

Attachment #1

WA Data Linkage Branch
Access and Charging Policy

Responsible Authority: Public Health Division,
WA Department of Health

Policy Contact: Data Linkage Branch

Email: DataServices@health.wa.gov.au

Issue Date: November 2015

Version: V1.01

Prepared by: Data Linkage Branch Management Team

Review: This document will be reviewed at least annually

Last Reviewed: November 2015



Data Linkage Access & Charging Policy

1. BACKGROUND

Established in 1995, the WA Data Linkage System (WADLS) operates within the Department of Health WA (DOH). It is both the oldest and most comprehensive data linkage facility in Australia. The data linkage infrastructure is managed by the Data Linkage Branch (DLB) within the Public Health Division. This document describes the access and charging arrangements for use of data linkage products and services provided by DLB. It has been developed to comply with DOH privacy and confidentiality requirements regarding the collection, use and disclosure of personal information.

2. DEFINING DATA LINKAGE PRODUCTS AND SERVICES

The DLB provides a diverse range of high quality products and services based on specialist knowledge and facilities. Using electronic data held in a variety of separate data collections, the DLB creates linkage keys that are thought to belong to the same person, event, family, or place. These linkage keys are created and maintained in the WADLS. They represent another level of intellectual input that refines and/or adds value to the original data source(s).

In total, the WADLS maintains linkage keys for over 40 state-based health and other data collections, in addition to overseeing value adding processes related to geocoding, genealogy, client services and data delivery. These products and services support DOH in its role as Health System Manager, as well as approved research, policy development, service planning and evaluation conducted by other government agencies, universities and non-commercial organisations within Australia.

The WADLS is maintained using rigorous, internationally recognised privacy preserving protocols, probabilistic matching and clerical review. Regular linkage updates are undertaken according to the availability of personal identifying information from Data Custodians (hereafter called Data Providers). With agreement from Data Providers, linkage results may be retained and updated within the WADLS. New datasets may be linked to the WADLS, provided approval from Data Providers and the DOH Human Research Ethics Committee (DOH HREC) is obtained.

Importantly, data linkage processes follow the 'Separation Principle', whereby personal identifying information needed for linkage is separated from service and clinical information by data providers prior to linkage. Following linkage, Data Providers authorise the extraction and delivery of each (linked) data extract when all the necessary approvals are in place.

3. DATA ACCESS AND APPLICATION

3.1 General data access principles

Use of data linkage services and resources must be consistent with WA Health Policies, including:

- *Data Stewardship and Custodianship Policy* (Operational Directive 0487/14)
- *Information Access and Disclosure Policy* (Operational Directive 0539/14)
- *Information Use Policy* (Operational Directive 0572/14)
- *Information Classification Policy* (Operational Directive 0537/14)

Access to linked data must also be consistent with the individual data disclosure models of each data collection requested, the disclosure model of the DLB and the DOH HREC Terms of Reference.

Projects must comply with the following DLB, Data Provider(s) and ethics committee requirements. They must:

- be of public benefit or wellbeing;
- be aimed at understanding and improving the health and wellbeing of WA people;
- be of scientific merit;
- include an undertaking to report results in the public domain within a specified timeframe¹;
- be approved by the relevant Data Provider(s);
- have access to appropriate facilities and resources to undertake the proposed research; and
- be conducted in accordance with the applicable legislation, regulations and guidelines.

Applications will be accepted from investigators who can demonstrate sufficient training and experience to undertake the analyses, and who are affiliated with recognised institutions that accept responsibility for conduct of the project.

Linked data extracts may be provided for:

- research projects that contribute to the promotion, protection and maintenance of the health and wellbeing of the people of WA;
- planning, evaluation and delivery of health and social services;
- improvement in research methodologies, data interpretation, link quality assessment, and development of advanced statistical techniques;

DLB will not accept applications for linked data where:

- the purpose relates to clinical governance, auditing, monitoring or surveillance of individual patients or clinicians;²
- it is supported by private funding, unless there is evidence that there is no real or perceived conflict of interest by the funding organisation;

¹ To permit public scrutiny and to add to public knowledge and understanding.

² These requests will be re-directed to the original Data Provider(s). This includes the use of linked data to populate patient administration systems.

- there is potential for commercial gain or competitive advantage insofar as profit, price, product (e.g., proprietary software), service or customer base.
- it involves the addition of major new linkage infrastructure to the WADLS without sufficient funding available for initial development or ongoing operational costs.

3.2 Prioritisation of access

Linked data extracts will usually be provided on a 'first come first served' basis, but the following factors may be taken into consideration:

- data availability;
- public interest;
- availability of resources;
- complexity of the project ;
- technical and logistical feasibility;
- priority research areas determined by the WA Director General of Health, WA Minister for Health, the Australian Health Ministers' Conference (AHMC) or the National Health and Medical Research Council.

DLB actively discourages applications for time constrained projects, noting the time and resources DLB needs to prepare, submit and assess proposals, authorise their feasibility and then prepare, extract, assemble, check and deliver linked data extracts. See also Section 3.3.

3.3 Data delivery timeframes

Projects are placed in a queue when DLB experiences high levels of demand. This impacts data delivery timeframes. The queue is generally administered on a 'first come, first served' basis to promote equity of access. The waiting time varies according to the considerations listed in 3.2. The longest waiting times are associated with projects that require new major linkages, or are awaiting action by Data Providers or Researchers before they can be progressed by the DLB. Currently, DLB has capacity to process ~60 applications for linked data annually.

