken by staff within the AIHW's DLU and Data Integration Services Centre but also within various AIHW subject area units depending on the nature of the project

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>WADLB projects) Project Officer (role processes EOIs and coordinates that phase of the application process) Cross-jurisdictional Program Coordinator (role finalises existing cross-jurisdictional projects) Data Coordinator of CARES (role develops and oversees CARES) Director, International Health Data Linkage Network (role is to establish an international health data linkage consortium) (See http://www.data-linkage-wa.org.au/about-us/staff-profiles)</p>						
Application support including answering questions regarding the approval and application process	Yes. The Program Manager provides advice on access and use of WADLB services and the exercising of Access and Pricing Policy controls. (See Access Policy, Section 4.3 Application Process)	Yes. Researchers can discuss their study with Research Project Manager before submitting their Application for Data Form. Research Project Manager can also provide approximate costing for study. (See	Yes. Health LinQ work with researchers to streamline application processes and advise researchers about the approval and application process. (See http://www.healthli	Yes.	Yes. The approval process is facilitated by SA NT DataLink. Researchers can contact Client Services to ask questions and gain assistance. A member of SA NT DataLink Client Services reviews the	Under development.	Yes

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	WADLB Project Manager and Officer also do this and refer things to Program Manager when necessary.	http://www.cherel.org.au/apply-for-linked-data)	nq.org.au/how-to-apply) Researchers in QLD must submit Request for Data Form, HREC application, Public Health Act Application.		application form, provides feedback and facilitates meeting with Researchers, Data Custodians and Data Providers. (See https://www.santdata.link.org.au/application_process)		
Project design including: cohort selection control selection variables/time periods required power calculations	Yes but not upfront/clear on website (Information not located in one place).	Yes. As part of Step 2 CHeReL will take enquiries from researchers about project formulation. (See http://www.cherel.org.au/apply-for-linked-data)	Yes. Health LinQ provide advice on project feasibility, scope, availability and quality of data. (See http://www.healthlinq.org.au/how-to-apply)	Yes.	Yes. Researchers can contact the Metadata and Research Advisory Services (Business and Data Analysts) for assistance with completing the application forms. (This information is written on application forms)	Subject to staff recruitment.	Yes.
Provision of feasibility review and quotation estimates for grant applications	Yes. Feasibility review provided once project has cleared EOI stage. (See http://www.data-linkage-wa.org.au/access-and-application/application-process) Yes. A quote for linkage will usually be provided with feedback to an EOI, however a quote can	Yes. As part of Step 2 CHeReL will provide an approximate cost for the linkage in initial discussions with researcher about the project. As part of Step 5 CHeReL will provide a written quote for the linkage. Quotes are valid for a period of one year. Some data custodians charge a fee for extraction of data from their collections. (See	Yes. Health LinQ provide advice on project feasibility to the researcher and quotation estimates if required.	Technical feasibility letter provided from VDL but no quotation estimate because VDL currently do not charge for data or data linkage.	Yes.	Manager TDLU.	Yes.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	be provided before applying for a grant or to scope project. (See http://www.data-linkage-wa.org.au/access-and-application/charging)	http://www.cherel.org.au/apply-for-linked-data)					
Assistance with completing HREC forms	No, but this may change at some point in the future.	We briefly view the NEAF to ensure that all datasets are included, but refer queries regarding completion of this form to the ethics secretariat.	Yes. Health LinQ provides assistance with completing HREC forms including provision of feedback regarding project feasibility, scope, availability and quality of the data. (See http://www.healthlinq.org.au/how-to-apply)	Yes	Yes	Subject to staff recruitment.	Yes, the AIHW Ethics Secretariat has an Ethics Manager that can also assist.
Assistance with completing data custodian approval forms	Yes. WADLB Project Officer will process EOI and present it to relevant data custodian for review. (See http://www.data-linkage-wa.org.au/access-and-application/application-process)	Yes. CHeReL forwards the Application for Data Form to the relevant custodians for review and feedback - this provides the opportunity for the CHeReL and data custodians to make suggestions and identify potential problems early in the application process. The CHeReL collates this feedback and	Yes. Health LinQ assists researchers in the entire application approval process.	Yes.	Yes. – Although there aren't many SA Data Custodians with 'forms' or a formal process - at least, not yet.	Subject to staff recruitment.	Yes, we are currently engaging with key Commonwealth data custodians to formalise approval procedures

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
		forwards to the researcher within 2-3 weeks of receiving the Application for Data Form. Researchers then amend the Application for Data Form and lodges with CHeReL who then forward the final Application for Data Form, variable lists, NEAF and protocol) to the relevant data custodians for approval. The custodian provides sign-off and sends the approval letters to CHeReL. (See http://www.cherel.org.au/apply-for-linked-data)					
Review of submitted formal application to ensure completeness	Yes. Feedback will be given to researcher and the final version of the approval form will be reviewed by Project Officer prior to formal submission. (See http://www.data-link-wa.org.au/access-and-application/application-process)	Yes. Researchers must email the amended Application for Data Form and variable lists for review. The CHeReL feasibility letter is based on the information contained in the Application for Data. The NEAF and protocol are also forwarded to the CHeReL, however a detailed review of	Yes. Health LinQ ensures completeness before submission.	Yes.	Yes.	Subject to staff recruitment.	Yes.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
		these documents is not performed. (See http://www.cherel.org.au/apply-for-linked-data)					
Assistance with HREC liaison	No. This is the responsibility of the HREC Executive Officer.	No. When the researcher has received the data custodian approvals and CHeReL technical feasibility letter, researchers submit their ethics documentation to HREC including the Application for Data form and variable lists, NEAF, project protocol, CHeReL technical feasibility letter and data custodian sign-off forms, and any other documentation specified by the HREC. (See http://www.cherel.org.au/apply-for-linked-data)	Yes. Health LinQ liaise with HREC (Research and Ethics Governance Unit).	Yes.	Yes.	Subject to staff recruitment.	Yes.
Assistance with brokering data release agreements with data custodians	Yes. Assistance with writing MoUs, standing agreements etc.	Yes. CHeReL arranges data custodian sign-off. Researchers may choose to organise data custodian sign off themselves for data that is not held in the Master Linkage Key.	Yes. Health LinQ liaise with custodians to finalise data release agreements.	Yes.	Yes. Research Deed of Confidentiality and Compliance can be found at Attachment 2 of the Application Form.	Subject to staff recruitment.	Yes, particularly with key Commonwealth data custodians , we are currently with data custodians to build processes
Preparation of data	WADLB Project	This is done by	Yes, Health LinQ	Yes.	SANT DataLink and	Subject to staff	AIHW staff, though

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
extraction plan	<p>Manager sends out encrypted project specific linkage keys to data custodians. (See http://www.data-linkage-wa.org.au/data-linkage/extraction-process)</p> <p>The summary we write for EOI (and then for the formal project) is similar to a data extraction plan. It gives a rough idea of logistics.</p>	linkage staff prior to linking the data, rather than client services, but may require the involvement of both teams for efficient and accurate specification.	assist in creating this plan through data specifications in the PHA.		Data Custodians. We draft and seek signoff from the researcher on a Technical Specifications document, which is used to brief the SA NT DataLink, linkage team.	recruitment.	staff from with Commonwealth data custodians are often also involved
Merging of de-identified datasets	<p>Researcher merges and analyses data. (See http://www.data-linkage-wa.org.au/data-linkage/extraction-process)</p>	Researchers.	RLG at Queensland Health.	Researchers. Merging may sometimes be done by VDL, will depend on project.	Yes. Researchers merge de-identified datasets for analysis. (See https://www.santdata-link.org.au/application_process)	Subject to staff recruitment.	Yes
Checking of datasets prior to delivery to researchers	<p>WADLB Client Services Analyst checks data matches request, writes reference information and converts files to standards forms. (See http://www.data-linkage-wa.org.au/data-linkage/extraction-process)</p>	Data custodian forwards the de-identified data to the Principal Investigator. (See http://www.cherel.org.au/information-for-data-custodians)	RLG at Queensland Health put effort into validating data, e.g. checking matches, mismatches, non-matches.	Yes.	Under the current model of delivery, linked data is not checked prior to provision to Principal Investigator. SANT DataLink follows the WA model, so we don't ever see the service data. This goes directly from Custodian to Researcher.	It is likely that data will be released directly to researchers by custodians.	Designated data custodian of linked dataset
Addition of SEIFA or ARIA codes to	SEIFA and/or ARIA values can be	Data custodians.	RLG at Queensland	VDL can add SEIFA but not ARIA codes	Not currently a service offered.	Possibly; will depend on individual	Yes, but some centralised advice to

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
extracted data	provided with HMDC, MNS, EDDC and Death records at CD and SLA level. In most cases SLA, LGA and radius are supplied on data extracts where needed. (See http://www.data-linkage-wa.org.au/data-linkage/geographical-information)		Health if requested.	to extracted data.	These are sometimes coded within disparate data sets, for internal reporting etc. Given ethics approval, their release to researchers may be negotiated with Custodians. SANT DataLink, however does not currently derive any variables.	circumstances. Likely that standard code sets will be made available to researchers.	researchers regarding what data they need to do this and limitations/pitfalls would be helpful
Provision of datasets to researchers	For core data collections, the data custodians send datasets to WADLB. For most external datasets, the service data is released directly to the researcher. (See http://www.data-linkage-wa.org.au/data-linkage/extraction-process)	The data custodian forwards the de-identified data to the Principal Investigator. (See http://www.cherel.org.au/information-for-data-custodians)	The RLG at QH can provide datasets direct to researchers, or if specified on the PHA, Health LinQ can be the nominated recipient.	Currently doing it under 2 models – from VDL or provide the linkage keys to the data custodians and then data custodians provide datasets to researcher.	Yes. Data custodians use the project specific linkage keys and produce de-identified datasets which they provide to researchers. (See https://www.santdatalink.org.au/application_process)	It is likely that data will be released directly to researchers by custodians.	Designated custodian of linked analysis dataset
Mode of delivery of data extracts	The WADLB Project Manager prepares the data for release by encrypting it and burning it to a disc, then arranges for secure delivery to the researcher. (See http://www.data-linkage-wa.org.au/data-linkage/extraction-process) Linked data files are	Encrypted disc.	On encrypted disc or encrypted (using WinZip) and password protected and attached to email from custodians or RLG at Queensland Health. The password is provided via a separate medium - usually over the telephone.	Secure data exchange.	Encrypted DVD, with consideration of the design and development of secure access facility underway.	Planned to deliver electronically via secure data delivery system.	Currently on encrypted DVD or through a secure messaging system, however in future 'high-risk' datasets will only be able to be accessed through the AIHW on-site lab or a SURE-type facility

