

APPLICATION AND PRICING ARRANGEMENTS

DATA LINKAGE

Public Health and Clinical Services

DEPARTMENT OF HEALTH WA



Data Linkage Application & Pricing Arrangements

1. INTRODUCTION

A centralised data linkage facility has been operating within the Department of Health WA (DoH) since 1995. The data linkage infrastructure is managed by the Data Linkage Branch (DLB) within the Public Health and Clinical Services Division.

Data linkage staff members collaborate with internal and external Data Custodians to build data linkage infrastructure for projects that focus on understanding and improving the health and wellbeing of the people of Western Australia (WA). This service is provided within the DoH to comply with privacy and confidentiality constraints on the collection, use and disclosure of personal information.

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.

The WA Data Linkage System (WADLS) is an electronic system, specifically designed to connect information from different sources for the same person, place, event or family. The WADLS is maintained using rigorous, internationally recognised privacy preserving protocols, probabilistic matching and extensive clerical review. Regular linkage updates are undertaken according to availability of personal identifying information from 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 for specific projects, provided approval from data providers and the DoH Human Research Ethics Committee (DoH HREC) is obtained.

Specifically tailored, linked data extracts can be provided for approved research, monitoring and policy and program evaluation. Due to the increased probability of re-identification in linked datasets, the requirements outlined in the *Practice Code for the Use of Personal Health Information provided by the DoH* will apply for all data linkage applications, whether or not direct identifiers are requested.

The detailed application process for use of data linkage resources and services is described in www.datalinkage-wa.org.au

2. SCOPE

This document describes the application and pricing arrangements for use of data linkage resources and services, undertaken by the DLB.

3. PROJECT COMPLIANCE

Use of data linkage services and resources is to be consistent with the *WA Health Information Access and Disclosure Model* ([Operational Directive 0360/12](#)) and *Information Use Policy* ([Operational Directive 0390/12](#)).

Project proposals must demonstrate the following to comply with data provider and ethics committee requirements:

- they are of scientific merit and have been approved by the DoH HREC

- they are aimed at understanding and improving the health and wellbeing of West Australians
- they have access to sufficient resources to undertake the proposed research and analysis through to publication
- they will be conducted in accordance with the applicable legislation, regulations and guidelines and have the support of the relevant data custodians and stewards.

4. PURPOSE & CAPACITY

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 will 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

The probabilistic techniques used for linkage deliberately balance the number of missing links with the number of incorrect links and so a small (unmeasurable) number of incorrect links are likely to remain.

Applications for clinical governance or auditing to follow individual patients or clinicians will not be accepted and such applicants will be directed to original data providers.

Applications supported by private funding will not be accepted, unless there is evidence that there is no real or perceived conflict of interest or inappropriate involvement by the funding organisation.

Due to the time and resources needed to prepare, submit and assess proposals, authorise their feasibility and then prepare, extract, assemble, check and deliver linked data extracts, applications for time constrained projects are actively discouraged.

An undertaking to publish results, regardless of research findings, in publicly available media within a specified timeframe will also be required. Any request to waive this requirement must be explained in the project application.

Prioritisation

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

- Prior commitments;
- 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.

Increased priority will only be given to a particular application or request for services if it has the authorisation of a DoH Executive Director or equivalent.

Application Process

A standard application process is advertised at www.data-linkage-wa.org.au. This process includes a draft review phase, which allows DLB staff and data providers the opportunity to comment on applications for linked data. Once these stakeholders have provided in principle support for the project, a Feasibility Letter will be provided by the DLB which will allow the applicant to proceed with their formal submission to DoH HREC.

The DLB Client Services Unit (CSU) coordinates and documents all requests submitted through the Data Services email portal, in collaboration with relevant Data Stewards, Custodians and Managers. The Project Manager and Project Officer are available to provide preliminary advice on data availability, agreements, linkage protocols, project feasibility, timelines and pricing.

The DLB Program Manager, Manager, Data Linkage Systems and Senior Data Linkage Consultant are also available to provide advice on interpretation of agreements, resourcing and pricing arrangements, as well as the final determinations on the technical feasibility of the project and expected timelines.

Terms and Conditions

Data will not be released to applicants unless:

- All the relevant data providers have approved the use of data under their supervision;
- The project is approved by the DoHWA HREC, under its Terms of Reference to review projects applying to access personal health information;
- The Director General or delegate has approved the release of DoHWA and other information for the project;
- All other relevant approvals have been provided (e.g. approval from Chief Executives of Area Health Services, and external data providers).

Applicant Obligations

Applicants wishing to receive linked data under this policy must agree to:

- include an organisation or investigator based in WA. Rationale for why this condition is necessary will be provided on the DLB website. A request to waive this condition will require a communication proposal that ensures feedback to the WA Community;
- adhere to the *Practice Code for the Use of Personal Health Information provided by the DoH*;
- apply for 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 quoted in the Feasibility Letter or subsequent written advice;
- acknowledge the role of the WA Data Linkage Branch in all publications or reports.
- provide a copy of any draft reports, journal articles or presentations to the DLB and Data Custodians 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;

- submit a plain language summary of research results to the DLB for publication on its website;
- with guidance from the DLB, undertake to disseminate results to the community through print or social media, lecture, seminar or other format as appropriate.

5. FEES AND CHARGES

The WA Data Linkage System (WADLS) has been developed with funds provided by Lottery West, WA Health and other WA agencies, supplemented with contributions from research infrastructure grants and fees for linkage and client services. WADLS system development and technical support rely on contributions from research grants and cost recovery sources.

Pricing principles

The following principles apply to applications for data linkage resources and services:

- Services provided by DLB not covered by specific funding arrangements will attract a fee based on the resources required to deliver the service.
- The pricing structure for these services is well-defined and quotes for specific services will be provided on request
- Additional fees may be charged for and on behalf of data custodians 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.

Discretionary Pricing

Provided sufficient resources are available to complete the work in the required timeframe, projects undertaken by DoH staff will not attract a fee for linkage and related services, if the project is supported by Executive Director or equivalent.

Fees may also be waived for projects covered by joint research infrastructure grants or in-kind support, or as negotiated prior to the provision of the service.

Quotes

A preliminary estimate of the linkage, extraction and client services costs can be provided to applicants prior to submission of the draft application for linked data. A firm quote covering costs for all services will be provided with the Feasibility Letter, once all Data Custodians have agreed in principle to the detailed application. Additional charges may apply for subsequent changes to the scope of the application.

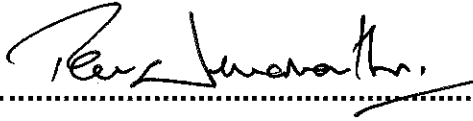
Refunds

Once invoicing for services has occurred and payment received, a refund of charges will not normally be possible. However, a credit against future data requests may be negotiated in exceptional circumstances.

In the event of a dispute, an applicant may make representation to the Executive Director, Public Health and Clinical Services Division for a resolution of the dispute.

6. POLICY APPROVAL

This Policy has been approved for release via web and other media by the Executive Director,
Public Health and Clinical Services Division. **Signed by**



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17th March 2014

**Executive Director
Public Health and Clinical Services
Department of Health, WA**