4. DATA LINKAGE BRANCH PROJECT APPLICATION PROCESS

DLB's standard application process is published at www.datalinkage-wa.org.au. It must be followed for all projects, including cross-jurisdictional projects.³ In brief, the steps are:

- an initial draft application that is reviewed by the DLB and Data Providers, with the aim of achieving in-principle support for the proposed project (and formalised in a Feasibility Letter);
- approval from the DOH HREC where appropriate;
- final approval from the Data Providers.

³ DLB does not currently accept the Population Health Research Network (PHRN) online application form. This decision will be reviewed pending improvements in its features and functionality.

The DLB Client Services Team coordinates and documents all requests submitted through the Data Services email portal, in collaboration with relevant Data Providers (Data Stewards, Custodians and Managers). The DLB Client Services Team is available to provide preliminary advice on data availability, agreements, linkage protocols, project feasibility, timelines and charging. The DLB Program Manager, Manager of Data Linkage Systems and Senior Data Linkage Consultant are also available to provide advice on interpretation of agreements, resourcing and charging arrangements, as well as final determinations on the technical feasibility of the project and expected timelines.

4.1 Terms and conditions of data release

Data will be released to Applicants when:

- all relevant Data Providers have approved the use of data under their custodianship;
- the project has been approved by the DOH HREC where necessary;
- the Custodian of the WADLS has approved the use of DLB services (e.g. links, geocodes, family connections);
- all other relevant approvals have been provided (e.g., approval from Chief Executives of Area Health Services, and external Data Providers).

4.2 Applicant obligations

Applicants for linked data must agree to all of the following obligations.

- Inclusion of an organisation or investigator based in WA. A request to waive this condition will require a written communication proposal that ensures feedback to the WA Community and approval from the DLB Program Manager.
- Adherence to the *Practice Code for the Use of Personal Health Information provided by the DOH*.
- Approval for any changes to the application, including: security arrangements and location of data; changes to the Research Protocol; changes to Research Personnel; changes to Termination Plan.
- Agree to pay the costs, as estimated in the Feasibility Letter or subsequent written advice.
- Acknowledge the role of the DLB and Data Providers in all publications or reports.
- Provide a copy of any draft reports, journal articles or presentations to the DLB and Data Providers for review and comment within 10 working days, prior to distribution or publication.;
- Provide a copy of final reports or journal articles to the DLB for its research outputs collection.
- Provide an annual progress report to the DLB for the life of the project and a final progress report at the completion of the project. As a convenience for the applicant, DLB will accept the report forms submitted to DOH HREC.
- Submit a plain language summary of research results to the DLB for publication on its website.

- With guidance from the DLB and Data Providers, undertake to disseminate results to the community through print or social media, lecture, seminar or other format as appropriate.

Applicants who do not adhere to these criteria jeopardise future linked data access and may be reported to DOH HREC and/or other relevant bodies for administrative breach of protocol.

5. COST RECOVERY AND CHARGES

DLB activities are funded from different revenue sources. DLB seeks cost recovery to support its sustainability in terms of staff, equipment, and creating, maintaining, improving and delivering high quality data linkage products. These charges help bridge the gap between the public funding that DLB receives from DOH and external funding sources. DLB has prepared this policy on recovering costs for data linkage products and supporting services in order to:

- explain why, when and how DLB will apply charges;
- enable any charges to be applied transparently and consistently; and
- improve stakeholder awareness of how much DLB activities cost.

5.1 Charging principles

The following principles apply to DLB charges for products and services.

- DLB charges cost recovery for all linked data projects to offset its operating costs.
- DLB reviews charges at least annually in response to finite public sector budget resources and the uncertainty, time-limited and project-specific nature of external funding.
- DLB reserves the right to vary access to its products and services and the schedule of charges, with approval from the Assistant Director General, Public Health Division, DOH.
- The charging structure for DLB products and services is well-defined and covers the following components: client services, linkage, case/control/cohort selection, extraction of linkage keys, family connections, geocoding, data extraction (also incorporating quality assurance) and amendments/updates.
- Applicants are responsible for requesting an estimate of DLB charges and ensuring sufficient funds are available prior to embarking on a project.
- Additional fees may be charged for and on behalf of Data Providers to offset costs associated with a particular request. These charges will be bundled with those of DLB and dispersed as required.
- Additional charges may apply for cross-jurisdictional projects due to the added complexity and work time associated with these requests.

5.2 Charging estimate

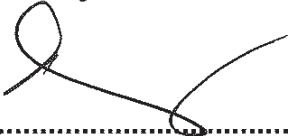
A preliminary estimate of DLB charges can be provided to Applicants prior to submission of the draft application for linked data. A formal estimate of charges covering all associated DLB services will be provided with the Feasibility Letter,

once all Data Providers have agreed in principle to the detailed application. The final charge may vary from the estimated charge if unanticipated additional work is required by DLB (e.g., if the format of data provided for linkage is different to what is documented in the approved application). Additional charges may also apply for subsequent changes to the scope of the application.

6. POLICY APPROVAL

This Policy has been approved for release via web and other media by the Director General, DOH.

Signed by



.....
Dr D J Russell-Weisz
DIRECTOR GENERAL
DEPARTMENT OF HEALTH, WA

Date 2/12/15