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	usually provided on a CD as fixed width, text files. They will be encrypted/password protected using WinZip, 7zip or the WADLB's own encryption program. (See http://www.data-linkage-wa.org.au/data-linkage/linked-data-preview)						
Provision of privacy/security training to researchers	No.	No. The website provides information about CHeReL's approach to preserving privacy and data governance. (See http://www.cherel.org.au/privacy-ethics) The website has information about training providing by other organisations in their event calendar. Training is not privacy/security specific. (See http://www.cherel.org.au/events)	No formal training is provided, however Health LinQ staff do advise researchers on best practise methods for privacy/security of data.	Yes.	Yes.	Planned for future once the TDLU is fully operational. It is likely that information / fact sheets will be provided as part of data application process.	No.
Preparation of metadata about data extracts and provision to researchers	A combination of WADLB & Data Collections. Metadata is held in data dictionaries created by the	The CHeReL provides a paper outlining the results of the linkage. Data custodians may choose to provide	RLG prepares a text explanation of what is being sent including caveats and data quality issues with datasets	Yes. Researchers provided with statement about linkage quality.	Yes.	Planned for future once the TDLU is fully operational.	Varies with project and availability of metadata.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	original data collections. WADLB has a few additional tables that are available on the website. There are some that are WADLB only (e.g. mortality) where WADLB are the delegated custodians. The data collections usually provide some notes to WADLB with the extractions and this is either given directly to the researchers, or used to prepare the WADLB written 'information form'.	metadata on the extract to the researchers.	(e.g. incomplete records or years).				
Support for use of the extracted data, including answering questions about data fields and coding specifics	On receipt of the data, researchers will be given an information form. (See http://www.data-linkage-wa.org.au/data-linkage/linked-data-preview) Most enquiries come to the Client Services WADLB Project Manager, who filters the enquiry to the appropriate person. At times the Linkage Team, Data Analysts	CHeReL provides support regarding queries about the linkage, however specific questions about clinical data fields, coding etc are directed to the data custodians.	RLG at Queensland Health.	Yes.	Yes	Planned for future once the TDLU is fully operational.	Designated custodian of linked analysis dataset.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	and the Data Custodians assist in answering questions.						
Collation and archiving of all project documentation	Yes – WADLB manages project files. This is additional to HREC files.	Yes.	Yes.	Yes.	Yes.	Planned for future once the TDLU is fully operational.	Yes.
Collation of annual reports	The WADLB Project Manager collates annual reports from recipients of linked data. (See http://www.data-linkage-wa.org.au/downloads/reporting)	No. CHeReL does not require researchers to submit annual reports.	No. HealthlinQ does not have annual reporting requirements.	Yes.	No.	Planned for future once the TDLU is fully operational.	Not required.
Publication of lay summaries of current and completed projects on DLU website	Website has information about Cross-Jurisdictional Program, Developmental Pathways Project, Family Connections Project, Indigenous Identification Project, and WA Road Safety Project. (See under 'Projects') Current projects: A list of new projects received in March 2012 detailing the title and investigators and brief summary. The Application for Data form now includes a	Yes. A list of completed projects including title, investigators and project summary is available on the website. (See http://www.cherel.org.au/completed-projects) Current projects do not appear on CHeReL website.	No.	No.	Yes. Summaries of current projects can be found on 'Statistical Linkage Projects' webpage. (See https://www.santdata-link.org.au/Projects)	Planned for future once the TDLU is fully operational.	Yes. Projects approved by the AIHW Ethics Committee during 2011 and project extensions and variations approved by the AIHW Ethics Committee during 2011 are available on website. (See http://www.aihw.gov.au/data-integration)

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>request for a lay summary. (See http://www.datalinkage-wa.org.au/projects/new-projects)</p> <p>Completed projects: A list of all projects from 1995 to 2010 detailing the title and investigators is available on the website. (See http://www.datalinkage-wa.org.au/projects/past-research)</p>						
Publication of research outputs on DLU website	<p>The Summary Report of the Research Outputs Project, including a list of project outputs from 1995 to 2003 is available on the website. (See http://www.datalinkage-wa.org.au/projects/publications-and-results)</p> <p>A register of all applications for data is maintained, and a system for logging outputs from these projects is being developed. Researchers who obtain linked data are asked to submit</p>	<p>A list of published journal articles and reports that have used data linked by CHeReL are available on the website. (See http://www.cherel.org.au/publications)</p>	No.	No.	<p>No. But on 'Sample Linkage Projects' page on the website has list of projects which use linkage (range of projects that have not used SANT Datalink). (See https://www.santdatalink.org.au/Linkage-projects)</p>	Planned for future once the TDLU is fully operational.	No.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	a copy of any report, journal article, other publication, conference presentation or media interest generated from data supplied. (See http://www.data-linkage-wa.org.au/projects/past-research)						
Marketing of data linkage	Yes. Client Services Team and data linkage marketed through WADLB website. (See http://www.data-linkage-wa.org.au/about-us and other web pages on this site) WADLB present to researchers and have also done presentations for ethics committees at institutions (e.g. universities, hospitals).	Yes. Client Services Team and data linkage marketed through CHeReL website.	Yes. Client Services Team marketed through Health LinQ website and seminars/workshops within the research community.	VDL website.	Yes. Client Services Team and data linkage marketed through SA NT DataLink website, e-newsletter, dissemination of <i>What is Data Linkage</i> , an animation developed by SA NT DataLink for a broad audience, regular engagement with universities and local research community. SA NT DataLink Consumer Reference Group – lay and professional review of projects, to encourage community participation and information events to raise awareness and promote data linkage, regular	Draft marketing, promotion and publicity strategy prepared.	AIHW website (See http://www.aihw.gov.au/data-integration/)

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					delivery of papers at national and international conferences.		
Summary of project-related documents maintained by Client Services	<p>Application for Data form/Amendment Request Form</p> <p>Data services forms including Linkage Form/Extraction Form/Geocoding Specifications/Sample Selection Form/Family Connections Form</p> <p>Variable lists including Birth Data, Mortality Data, WA Cancer Registry Data, Midwives Notification Data, Hospital Morbidity Data, Mental Health Ambulatory Data, Emergency Data, Electoral Roll Data, RM27 Form (if identifiable electoral data used).</p> <p>The WADLB Project Manager also tries to get variable lists for non-core datasets (e.g. at the moment the WADLB Project Manager has 12 extra lists that she has created with assistance from the</p>	<p>Application for Data Declaration of Undertaking by the Data Custodians and Chief Investigator</p> <p>Completed NEAF and Privacy Addition to NEAF</p> <p>Research Protocol</p> <p>Approved quotation</p> <p>Metadata about data extracts</p> <p>Approved summary of project aims for website/ newsletter</p> <p>Amendment/ update applications</p> <p>Project publications</p> <p>Variable lists</p>	<p>EOI form</p> <p>PHA Application</p> <p>HREC Application</p> <p>HREC approval letter</p> <p>Project publications – if applicable</p>	<p>Interim Project Description (EOI)</p> <p>Researcher Data Access Request (RDAR)</p> <p>Technical feasibility letter from VDL</p> <p>Condition of release form</p> <p>In-principle support letter from individual Data Custodians</p> <p>HREC application (NEAF or other) and associated documents</p> <p>HREC approval certificate</p> <p>Quotation and acceptance</p> <p>Research Data Access Agreement with each Data Custodian</p> <p>Information Sharing Agreements (between DC and VDL)</p> <p>Research Data Services Agreement (between the researcher and VDL including quote)</p> <p>Amendment/ update</p>	<p>Statistical Linkage Project Application Form (incl EOI section)</p> <p>Researcher Agreements</p> <p>Deed of Confidentiality and Compliance</p> <p>Approvals in Principle</p> <p>Final approvals</p> <p>NEAF or other HREC application</p> <p>Public Interest Determination form (if required) (NT ONLY)</p> <p>HREC approval letter</p> <p>Privacy Commissioner approval letter (if required) (In SA & NT Privacy Exemption is only sought once for each dataset, upon inclusion to the MLF. No Privacy approval is required for an individual project, an Ethics approval is used to cover this.</p> <p>Certificate of destruction – where</p>	Planned for future once the TDLU is fully operational.	As before, and AIHW are also launching an Online Ethics System (ETHOS).

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>custodians). These aren't available on the website but are given out to researchers when they request them.</p> <p>Any supporting documentation (e.g. participation information sheets, consent forms & information about data collections required outside of DOHWA)</p> <p>DOHWA HREC Application for Ethical Review. (Filed for information only, HREC support team is responsible for maintenance)</p> <p>Detailed research proposal/protocol.</p> <p>Any documentation regarding approval from other Human Research Ethics Committees.</p> <p>Confidentiality agreement/acknowledgement for all personnel listed on the project (either for Researchers or WA public sector employees).</p> <p>(See http://www.dataLink)</p>			<p>applications</p> <p>Annual reports</p> <p>Project closure documentation</p> <p>Project publications</p> <p>Written notice of data destruction</p>	<p>applicable</p> <p>Project publications – copy of manuscript to be provided by researcher to each data custodian and SANT DL, at least 2 weeks prior to submission for publication.</p>		

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	<p>age-wa.org.au/access-and-application/submission-instructions)</p> <p>Project Summary. (See http://www.data-linkage-wa.org.au/projects/new-projects)</p> <p>Summary of outputs including report, journal article, other publication, conference presentation or media interest generated from data supplied. (See http://www.data-linkage-wa.org.au/projects/past-research)</p> <p>Annual reports. (See http://www.data-linkage-wa.org.au/downloads/reporting)</p>						
Agreements	<p>Confidentiality Agreements and Acknowledgements between DOHWA HREC and researchers. (See http://www.health.wa.gov.au/healthdata/HREC/index.cfm)</p> <p>Confidentiality</p>	<p>Before releasing any data, the Ministry of Health requests a signed confidentiality agreement from the researchers. Custodians of other collections are also encouraged to</p>	<p>Yes. Copy of approved PHA application containing signed Confidentiality agreements, copy of approved Ethics application and copy of Custodian approved consent</p>	<p>MOU with data custodians</p> <p>Research Data Access Agreement with each Data Custodian</p> <p>Information Sharing Agreements (between DC and VDL)</p>	<p>Researcher Agreement Section 5 of the SA Statistical Linkage Application Form. Researchers applying for SA Department of Health data sets are subject to an additional SA Health</p>	<p>Under development.</p>	

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	Agreement/Acknowledgement for all personnel listed on project. (See http://www.datalink.wa.org.au/access-and-application/submission-instructions)	obtain a signed confidentiality agreement and follow the data disclosure policies of their organisation. (See http://www.cherel.org.au/information-for-data-custodians)	forms (for identifiable data).	Research Data Services Agreement (between the researcher and VDL including quote)	Deed of Confidentiality		
Subscription	No.	Researchers can subscribe to CHeReL's newsletter and data update announcements. (See http://www.cherel.org.au/subscribe)	Yes. Researchers can subscribe to a mailing list. (See http://www.healthlinq.org.au/mailling-list)	No.	Researchers can subscribe to SA NT Datalink mailing list/newsletter. (See https://www.santdatalink.org.au/news_and_events)	Planned for future once the TDLU is fully operational.	Email alerts.
Metadata							
Availability of online information	Website has metadata for a number of core datasets including Hospital Morbidity Data Collection, Emergency Department Data Collection, Mental Health Information System, Western Australian Cancer Registry, Midwives Notification System, Death Registrations and WA Electoral Commission Records. These collections all have information about	CHeReL website has details of core and external data sets. Metadata and variable lists for each core data collection are found on the Data Dictionaries webpage. (See http://www.cherel.org.au/data-dictionaries) CHeReL have information about how to apply for linked data, pricing quality assurance (quality checks and procedures), provision of statistics	Health LinQ website contains the following metadata: List of core datasets: 1 Queensland Hospital Admitted Patient Data Collection 2 Queensland Perinatal Data Collection 3 Registrar General – Birth notification 4 Registrar General – Birth registration 5 Registrar General – Deaths List of other data	To find metadata information you need to click on 'Data dictionaries' link on VDL website, which then takes you to the HOSdata website, and from there you click on the Health Data Standards and Systems website to access user manuals for VAED (See http://www.health.vic.gov.au/hdss/vaed/index.htm) , VEMD (See http://www.health.vic.gov.au/hdss/vemd)	SA Statistical Linkage Application Form indicates that there is a data dictionary available for metadata on specific data items on the website (documentation on metadata and research utility are currently being developed). (See Application Form, Section 2.4) Data Quality Statements available for many existing linked datasets. Data Quality Statements	Under development.	Metadata available in METeOR including National Data Dictionaries and NMDS Data Set Specifications (See http://meteor.aihw.gov.au/content/index.phtml/itemId/181162)

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>content of data collections, data collection date range, and frequency of linkage. Website has name of 'satellite' data collections with the following custodians: WA Government, Other organisations, Geocoding, Family Connections, WA Health, and Australian Government.</p> <p>Website has variable lists in table form including Mortality Data Variables, Emergency Data Dictionary, HMDS Reference Manual, HMDS Data Variables, ICD and DRG Versions, MHIS Ambulatory Data Dictionary, Midwives Data Variables, and Notification of Case Amendment Form.</p> <p>Access Policy and Practice Code for the Use of Personal Health Information available.</p> <p>List of References applicable to data linkage research methods.</p>	<p>regarding linkage system and core data sets, validation studies, information for data custodians (process) and data custodian contact details.</p>	<p>collections:</p> <ol style="list-style-type: none"> 1 Queensland Cancer Registry 2 Queensland Ambulance Service 3 Queensland Trauma Registry 4 Community Integrated Mental Health Application (CIMHA) 5 Emergency Department Information System (EDIS) <p>Data Variable Lists for Queensland Hospital Admitted Patient Data Collection and/or the Queensland Cancer Registry.</p> <p>Geographical, Remoteness and Socio-Economic Indicators.</p> <p>Links to QLD, national and international organisations.</p> <p>QLD Health Website contains the following:</p> <p>In Public Health Act 2005 Application there is some information on</p>	<p>/index.htm , ESIS (See http://www.health.vic.gov.au/hdss/esis/index.htm) and VINAH (See http://www.health.vic.gov.au/hdss/vinah/index.htm) . The manuals include information on concept and derived element definitions and data definitions.</p>	<p>provide the following details:</p> <p>Institutional environment: Organisation and authority for collection;</p> <p>Relevance: Purpose of the collection, population covered, geographic coverage and reference period.</p> <p>Timeliness: Frequency of collection, frequency of release, and timeliness of release.</p> <p>Accuracy: Quality assurance and coverage.</p> <p>Coherence: Internal consistency, comparability, and linkage variables.</p> <p>Interpretability: Metadata.</p> <p>Accessibility: Data custodian, researcher inquiries, method of access, and data availability.</p> <p>The 'Available Datasets' Page on the website has a summary of existing datasets linked in the Master Linkage File. Details included</p>		

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>Provision of statistics regarding linkage system and core data sets.</p> <p>Frequently Asked Questions.</p> <p>Contact details for WADLB.</p> <p>Links.</p>		<p>dataset guidance which refers to the AIHW's national minimum data sets and datasets specification.</p> <p>Queensland Health Data Dictionary. (See http://www.health.qld.gov.au/performance/docs/QHDDRreport.pdf)</p>		<p>in the summary are the name of the dataset, years range, name of data custodian/delegate, availability of data quality statement, availability of metadata, whether a supplementary data request form is required, and whether an additional confidentiality agreement is required. The name of datasets are as follows:</p> <p>LINKED</p> <p>South Australia Cancer Registry</p> <p>South Australia Women's and Children's Health Network – Midwife's Universal Contact</p> <p>South Australia Women's and Children's Health Network – Family Home Visiting for Mothers and Infants at Risk</p> <p>South Australia Women's and Children's Health Network – Mother's</p>		

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					Day Service South Australia Women's and Children's Health Network – Universal Neonatal Hearing Screening Program South Australia Women's and Children's Health Network – Childhood Immunisation Registry South Australia Women's and Children's Health Network – “Blue Book”, Child Health Checks South Australia Dental Service South Australia Emergency Department Data Collection South Australia Public Hospitals Inpatient Separations South Australia Public School Enrolments (Census) South Australia Public School Students – Years 1 to 3 Reading Assessments		

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					South Australia Public School Students English as a Second Language Scale NAPLAN Families SA– Child Protection database Families SA– Alternative Care Arrangements database Families SA– Care and Protection Orders database SA Births Registry SA Deaths Registry South Australian Perinatal Statistics Collection Australian Early Development Index AEDI NT Department of Health – Client Master Index Database NT Department of Health – Midwives Collection NT Department of Health – Immunisation Registry NT Deaths Registry NT Births Registry NT Department of		

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					Education and Training – School Enrolments NT Department of Education and Training – School Attendance SOON TO BE LINKED Housing SA – Public Housing Program Housing SA – Aboriginal Rental Housing Program Housing SA – Student Housing Program Housing SA – Disability Housing Program Housing SA – Private Rental Assistance Program UNDER NEGOTIATION SA Mental Health and Substance Abuse Client database SA Drugs of Dependence Registry SA Disability Services Client database SA Private Pathology Services SA Public Pathology Services SA Childcare		

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					<p>Management System Data</p> <p>SA Courts Administration Authority database, Crimcase</p> <p>SA Attorney General's Department - Office of Crime Statistics and Research database</p> <p>SA Department of Correctional Services – Custodian and Non-custodial database</p> <p>Australia and New Zealand Renal Dialysis and Transplant Register</p> <p>Other information on the 'Available Datasets' page on the website include datasets that are under negotiation and information about accessing other datasets. (See https://www.santdatalink.org.au/available_datasets)</p> <p>SANT Dataset Status Report on Master Linkage Files.</p> <p>The website also refers researchers to</p>		

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					metadata available via METeOR.		
Frequency of updates	Generally they don't get updated – that is the responsibility of the data collections. However for the ones we manage, updates happen perhaps once a year? Not needed very often. Variable lists are changed much more often.	Annually.	Data custodians at Queensland Health do not publish metadata online so researchers must use existing manuals and discuss with HealthlinQ staff to determine variables available.	Annually.	Annually	Monthly.	Regular
Responsibility for collation/updating	Data custodians and WADLB staff.	Research Project Manager.	N/A.	Funding and Information Policy Branch of the Hospital and Health Service Performance Division of the Victorian State Government, Department of Health. (See http://www.health.vic.gov.au/hdss/index.htm)	2.5 x Business Analysts. (Stacy 1.0 FTE/Almond 0.6 FTE/Nicky (NT) 0.9 FTE)	Manager TDLU.	AIHW Metadata Infrastructure Services Unit.
Application process							
Form available online	Yes. EOI and Formal Application Form online. (See http://www.data-link-wa.org.au/forms)	Yes. Application for Data form is available online. (See http://www.cherel.org.au/apply-for-linked-data)	Yes. EOI can be found at http://www.healthlinq.org.au/forms	Yes. Initial Project Description is available online. (See http://www.health.vic.gov.au/vdl/downloads/ipd_form_v1-7.doc) Yes. The HOSdata application form is	Yes. There are two forms for accessing linked data through SA NT Datalink (1)SA and (2) NT. The forms are available at https://www.santdatalink.org.au/application_process	Under development, planned to put all documentation relating to application, approval and release of data online at MRIT website.	Yes. Client Ad-Hoc Data Request Form. (See http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421903) AIHW is planning to develop an online Ethics Committee

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
				<p>available on line but not via the VDL website. Must click on data dictionaries on VDL website to be taken to Victorian Hospital Data Reports website. (See http://www.health.vic.gov.au/hosdata/requests.htm)</p> <p>No. Application for Data Form is not available on line.</p>			<p>application and approval process led by their Information and Governance Group – currently in acceptance testing</p>
Clear process overview available	<p>Yes. Clear diagram which illustrates the application process. (See http://www.data-link-wa.org.au/access-and-application/application-process)</p> <p>Submission instructions available online. (See http://www.data-link-wa.org.au/access-and-application/submission-instructions)</p>	<p>Yes. Steps 1 to 6 are clearly described using a diagram and text. (See http://www.cherel.org.au/apply-for-linked-data)</p>	No.	<p>Yes but only in the 'Researchers' Guide' which is available with the Application for Data Form.</p>	<p>Yes. Clear diagram which illustrates the application process. (See https://www.santdata-link.org.au/application_process)</p>	Under development.	Yes.
Approx. timelines provided online	<p>No. Very subjective. WADLB generally advise it takes about 3 months to get through the</p>	<p>No. These are not currently included on the website.</p>	No.	No.	<p>No but a note appears at the end of the application process information which informs</p>	Under development.	No.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	application process.				researchers that a dataset that's not readily available in the Master Linkage File will add significant delay due to the 'acquisition process' of datasets. (See https://www.santdataalink.org.au/application_process)		
EOI process prior to formal application	Yes. Step 1 in the application process is for the researcher to submit an EOI to WADLB. The EOI is essentially a draft application and allows for any issues to be identified and corrected before work begins on the project. The EOI should include the Application for Data form, relevant data services forms and variable lists and a research protocol. No signature is required. (See http://www.dataalink.wa.org.au/access-and-application/application-process and http://www.dataalink	Yes. Researchers must complete an Application for Data Form and submit to CHeReL for data custodian and CHeReL feedback prior to formal submission. (See http://www.cherel.org.au/apply-for-linked-data)	Yes. Researchers must submit an EOI to HealthlinQ. (See http://www.healthlinq.org.au/forms). Final application is the Request for Data Form and relevant documentation including ethics (NEAF), Public Health Act Application, and custodian approvals.	Yes. Researchers can use the Initial Project Description Form.	<u>SA Statistical Linkage Application Form:</u> Yes. Researchers complete Sections 1-3 of the form and then collaborate with SA NT Datalink and data custodians to refine and complete the application. (This information is written on SA application form.) <u>NT Statistical Linkage Application Form:</u> Yes. The form can be used as an EOI, application for data amendment/update for an existing project, or application for data (final).	Yes, planned.	Discussions with AIHW staff prior to submitting formal application.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	age-wa.org.au/access-and-application/submission-instructions)						
Do Data Custodians provide input to EOI prior to formal application submission?	Yes. Data custodians review and provide feedback on EOI via WADLB. (See http://www.data-linkage-wa.org.au/access-and-application/application-process) Applicants cannot submit formal application until they have cleared EOI and a feasibility letter has been provided.	Yes. Data custodians have the opportunity to review and provide feedback on Application for Data form (EOI) via CHeReL. (See http://www.cherel.org.au/apply-for-linked-data)	Health LinQ consults with Data Custodians prior to the final submission of the PHA.	Yes	Yes. (See https://www.santdata-link.org.au/application-process)	Yes, planned.	Yes.
Application form content						Draft Application for Linked Data Framework developed.	
Personnel details	Yes; Sections 2 and 7 of Application for Data Form. All personnel including PI, students and project personnel need to be identified. Details to be included are as follows: Title, Full Name, Qualifications, Institution, Employing	Yes; Section 2 of Application for Data Form. All personnel including applicant/CI, project contact and co-investigators to be identified. Details to be included are as follows: Name/Title, Organisation, Position, and Role.	Yes; Section 1 of the Request for Data Form requires the PI (person who has overall responsibility for the management of the project) and contact person (person to be contacted for queries about this project) to provide the following details: Name, Title and	<u>Initial Project Description</u> Applicant(Name and title, Organisation, Telephone, Email) and Supervisors (if applicable) <u>Application for Data Form</u> Project contact (Name, Organisation, Telephone, Email)	<u>SA Statistical Linkage Application Form</u> : All personnel including Applicant/PI/Responsible Senior Officer, Contact Person and Co-investigators/Researchers need to be identified in Sections 1.2, 1.3 and Co-investigators/Researchers. Details to be included are as	Yes, planned.	Note: The HREC application form is the same as the application form. There are 2 forms: AIHW staff wanting to access linked data and external researchers wanting to access linked data Contact within AIHW (relevant custodians) Principal Investigator

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	Institution, Email, expertise/role in the project and who requires access to data.		<p>Organisation, Contact address, Email address, Fax, Phone numbers.</p> <p>Yes; Sections 3, 4, and 5 of the Public Health Act Application. Section 3 requires PI, Co-investigator and Additional Applicants to be identified. Section 4 requires the contact details for the PI and Co-investigator and Section 5 requires the name of supporting institution.</p>	<p>Principal Investigator (Name, Organisation, Telephone, Email)</p> <p>Secondary Investigator (Name, Organisation, Telephone, Email)</p>	<p>follows: Title and Name, Organisation, Contact details.</p> <p><u>NT Statistical Linkage Application Form:</u> Requestor needs to be identified in Part A. Details to be included are Name, Position Title, Section/Branch/Organisation, Telephone, Email, Supervisor's Designation, and Supervisor's Title.</p>		Contact officer Individuals/groups/organisation that will be participating in / supervising project
Project details	<p>Yes; Section 5 of Application for Data Form. Researchers must provide a detailed outline (approximately one to two pages) including the background, aims, design and methodology of the project. The aims should reflect the datasets, time frames and variables requested. The methodology should contain detailed information of what</p>	<p>Yes; Section 3 of Application for Data Form. Researchers must provide a concise and simple description of the project in not more than 400 words including the background, aims, research design, and methods.</p> <p>Yes; Section 6 of Application for Data Form. Researchers must provide details of duration/length of project.</p>	<p>Yes; Section 2 of the Request for Data Form. Researchers must provide a detailed outline which includes the project title, context, objective, design, methodology, timeline (start and end dates).</p> <p>Yes; Sections 1, 2, 6 and 7 of the Public Health Act Application. Researchers must provide a the project</p>	<p><u>Initial Project Description</u></p> <p>Part A. Initial project description includes the following:</p> <p>Research topic/title</p> <p>Summary</p> <p>Problem statement/Study purpose</p> <p>Study objectives/Research questions</p> <p>Research design</p> <p>Statistical methods</p> <p>Part B. Project status sheet includes the</p>	<p><u>SA Statistical Linkage Application Form:</u></p> <p>Yes. Section 1.1 Project title and description.</p> <p><u>NT Statistical Linkage Application Form:</u></p> <p>Yes. Part B 'Data request details' requires the researcher to provide a (1) description of project/activity including, where relevant, details of cooperating agencies and other</p>	Yes, planned.	<p>Title</p> <p>Plain language description (100 words)</p> <p>Scientific objectives</p> <p>Value/benefit of conducting study</p> <p>Timelines (start/end dates)</p>

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	methods will be used in the data analysis.		<p>title (Section 1), identification of research category (Section 2), location where project is conducted (Section 6), and in Section 7 a detailed outline which includes the following:</p> <p>Research objectives Research benefits Research outcomes Methodology Rationale for using identifiable confidential health information Community benefits Benefits vs risks Estimated timeframe of the project</p>	<p>following:</p> <p>Project type Data linkage services required/requested Critical dates External datasets required/requested Ethics Funding <u>Application for Data Form</u> Project Title Goals/Objective/Purpose (max 500 words) Project Keywords Inclusion/Exclusion Project deadlines Data output format</p>	<p>stakeholders, funding sources and approvals, including ethics approvals. Researchers must also outline the (2) objective of the project/activity including the aims and objectives of the project/activity including any legislative requirement authorising collection of the data, and the purposes for which it will be used in relation to the project/activity.</p>		
Data services required e.g. linkage, extraction	Yes; Section 9.1 of Application for Data Form. Researchers must indicate the data services they require including extraction from collections, new linkage, geocoding, sample selection (e.g. from electoral roll), genealogical data (family relationships), and study recruitment (use of core data for	Yes; Section 4 of Application for Data Form. Researchers must indicate the data services they require including extraction of records from the Master Linkage Key, linkage of an external dataset to the MLK, linkage of two or more external datasets or other.	Not specifically asked although Section 5 of the Data Request Form is about extraction and linkage.	<p><u>Initial Project Description</u> Extraction of data based on existing linkages of core dataset linkages Linkage of one external dataset to records in the core dataset Linkage of two or more external datasets for linkage Other <u>Application for Data</u></p>	<p><u>SA Statistical Linkage Application Form:</u> Yes; Section 2.1. Researchers are must identify whether their data requirements require once-off extraction or ongoing extraction. <u>NT Statistical Linkage Application Form:</u> Yes, Part B 'Data request details' requires the researcher to</p>	Yes, planned.	The researcher will generally specify these details, but the application process does not specifically collect details.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	recruitment). A data service form for each service needs to be completed and attached to the application.			<u>Form</u> No.	identify the (1) data request category i.e. ad hoc report or period report, (2) required delivery time i.e. this week or this month, (3) level of request i.e. urgent or important.		
Details of Data Collections for extraction	<p>Yes; Section 9.2 of Application for Data Form. Researchers must indicate which data collections they need and the year span required.</p> <p>Researchers must attach a separate word document outlining the details of the dataset name, data custodian contact name, phone number and email address and data variables sought.</p> <p>If applying for an extraction of data, researchers must complete a variable list for each dataset requested. All requested variable lists must be attached to your application.</p> <p>Researchers must indicate the personal</p>	<p>Yes; Section 8 of Application for Data Form. Researchers must indicate data required for cohort including which collections and years required.</p>	<p>Yes; Section 5 of the Data Request Form requires researchers to identify the following information:</p> <p>Source: collection(s) from which data will be extracted</p> <p>Scope: years for which the data is requested, the hospital type(s), the age groups required, and any other information that clearly identifies what data needs to be extracted for each data source)</p> <p>Variables</p> <p>Yes; Section 8 of the Public Health Act Application. Researchers must list the name/description of database and data items required,</p>	<p><u>Initial Project Description</u></p> <p>Checklist of datasets available for extraction:</p> <p>Victorian Admitted Episodes Dataset (VAED)</p> <p>Victorian Emergency Minimum Dataset (VEMD)</p> <p>Deaths Data from the Registry of Births, Deaths and Marriages</p> <p><u>Application for Data Form</u></p> <p>Checklist of datasets available for extraction:</p> <p>Victorian Admitted Episodes Dataset (VAED) – data field description, definition, required yes/no, justification (researcher to indicate if required and justification)</p>	<p><u>SA Statistical Linkage Application Form:</u></p> <p>Yes; Section 2.2. Researchers must indicate which data collections they need, in Section 2.4 indicate the years required and in Section 2.5 the data items required.</p> <p><u>NT Statistical Linkage Application Form:</u></p> <p>Yes, Part B 'Data request details' requires the researcher to (1) name the data collection (2) data elements required (3) date range/s required (4) Period of approval i.e. ongoing or fixed.</p>	Yes, planned.	Which databases will be accessed, created or modified (no specific details requested).

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	information variables required and explain rationale for personal information in the data extract.		specific time periods and data intervals.	Victorian Emergency Minimum Dataset (VEMD), – data field description, definition, required yes/no, justification (researcher to indicate if required and justification) Elective Surgery Information Systems (ESIS) Victorian Death Index (VDI) Time period also required.			
Details of non-core data sets to be linked in	Yes. In Application for Data Form researchers must indicate the other sources of information and describe the source of the information, the information that will be collected from each source and specify whether the project involves the matching of records from different sources. Researchers must attach a separate word document outlining the details such as dataset name, data custodian contact	Yes. For researchers who require an external dataset to be linked, Section 5 of Application for Data Form requires researchers to provide details including name/brief description of dataset, number of records, custodian name and contact details, personal identifiers available for linkage, year span of dataset, and comment on the expected linkage rates of data based on previous research if available. Researchers must	Yes, Section 5 of the Data Request Form requires researchers to include a basic description of the data along with information on the number of records, the number of people (unique IDs), data fields, data formats and the years of data. Yes; Section 8 of the Public Health Act Application. Researchers must list the name/description of database and data items required, specific time periods	<u>Initial Project Description</u> Type of dataset Purpose of the dataset Years over which the data has been collected Number of cases/records it includes Details of the data holder/custodian <u>Application for Data Form</u> Name of dataset Custodian details Data field description, definition, justification	<u>SA Statistical Linkage Application Form:</u> Yes; Section 2.3 'Other data sources to be sourced for this project'. Researchers indicate additional datasets required for the project. <u>NT Statistical Linkage Application Form:</u> No.	Yes, planned.	Not specifically requested.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	name, phone number and email address and data variables sought if a standard variable list is not available.	also attach a list of variables for external datasets.	and data intervals.	Time period			
Cohort definition	<p>Yes. In Application for Data Form researchers must complete the data extraction form and provide the following details of the cohort: cohort description, disease and procedure codes, geographical areas, service data extraction including data sets and time period, as well as rationale.</p> <p>Yes. In Application for Data Form researchers must complete the data extraction form and provide the following details of the controls: control group description, disease and procedure codes, geographical areas, service data extraction including data sets and time period, as well as variables.</p>	<p>Yes; Section 7 of Application for Data Form. Researchers must describe cohort including exclusion/inclusion criteria, how many individuals/records are in cohort, how cohort is to be defined (i.e. ICD codes), whether ICD codes relate to principle diagnosis/procedure or multiple diagnosis/procedure, and whether all linked records are required or only those with specified condition.</p>	<p>The Data Request Form and the Public Health Act Application do not explicitly ask for details about cohort and controls. However:</p> <p>Section 5 of the Data Request Form requires researchers to include a basic description of the data along with information on the data fields, data formats and the years of data.</p> <p>Section 8 of the Public Health Act Application. Researchers must list the data items required, specific time periods and data intervals. Applicant/s must list specific data items required to undertake the research. This may</p>	<p><u>Initial Project Description</u> Sampling frame Dependent/independent variables Time period <u>Application for Data Form</u> Data field description, definition, justification.</p>	<p><u>SA Statistical Linkage Application Form:</u> Yes; Section 2.4 requires the researcher to identify the selection criteria required to define the primary dataset. <u>NT Statistical Linkage Application Form:</u> No.</p>	Yes, planned.	Not specifically requested.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
			include but is not limited to – demographics (eg. date of birth, sex), hospital episode information, details of diagnostic data and/or details relating to health services accessed by individuals. It is important that all items of data are listed to ensure that data custodians can determine the availability of data requested and/or time and resources required in providing the data.				
Funding sources	No; not found in Application for Data Form.	No; not found in Application for Data Form.	Funding source is not found in the Data Request Form or the Public Health Act Application. This question is asked in NEAF.	<u>Initial Project Description</u> Researchers must indicate one of the following: Currently funded (Details of source, duration and commencement of funding). Subject of a current funding application (Details of funding applied for and date of outcome) Basis for a future funding application (Details of funding to	<u>SA Statistical Linkage Application Form:</u> No. <u>NT Statistical Linkage Application Form:</u> Yes. Part B 'Data request details' requires the researcher to provide a description of funding sources.	Yes, planned.	Yes – source of funds required.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
				apply for and submission date) Unfunded/no intention to apply for funding Other (Details) <u>Application for Data Form</u> No.			
Other information	Yes. In Application for Data Form researchers are required to provide information under the following headings: Section 1: Project title. Section 3: Organisation responsible for application. Section 4: Project Summary. Section 6: Project Duration. Section 8: Ethics review. Section 10: Privacy and Consent. Section 11: Other Sources of Information for the Project. Section 12: Security Plan. Section 13:	Section 9 of the Application for Data Form relates to mother-baby linkage.	Yes; Section 6 of the Data Request Form requires researchers to indicate output file format required (e.g. csv,txt, xml, SAS).	<u>Initial Project Description</u> No. <u>Application for Data Form</u> Data output format (e.g. SAS, SPSS, SDE, other) Is this an update/extension of a previous data request? (Question found in the request details)		Yes, planned.	Consent details Breaches of IPP Undertaking Forms for people accessing data.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	Retention and Disposal Plan. Section 14: Analytical Tools. Section 15: Governance. Section16: Declaration and Signatures.						
Approvals							
Ethics Review – questions in DLU application form	<p>Yes; Section 8 of Application for Data Form.</p> <p>8.1 Will your project involve contact with participants/ patients or health service providers?</p> <p>8.2 Does your project require review by the DOH HREC?</p> <p>8.3 Does your project require approval by any other ethics committee? If yes, list the other committees that must approve this application and the current status of applications for approval. Please attach a copy of each approval granted.</p> <p>8.4 Does your</p>	<p>No. Application for Data Form does not contain questions regarding ethics review. Researchers must contact CHeReL once the ethics committee approve the study. (See http://www.cherel.org.au/apply-for-linked-data)</p> <p>The HREC will not review research proposals unless researchers have contacted data custodians and an assessment of data governance issues has started. (See http://www.cancerinstitute.org.au/research-grants-and-funding/ethics/nsw-population-health-services-research-</p>	<p>Yes; Section 3 of the Data Request Form contains the following questions: Will your project involve contact with participants/ patients or health service providers?</p> <p>Does your project require review by any ethics committee? If yes, list the committees that must approve this application and the current status of the application(s).</p> <p>Yes, Section 7 of the Data Request Form (Declaration) asks the researcher to confirm that the project will be conducted in accordance with the ethical and research arrangements of the</p>	<p><u>Initial Project Description</u></p> <p>Yes. Does this project require approval from a HREC? If no, why? If yes, has approval been sought? If yes, provide approvals.</p> <p><u>Application for Data Form</u></p> <p>Yes.</p> <p>Does this project require HREC approval? If yes, has approval been sought? If no, explain why ethics is not required.</p>	<p><u>SA Statistical Linkage Application Form:</u></p> <p>Yes. Sections 3.3 and 8 requires the researcher to indicate whether they have HREC approval.</p> <p><u>NT Statistical Linkage Application Form:</u></p> <p>Yes; Part C 'Data request details' requires the researcher to indicate whether they have HREC and Corporate Information Services (CIS) approvals.</p>	Yes, planned.	<p>Does your research relate to:</p> <p>Women who are pregnant/ the human fetus</p> <p>Children / young people</p> <p>People in dependent / unequal relationships</p> <p>People unable to give consent</p> <p>If yes have you complied with the requirements of the National Statement? Provide details.</p> <p>If your research related primarily to A&TSI peoples, have they been consulted? Provide details.</p>

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>project require any other approvals? If yes, list the other approvals required and the current status of applications for approval. Please attach a copy of each approval granted. (This question refers to other possible approvals rather than ethics approval e.g. if requesting hospital code, a researcher must get approval from the Area Health Service Chief Executive.)</p>	<p>ethics-committee)</p>	<p>organizations involved.</p> <p>Yes; Section 11 of the Public Health Act Application requires the researcher to state the name of the HREC that approved the research proposal. Researchers must attach a copy of the HREC approval with the Public Health Act Application.</p>				
<p>Privacy/Consent-questions in DLU application form</p>	<p>Yes; Section 10 of Application for Data Form.</p> <p>10.1 Are you applying for the release of personal information from a DOH data collection?</p> <p>10.2 If the answer is yes please explain below why non-identifiable information cannot be used.</p> <p>10.3 If the answer is no please explain how privacy will be maintained.</p> <p>10.4 Please indicate</p>	<p>Yes; Section 10 of Application for Data Form. Researchers must indicate if consent will be sought from study participants to use information collected about them. If yes, researchers must attach consent forms and information sheets.</p>	<p>Yes; Section 4 of the Data Request Form contains the following questions:</p> <p>Are you applying for identifying information from any of the data collections? If yes, please explain why non-identifiable information is not sufficient.</p> <p>Do you have consent from the participants for the use and disclosure of their information? If yes, please explain the consent process. If</p>	<p><u>Initial Project Description</u></p> <p>No.</p> <p><u>Application for Data Form</u></p> <p>No.</p>	<p><u>SA Statistical Linkage Application Form:</u></p> <p>Yes. Sections 3.4 and 8 requires the researcher to indicate whether they have privacy approvals.</p> <p><u>NT Statistical Linkage Application Form:</u></p> <p>Yes; Part A 'Requestors Details' requires the applicant to certify they have read, understood and agreed to comply with the DHCS Privacy Policy.</p>	<p>Yes, planned.</p>	<p>Does your project breach any of the IPPs (provides links to IPPs)</p> <p>If yes, which principles and how will you address these?</p> <p>Describe how your organisation (AIHW if internal) will store and maintain the security and confidentiality of information?</p> <p>How will information held by your organisation (AIHW for internal studies)</p>

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	below (“Yes” or “No”) whether you need any of the listed information (personal information variables) in your data extract.		<p>no, please explain why it is not possible to obtain consent.</p> <p>Yes; Section 9 of the Public Health Act Application contains the following questions related to privacy and confidentiality:</p> <p>Who is providing the confidential information and how will the disclosure take place?</p> <p>In what form will data be disclosed (electronic or paper)?</p> <p>How will the security associated with the transfer of data be maintained?</p> <p>How will data security be maintained?</p>				be disposed of at the conclusion of the project? If information is to be retained how will this be done?
HREC approval sought before final DC approval?	Confidentiality agreements have always been submitted <i>with</i> the HREC application (not after approval). Data Custodians always sign after HREC approval.	Yes. When the researcher has received the data custodian approvals and CHeReL technical feasibility letter, the researcher can submit their ethics application documents to the HREC. (See	Yes. Researchers must attach a copy of the HREC approval with the Public Health Act Application.	Yes. In ‘Researchers’ Guide’ in the Application for Data form: Researcher gains HREC approval and provides VDL with application and approval letter. Then VDL presents request for data application to	Yes. Step 6 in the data application process is to submit the completed SA NT Datalink application form with complete supporting documents (ie. Ethics Approvals) to Data Custodians for final approval. (See	Yes, planned.	Yes – however confidentiality undertaking must be signed by Institution and PI and Linkage Undertaking must be signed by custodians and AIHW linkers before the AIHW HREC will consider a project Researchers also

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
		http://www.cherel.org.au/apply-for-linked-data)		Department of Health Data Custodian and seeks approval.	https://www.santdatalink.org.au/application_process)		need prior approval by host Institution HREC prior to AIHW HREC consideration.
HREC application form used	A full DOH HREC application comprises the WA Health Ethics Application Form or the National Ethics Application Form v2.0 (NEAF) with the WA Specific Module, plus the Application for Data Form and any relevant supporting documentation. (See http://www.health.wa.gov.au/healthdata/HREC/)	NEAF. Other documents to be submitted with the NEAF include: Application for Data Form and variables list CHeReL technical feasibility letter Research Protocol Data Custodian Sign-Off Form NSW Privacy Form Submission checklist	NEAF and Low and Negligible Risk Ethics Application Form.	NEAF and Victorian Specific Module that must be submitted with NEAF including modules on: Section 1 – Projects involving drugs & therapeutic devices Section 2 – Recruitment of adults who may be incompetent to consent Section 3– Research Involving the Collection/Use/Disclosure of Information Section 4 – Use of Ionising Radiation Section 5 - Research Involving the Use of Human Tissues or Blood, or Performance of Post Mortem	NEAF or South Australia’s Department of Health HREC Core Application Form and Checklist or South Australia’s Families and Communities Research Ethics Committee (FCREC) Application Form. Note: NT ethics approvals processes use NEAF.	NEAF.	The AIHW Ethics Committee Application Form - AIHW staff The AIHW Ethics Committee Application Form - Researchers external to the AIHW (Suitable for applications from external researchers for one centre research studies seeking linkage with the National Death Index; \$600). NEAF (Suitable for external researchers involved in multi centre studies.)
Data Custodians	Data custodians review and provide feedback to researchers via the EOI. Data custodians and DOHWA DG delegate review formal application for data	Data custodians are required to sign off on all requests for data from registries owned or managed by NSW Health or the Cancer Institute. The Data Custodian Sign-Off Form must	No; the Data Request Form does not contain a section for data custodians to complete. Yes; Section 10 Public Health Act Application is about	<u>Application for Data Form</u> Q. Is an investigator also a data custodian? If no, has approval been sought from data custodians?	<u>SA Statistical Linkage Application Form:</u> Yes; Section 3. Each Data Owner’s Representative identified in Sections 2.2 and 2.3 must provide in principle and final approval of	Yes, planned.	Must sign the Linkage Undertaking for each project following sighting of the HREC submission – this goes in with the HREC submission A data custodian is appointed for the

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	once HREC application is approved. (See http://www.datalink.wa.org.au/access-and-application/application-on-process)	be submitted with the ethics application. (See http://www.cancerinstitute.org.au/research-grants-and-funding/ethics/nsw-population-health-services-research-ethics-committee)	Authorisation from Data Custodian. The Data Custodian must authorise that they have considered the proposal and consulted with the appropriate personnel, and seen all relevant documentation. Data Custodians are asked to confirm whether they are able or unable to provide the data services required.		this application before it can proceed. Section 3.2 requires the researcher to list the data custodians. <u>NT Statistical Linkage Application Form:</u> Part D 'Approvals' requires signature of data sponsor, name of data sponsor, approval date and approval by CIS Branch (where required).		resulting linked dataset and must also sign the Linkage Undertaking If researchers want to access data that has been previously linked for other analysis the custodians must sign a form agreeing to the use of this data for different analysis and a new HREC submission is required.
Technical feasibility letter from DLU provided?	Yes. WADLB provide this now and HREC looks for it to ensure a project has cleared EOI.	Yes. ChERel will provide the researcher with a technical feasibility letter (based on the information contained in the AFD), stating that the linkage is feasible and ChERel is able to do it. (See http://www.cherel.org.au/apply-for-linked-data)	No letter is provided re. the feasibility of the linkage. This tends to be covered by the checks between Health LinQ and the data custodians which are required in order for the PHA application process to go ahead (this may be unique to Qld since the linkage is undertaken by the unit that is the data custodian for the main health datasets of interest).	Yes. Step 2 in the 'Researchers' Guidelines' of the Application for Data Form states that Victorian Data Linkages - Research Services & Data Integration team has regular meetings to review submitted applications for data and ascertains technical feasibility. Feedback is provided researcher. At this stage, VDL may request to meet with the researcher to further refine/confirm request details, and have the researcher	Yes.	Yes, planned.	The DLU briefs the EC on technical feasibility and this forms part of the basis of the approval.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
				re-submit their application for data.			
Data Security							
Security Plan	<p>Yes; Section 12 of Application for Data Form. All applications for linked data must include a detailed security plan. The plan should adhere to the DOHWA Practice Code for the Use of Personal Health Information and address both technological and physical security. The Security Plan should specify the measures that will be taken to protect the information from misuse, loss or unauthorised access during the research project.</p> <p>Website outlines the WADLB's security processes at the DOHWA offices in East Perth. (See http://www.data-linkage-wa.org.au/privacy-and-security/security)</p>	<p>Yes; Section 13 of Application for Data Form. All applications for linked data must include a detailed security plan. The security plan should specify the measures taken to ensure the security of information from misuse, loss or unauthorised access during and after the research project.</p>	<p>No; the Data Request Form does not contain a section about data security.</p> <p>Yes; Section 9 of the Public Health Act Application contains the following questions: How will the security associated with the transfer of data be maintained? How will data security be maintained?</p>	<p>Conditions of release form require details of: Physical location and security of data Network security and backups Personal computer security and backups Data transfer security</p> <p>Also required in the Common HREC Application Form and the Victorian-specific module of the NEAF</p>	<p><u>SA Statistical Linkage Application Form:</u> Yes; Section 2.6 requires the researcher to describe their security plan.</p> <p><u>NT Statistical Linkage Application Form:</u> Yes; Part C 'Data request details' requires a detailed description of data security measures including how & where data will be stored.</p>	<p>Yes, draft framework developed.</p>	<p>Yes.</p>
Retention and Disposal Plan	<p>Yes; Section 13 of Application for Data</p>	<p>Yes; Section 14 of Application for Data</p>	<p>Yes. Health LinQ assist researchers in</p>	<p>Yes - Also required in the Common HREC</p>	<p><u>SA Statistical Linkage Application Form:</u></p>	<p>Yes, included in draft security framework</p>	<p>Yes.</p>

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	Form. All applications for linked data must include a retention and disposal plan. The plan should adhere to the Practice Code for the Use of Personal Health Information and be consistent with the National Statement. The Information Retention and Security Plan should specify the period of retention of the data after the completion of the project and the measures to be taken to secure the information during that period. It should also specify the date by which the information will be returned or destroyed.	Form. All applications must specify the period of retention of the data following completion of the project and how the information will be destroyed.	preparing a data security plan as part of the PHA and Ethics applications.	Application Form and the Victorian-specific module of the NEAF	Yes; Section 2.7 requires the researcher to describe the retention and destruction plan as well as destruction date. <u>NT Statistical Linkage Application Form:</u> Yes; Part C 'Data request details' requires a description of how data will be disposed of and period of data retention.		
Other information required		Yes; Section 11 and 12 of Application for Data Form. All applications must list all locations where the data will be stored and analysed and describe how the data will be stored during and after the project.		No.	<u>SA Statistical Linkage Application Form:</u> No. <u>NT Statistical Linkage Application Form:</u> Yes; Part C 'Data request details' requires name, position, role and all people with access to the data and		Plan for dissemination of results Assurance of scientific quality – has the project been scientifically reviewed by a group of independent peers? Provide details.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					details of any intended third party provision.		
Declarations							
Signatories	Yes, Section 15 of Application for Data Form requires signature of Head of Department/School/ Research Organisation. Section 16 requires signature of Applicant/PI and if applicable, supervisor of students.	No; not found in Application for Data Form. CI required to sign Declaration and Undertaking by the Data Custodian and Chief Investigator Form. (See http://www.cancerinstitute.org.au/research-grants-and-funding/ethics/nsw-population-health-services-research-ethics-committee)	Yes; Section 6 of the Data Request Form requires a signature. Yes. Section 12 of the Public Health Act 2005 Application Form requires the PI to sign the Undertaking of Confidentiality.	<u>Initial Project Description</u> None. <u>Application for Data Form</u> Yes. Certification by Principal Investigator. Certification by Head of Department.	<u>SA Statistical Linkage Application Form:</u> Yes. Section 5 'Researcher Agreements' requires signature from Applicant/PI/ Responsible Senior Officer, Supervisor of students, Head of Department/Schools /Research Organisation. Yes. Sections 7 and 9 data custodians/or their delegates signature required for approvals in principle and final approvals. Yes. Section 12 'Confirmation of compliance by the SA NT DataLink representative'. <u>NT Statistical Linkage Application Form:</u> Part A 'Requestors Details' requires signatures including Signature/Endorsement of Supervisor and Applicant's certification about the use of	Yes, planned.	Undertaking: Researcher's institution PI All others with access to data Linkage Undertaking: AIHW linkers Data custodians Data custodian of resultant linked dataset

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
					information.		
Monitoring of project							
System used	<p>Manual tracking on Excel spreadsheet of current projects and core and extra linkages. Access database of all projects (this contains more information than the index, e.g. datasets, personnel, ethics numbers).</p> <p>WADLB also maintain an Excel spreadsheet of EOIs (separate to the one of current formal projects).</p>	The CHeReL has developed a Workflow Management System for managing, tracking and reporting on projects.	Manual tracking on Excel spreadsheets.	Register.	Email at present - A project is currently underway to provide an electronic online application and approval process.	Yes, planned.	Manual tracking. Online system in acceptance testing.
Online tracking available for researchers?	No.	No.	No.	No.	No.	No plans at this stage; evaluating systems being developed by other jurisdictions.	Soon.
Annual reports required by DLU?	Yes. Recipients of linked data must provide annual reports to the WADLB Project Manager. (See http://www.data-link-wa.org.au/download/reporting)	No. CHeReL does not have annual reporting requirements. Cancer Institute NSW requires HREC Annual Progress Report to be submitted by researchers. (See http://www.cancerin	No. Health LinQ does not have annual reporting requirements. Queensland Health requires HREC Annual Progress Report to be submitted by researchers. (See http://www.health.q	No.	Currently not required, will be included in the revised application form. (Almond is not aware of SANT DataLink plans for this).	Planned for future.	No.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
		ststitute.org.au/research-grants-and-funding/ethics/reporting)	ld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp)				
Annual report template provided?	Yes. Annual report template found at http://www.data-linkage-wa.org.au/downloads/reporting and to be submitted to WADLB. Researchers must provide details about research/other outputs, project status, impact of project on health policy development or clinical practice, funding and general comments.	No. CHeReL does not have an annual report template. HREC Annual Progress Report template provided on Cancer Institute NSW website. (See http://www.cancerinstitute.org.au/research-grants-and-funding/ethics/reporting)	No. Health LinQ does not have an annual report template. There are an annual progress report and final report templates for the Public Health Act provided on QLD Health website. (See http://www.health.qld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp) There are also HREC annual report and HREC final report templates provided on QLD Health website. (See http://www.health.qld.gov.au/ohmr/html/regu/reporting_templates.asp)	HREC Annual/Final Report template is available on line. (See http://www.health.vic.gov.au/ethics/single/reporting_templates.htm)	Currently not required, will be included in the revised application form. (Almond is not aware of SANT DataLink plans for this).	Planned for future.	No. AIHW DLU templates. Yes. AIHW Ethics Committee templates including Routine (Annual) Monitoring Report and Final Monitoring Report.
Disposal/destruction of data at closure of projects	Yes. Recipients of linked data must provide a final report to DOHWA HREC and Section 5 refers to Retention and Disposal of Personal Data. Yes. Researchers are supposed to notify WADLB & Data	Yes; Section 14 of Application for Data Form. All applications must specify how the information will be destroyed.	Yes. Information on where, how and for how long is trial /study related data being stored is requested from researchers in the HREC and Public Health Act 2005 templates. (See http://www.health.q	Written notice of data destruction required to be provided to VDL upon destruction.	<u>SA Statistical Linkage Application Form</u> : In accordance with the conditions agreed with Custodians, on completion of the project and the data destruction date a <i>Certificate of Destruction</i> attesting to the destruction of	Yes, planned.	Researchers must specify data retention plan which includes data destruction.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	Managers of destruction-email/letter would suffice.		http://www.health.qld.gov.au/ohmr/html/regu/aces_conf_hth_info.asp and http://www.health.qld.gov.au/ohmr/html/regu/reporting_templates.asp)		the data associated with this project, including original data supplied and value added unit record data derived must be completed. The <i>Certificate of Destruction</i> must be returned to SA NT DataLink within 10 working days of the data destruction. Certificate of Destruction template included in application form. <u>NT Statistical Linkage Application Form: No.</u>		
Updates of project details e.g. changes in personnel	<p>Yes. WADLB has an amendment request form. (See http://www.datalink.wa.org.au/forms)</p> <p>Yes. DOHWA HREC has an amendment request form. (See http://www.health.wa.gov.au/healthdata/HREC/index.cfm)</p> <p>The form submitted depends on the type of amendment, e.g. to add extra unidentifiable</p>	<p>No. CHReL does not have an amendment request form.</p> <p>Yes. Cancer Institute NSW provides researchers to update project details via HREC Change in Personnel Form and Request for HREC Amendment Form. (See http://www.cancerinstitute.org.au/research-grants-and-funding/ethics/reporting)</p>	PI asked to advise Health LinQ of any changes.	<p>Yes. Researchers must advise VDL of any project changes.</p> <p>HREC Amendments to research project template is available on line. (See http://www.health.vic.gov.au/ethics/singlereporting_templates.htm)</p>	<p>Yes, asked to advise SANT DataLink of any changes. (Requirement of ethics approvals).</p> <p><u>NT Statistical Linkage Application Form:</u></p> <p>Yes. The form can be used as an application for data amendment/update for an existing project.</p>	Yes, planned.	Required to advise AIHW HREC/ custodians of any changes and new staff must sign undertakings.

	WA	NSW/ACT	QLD	VIC	SA/NT	TAS	AIHW
	<p>variables from a previously approved dataset doesn't usually need HREC approval. The WADLB Project Manager and HREC Executive Officer communicate about all changes to projects. Amendments submitted to HREC are run past the WADLB Project Manager first to check whether it needs to be checked with the Data Managers, before going to the Committee.</p>						

Appendix 2: Summary of international client services

	HIRU	ICES	MCHP	PopData BC
Client Services (general)				
Same organisation as linkage unit?	No, Linkage function performed by NHS Wales Informatics Service (NWIS)	Yes	No, linkage function performed by Manitoba Health	Yes: Linkage function performed by University of British Columbia
Staffing capacity for client services	<ul style="list-style-type: none"> Information Governance Coordinator (1FTE) – coordinates application and approval process Senior Research Analysts – (2 FTE) - project feasibility, training & access to remote access site. 	No, there are not dedicated staff, but several people contribute. The average FTE per request has worked out to be 0.019 for the analyst and 0.016 for the lead analyst. The internal organisation of ICES is changing to provide a single contact point for new partners	<ul style="list-style-type: none"> Associate Director, Data Access & Use (1 FTE) Manager of Repository Access and Documentation (1 FTE) Repository Access Coordinator Data Analysts (approx. 15) Associate Director, Repository Data Analysts for Data Management (4) Documentation of Repository Data (2+) 	<ul style="list-style-type: none"> Lead, Researcher Liaison (1 FTE) Researcher Liaison Coordinator (2 FTE) Lead, Education and Training (1 FTE) Lead, Privacy and Process (.8 FTE) SRE Support (0,5 FTE)
Metadata				
Availability of online information	<p>A list of available datasets from SAIL is provided on the website.</p> <p>http://hiru.swansea.ac.uk</p> <p>More detailed metadata is available on the intranet once projects have been approved.</p>	Well-developed data documentation and metadata repository available internally to ICES staff. More general data available on the internet.	<p>An extensive list of available datasets is provided on the website.</p> <p>http://umanitoba.ca/faculties/medicine/units/community_health_sciences/departmental_units/mchp/repositories/repository/index.html</p> <p>Descriptions include the data provider/agency, purpose and method of the data collection, size, years, and scope of the database, access requirements,</p>	<p>An extensive list of available datasets from is provided on the website.</p> <p>http://www.popdata.bc.ca/data</p> <p>Available online: descriptions including the data provider/agency, years, inclusions, exclusions, data quality, fields available, references and additional information.</p> <p>Available on request: More detailed data documentation</p>

	HIRU	ICES	MCHP	PopData BC
			and database highlights. Links are provided to more detailed information such as data preparation tips and analytical techniques as available	Available with approved data: data dictionary specific to data provided
Frequency of updates	Depends on specific dataset	Regularly updated	Will be annually, as needed. We are looking at some interactive 'blog' or Wiki type utilities that will allow people to provide comments and feedback over time as well.	As necessary – from quarterly to annually
Responsibility for collation/updating	Data Warehouse Manager	The Health Data Lead?	MCHP Data Management Team	Data stewards and PopData BC
Application process		Have answered this question from the CD-Link project as it is most comparable to other linkage units		
Form available online	No: email Information Governance Coordinator for form	No	Yes	Yes
Clear process overview available	Yes: Collaborative Review System described on website http://hiru.swansea.ac.uk	Yes: Access application and approval process described at (www.cd-link.ices.on.ca) http://www.ices.on.ca/webpage.cfm?site_id=1&org_id=26&morg_id=0&gsec_id=6159&item_id=6159	Yes: Access application and approval process described in detail at http://umanitoba.ca/faculties/med/ices/departmental_units/mchp/resources/access.html	Yes: Access application and approval process described in detail at http://www.popdata.bc.ca/dataaccess
Approx. timelines provided online	No	Yes: expect 6 weeks	Yes: expect 4 months	Yes: examples of timelines given
EOI process prior to formal application	Initial discussions take place with the Senior Research Analysts to establish feasibility.	Yes, application must receive preliminary acceptance by the HSR Program Leader before full review by the	No, but project feasibility form is like an EOI process.	No, but researchers strongly encouraged to contact Researcher Liaison office for help in preparing Data Access Request. The

	HIRU	ICES	MCHP	PopData BC
		faculty		feasibility and cost estimate also acts as a type of EOI.
Do Data Custodians provide input to EOI prior to formal application submission?	<p>No, as review by each data custodian is not required. However, review by the Information Governance Review Panel is required. The IGRP has representatives from the major data custodians who contribute to SAIL. The IGRP provides independent advice to HIRU to ensure proposed work conforms to the principles of information governance.</p> <p>Yes for certain datasets HIRU are required to notify and get approval for their datasets to be included in research questions.</p>	No	No for health datasets but sometimes required for non-health data sets	Not applicable but PopData BC have weekly meetings with Ministry of Health where issues can be raised.
Application form content		No form required but a 5 page proposal should include the following elements		
Personnel details	<ul style="list-style-type: none"> • Applicant/PI • All others who will have access to the data 	<ul style="list-style-type: none"> • Principal Investigator • List anyone who will touch the data 	<ul style="list-style-type: none"> • Principal Investigator 	<ul style="list-style-type: none"> • Applicant • Principal Investigator • Project Coordinator/Manager • Co-investigators • All persons who will have access to data • Thesis/dissertation supervisors

	HIRU	ICES	MCHP	PopData BC
Project details	<p>A detailed study protocol must be attached to the application</p> <ul style="list-style-type: none"> Title Aim Lay summary 	<ul style="list-style-type: none"> Rationale and objectives Planned analyses and planned use of the data Expected products Data custodian resources for ensuring data security Study timeline List of research staff with their role and contact information (include mailing address, e-mail and telephone number). 	<p>A detailed study protocol must be attached to the application</p> <ul style="list-style-type: none"> Title 	<p>A detailed study protocol must be attached to the application</p> <ul style="list-style-type: none"> Title Objectives, hypotheses, aims Project description How data will be used to achieve objectives
Data services required e.g. linkage, extraction	<ul style="list-style-type: none"> Extraction from collections New linkage 		<ul style="list-style-type: none"> Analytic requirements 	<ul style="list-style-type: none"> Linkage of external datasets Linkage to occur in location other than PopData BC
Details of Data Collections for extraction	<ul style="list-style-type: none"> Which collections A pre-defined list of variables is not required 	<ul style="list-style-type: none"> Data sources and variables requested, including justification for each variable 	<ul style="list-style-type: none"> Domain (eg Health, education, social ...) Database Data years required Fields or constructs required. 	<ul style="list-style-type: none"> Datasource Date range Data items requested
Details of non-core data sets to be linked in	<ul style="list-style-type: none"> Description of information, source Form just asked for datasets to be specified. 	<p>There is an opportunity to bring in external data sets, have them linked and de-identified, and returned via the cd-link process</p>	<ul style="list-style-type: none"> Name of data set Source of dataset Contact details Organisation approving use of dataset Database scope 	<ul style="list-style-type: none"> Name of data set Source of dataset Fields to be used for linkage and removed Fields to be used for linkage and retained for analysis
Cohort definition	No	Must be generally described, but defined in detail after the project is approved	Provided in attached protocol	Provided as attachment
Funding sources	<p>Yes:</p> <ul style="list-style-type: none"> Name of funding organisation Amount of funding 	Yes	<p>Yes:</p> <ul style="list-style-type: none"> Name of funding source Amount of funding Duration of funding Funding sources must be identified now before all approvals provided 	<p>Yes:</p> <ul style="list-style-type: none"> Name of funding source Amount of funding Duration of funding Copy of funding contract
Other information	<ul style="list-style-type: none"> Details of proposed analysis Publication plan Request for analysis by HIRU 		<ul style="list-style-type: none"> Details of proposed analysis Whether project forms part of a larger project 	<ul style="list-style-type: none"> Copy of peer review documentation eg grant funding reviewers comments and/or

	HIRU	ICES	MCHP	PopData BC
	<ul style="list-style-type: none"> • Whether project forms part of a larger project • What approvals are required • Stage of development of project • Proposed start date 		<ul style="list-style-type: none"> • Analytic requirements • Project location 	funding letter
Approvals				
Ethics Review – questions in DLU application form	Asks whether ethics review has been obtained, is being sought or is not required.	No	No	<p>Copy of ethics application and approval required as attachment</p> <p>Question about public benefit of proposal</p> <p>Copy of informed consent document and participant information</p>
Privacy/Consent - questions in DLU application form	The form asks about research ethics approval (and informed consent is covered in this if the project is considered for ethics issues) and about privacy issues at the publication/dissemination stage. The IGRP includes a representative of the National Research Ethics Service so that researchers are alerted to the need for ethical approval if required (if it has not already been sought).	No	No	<p>Description of privacy minimisation plan required as attachment</p> <p>Privacy impact assessment if available</p>
HREC approval sought before final DC approval?	SAIL model doesn't necessarily require HREC approval and/or data custodian approval. If one or the other is required not sure whether one needs to be obtained before the other.	HREB approval not required before ICES approval to conduct the project.	HREB approval required before final approval to conduct the project.	HREB approval required before final approval to conduct the project.

	HIRU	ICES	MCHP	PopData BC
HREC application form used	Not applicable	Not applicable	Not applicable	Not applicable
Data Custodians	SAIL model doesn't generally require individual data custodian approval for each project. If a project is solely using existing SAIL data then no additional approval is required, however if they plan to bring in additional project specific data formal approval from the data custodian is required.	Individual data custodian approval for each project not required	MCHP doesn't generally require individual data custodian approval for each project for health data but it can be required for non-health datasets.	Data custodian approval required
Technical feasibility letter from DLU provided?	Feasibility of the study is assessed during initial informal discussions	No	Researchers are provided with a formal quotation for cost of project. Usually a quote for total cost of project, not itemised.	Data feasibility and cost estimate letter available on request
Sharing of applications with review bodies	Applications are shared with Management team and IGRP electronically using SharePoint software.	No	? Not sure if application forms are shared with HREB but HREB annual reports are shared with MCHP.	DAR is shared with Data Stewards. No sharing of information with HREB.
Data Security				
Security Plan	No, as data can only be accessed at HIRU or through their (SAIL Gateway) researcher don't need to submit a separate data security plan	Yes as the Data custodian resources for ensuring data security should be included in the proposal	No, as data can only be accessed at MCHP researchers don't need to submit a separate data security plan	Yes
Retention and Disposal Plan	As above.	As above	As above.	Yes if not using Secure Research Environment
Other information required				

	HIRU	ICES	MCHP	PopData BC
Declarations				
Signatories	HIRU Enquiry form is not signed, it is submitted electronically. All researchers are required to sign the HIRU Data Access Agreement, this agreement must be countersigned by a senior member of their institution. Penalties may be imposed for breaches of security or confidentiality.	No, as no actual application form. After approval, the PI and an institutional representative have to sign a data use agreement. In addition, all personnel have to sign annual confidentiality agreements	Principle Investigator Evidence of relevant data sharing agreements also required	Signed by Applicant
Monitoring of project				
System used	Although there is no formal system in place, by signing up to the HIRU Data Access Agreement, researchers are required to keep HIRU informed of progress and outputs	?	?	A web based system called App Tracker
Online tracking available for researchers?	No	No	No	No, but planned eventually for new web-based tracking system
Annual reports required by DLU?	No	No	No, but HREB annual reports provided to MCHP	No
Annual report template provided?	No	No	No	No
Disposal/destruction of data at closure of projects	All project data is archived and stored	Yes, there is a data destruction certificate that must be signed by an institutional representative at the end of the projects	Responsibility of MCHP	Currently running a project to close off projects from old system. Clear procedures in place. For projects using PopData BC system this is handled through the SRE.

	HIRU	ICES	MCHP	PopData BC
Updates of project details e.g. changes in personnel	It is the responsibility of the researcher to inform HIRU of any changes in personnel	Yes, cd-link confidentiality agreements must be signed when new personnel start on the project	?	Researcher submits a request. Amendment summary form sent to Data Stewards. Special form for data retention extension requests.
SERVICES				
Application support including answering questions regarding the approval and application process	Yes	Yes	Yes	Yes, includes live chat opportunities
Project design including: <ul style="list-style-type: none"> ▪ cohort selection ▪ control selection ▪ variables/time periods required ▪ power calculations 	Yes	Yes	Yes – within the proposal or during feasibility review. Assistance in these areas is provided.	Try not to give project design advice but do provide advice about technical feasibility
Provision of feasibility review and quotation estimates for grant applications	Yes	Yes	Yes	Yes
Assistance with completing HREC forms	Not formally	No	Yes	No
Assistance with completing data custodian approval forms	Yes	Not applicable	Yes	Yes, Data Steward form is the same as PopData BC form (DAR)
Review of submitted formal application to ensure completeness	Yes	Yes	Yes	Yes
Assistance with HREC liaison	No	No	Yes	No
Assistance with brokering data release agreements with data custodians	Not required if data collections already included in SAIL. Provided if a new data collection is required.	No	Not required if data collections already included in MCHP Data Repository. Provided if a new data collection is required.	Yes

	HIRU	ICES	MCHP	PopData BC
Preparation of data extraction plan	Yes, HIRU data analysts are responsible for preparing data extraction plans	Yes, ICES data analysts are responsible for preparing data extraction plans	Yes, MCHP data analysts are responsible for preparing data extraction plans	Yes
Merging of de-identified datasets	As above	As above	As above	Yes
Checking of datasets prior to delivery to researchers	Not relevant to SAIL model	Yes, all datasets are assessed using the Privacy Analytics Risk Assessment Tool for disclosure risk.	Not relevant to MCHP model	Yes, check against approved DAR, ensure data dictionary is consistent, check sample of approx. 50 records. Planning to automate checking function in future.
Addition of SEIFA or ARIA codes to extracted data	SAIL can append the Welsh Index of Multiple Deprivation (WIMD) and Townsend Scores	Yes	<p>For SES measures we use the Statistics Canada income quintiles and something called SEFI2 which you can read more about here: http://mchp-appserv.cpe.umanitoba.ca/viewDefinition.php?definitionID=103983</p> <p>For the ARIA we generally use point to point distance calculations because Manitoba is so flat, there are plenty of roads and they are generally very straight and up north people fly in and out of remote communities. Where needed we could calculate road distances to/from locations using ARC GIS</p>	No, don't currently receive many requests. SFU have a Spatial Data Unit.
Provision of datasets to researchers	Researchers have access to datasets via a Secure Gateway.	Provided on encrypted DVD	If researchers are doing their own analysis within MCHP (or RAS) then datasets are built as required.	Via Secure Research Environment

	HIRU	ICES	MCHP	PopData BC
Mode of delivery of data extracts	As above	via a tracked delivery provider (courier)	Internal only – there are some rare situations where the data provider (custodian) may request a data extract be developed and sent back to them. Bonded courier, usually SAS format, encrypted.	Via Secure Research Environment
Provision of privacy/security training to researchers	One on one, face to face training provided for all new users.	No	Face to face group training session ((2x3hr) provided for all new users. Annual update for all users, web-based.	Yes, privacy training required before access to data
Preparation of metadata about data extracts and provision to researchers	Documents are made available to researchers within the SAIL Gateway	Yes (I can expand if necessary)	Extensive documentation and metadata prepared and made available to researchers by the Data Acquisition and Repository Access and Documentation teams.	Yes
Support for use of the extracted data, including answering questions about data fields and coding specifics	HIRU data analysts are very familiar with the data and offer enormous expertise to researchers in how to use the data.	ICES data analysts are very familiar with the data and offer enormous expertise to researchers in how to use the data.	MCHP data analysts are very familiar with the data and offer enormous expertise to researchers in how to use the data.	Yes, but try not to give advice about analysis. Support is available to researchers on My PopData website>
Collation and archiving of all project documentation	All project documentation and outputs are stored within the project folder on a secure server	No	?Yes – this is somewhat project dependent.	Yes
Collation of annual reports	Not applicable	Not applicable	Yes	Not applicable
Publication of lay summaries of current and completed projects on DLU website	Lay summaries are collected in the application process. These summaries will be made available on the new HIRU website	<ul style="list-style-type: none"> Summaries of work in progress and published work are available on website 	<ul style="list-style-type: none"> Summaries of current deliverables for Manitoba Health published on website Titles of current research projects published on website 	No, but investigating the possibility of asking researchers for consent to do this.
Marketing of data linkage	Website currently being updated.	Website	Website	Website, Facebook, bulletins, conferences, presentations to

	HIRU	ICES	MCHP	PopData BC
				universities
Summary of project-related documents maintained by Client Services	<ul style="list-style-type: none"> • HIRU Enquiry form • Project Protocol • Ethics approval letter • Data custodian approval 	<ul style="list-style-type: none"> • Project Proposal • Publications 	<ul style="list-style-type: none"> • Project Feasibility form • Project Protocol • Ethics approval letter YES • Data custodian approval YES • Accreditation completion • Publications – should be sent to MCHP and custodian (Yes) 	Yes
Agreements	<ul style="list-style-type: none"> • Data access agreement must be signed by all researchers. • Data sharing agreements with data custodians and HIRU 	<ul style="list-style-type: none"> • Data Use Agreement • Data Sharing Agreement • cd-link Confidentiality Agreement for Researchers 	<ul style="list-style-type: none"> • Section in Project Feasibility form which is like a data use agreement • Data sharing agreements with data custodians and MCHP 	Data steward researcher agreement; Population Data BC – Researcher Services Agreement, Pledge of Confidentiality