



A Guide to Applying for Data Linkage

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INTRODUCTION

The Tasmanian Data Linkage Unit (TDLU) is a node of the Population Health Research Network (PHRN) providing data linkage services for Tasmania and working collaboratively with other nodes to support research activities across Australia using high-quality linked data. The TDLU is located at the Menzies Institute for Medical Research in Hobart, Tasmania.

The process of applying for linked data requires applications and approvals from:

1. The data linkage unit (via the [Online Application System](#))
2. A NHMRC-registered human research ethics committee (HREC)
3. The data custodian responsible for each data set

It is the researcher's responsibility to submit applications to the TDLU and Tasmanian HREC. The TDLU will manage the approval process with data custodians.

Applications for linked data are carefully considered and reviewed by the data custodians and by the relevant HREC to ensure that only the information necessary for the fulfilment of the research project is provided.

Charges apply for the provision of linked data. The TDLU has 3 stages of invoicing, during the 5 phases of data linkage engagement with the TDLU. The 5 phases of data linkage are:

4. Design
5. Application
6. Approvals
7. Data Linkage
8. Data Provision

The cost for data linkage starts at \$5,500 and increases based on the number of datasets, time period of data required and complexity of the project. An indicative quote will be supplied by the TDLU after preliminary discussions, with a revised quote provided on completion of the design phase.

INITIAL ENQUIRY

Whether you are applying for a project in Tasmania, or a cross/multi-jurisdictional project using Tasmanian datasets, we encourage you to discuss your project with TDLU staff before applying. The TDLU will provide general linkage advice, documentation, and a meeting of up to 1 hour free of charge. An estimate of linkage costs will be provided in a quote following the initial enquiry.

You can contact the TDLU at menzies.tdlu@utas.edu.au or by phone on 03 6226 4291.

1 | DESIGN PHASE

During the design phase, the TDLU will provide guidance and advice on developing a feasible linkage project. This phase will include meetings, further email correspondence, development of suitable linkage methodology, creation of a linkage diagram, a revised quote for linkage services based on the final design and general researcher support. This phase will provide applicants with the necessary documents to submit to the Tasmanian HREC.

Each project is unique, and there may be overlap between the design and application phases in cases where an application is submitted prior to the TDLU being involved, or where the study design changes significantly during the application phase. This most often occurs in cross/multi-jurisdictional projects.

SUBMIT A QUOTE REQUEST

Quote requests for cross/multi-jurisdictional data linkage projects can be submitted via the [Online Application System \(OAS\)](#). The TDLU recommends that researchers begin with a Quote Request, as it is a shorter form more suited for the design phase of a project. Once a quote has been provided and accepted, the Quote Request can be converted to an Expression of Interest. If a quote for a feasible study design has already been obtained, researchers can proceed directly to the Expression of Interest.

2 | APPLICATION PHASE

During the application phase the TDLU will manage the linkage project and provide review and feedback of the TDLU data linkage application, consistency checking against ethics documentation and further researcher support and guidance. The application phase generally begins with the submission of an Expression of Interest.

EXPRESSION OF INTEREST

Expressions of Interest for both Tasmanian and cross/multi-jurisdictional data linkage projects can be submitted via the [Online Application System \(OAS\)](#).

The Expression of Interest can be viewed online by the applicant, and once submitted, the TDLU. It is a living document that can be revised in response to feedback or study design changes. All Expressions of Interest will go through at least one round of feedback from the TDLU, with complex projects often requiring more. As such, it is best to allow a reasonable amount of time to finalise the Expression of Interest.

As a minimum, a finalised Expression of Interest will include a clearly-formulated project plan that outlines the research aims and objectives, the data required to achieve the research aims, identifies the key stakeholders, and sets achievable timeframes. Completed data variable lists must be attached to the Expression of Interest.

Note that official variable lists as supplied by the TDLU are required; lists created by the applicant will not be accepted. Official lists can be found on the TDLU website [here](#).

APPLICATION

Once the Expression of Interest is finalised, the TDLU will convert it to an Application within the Online Application System. As with the Expression of Interest, the Application can be modified if necessary, however, this is not recommended as it can delay the approval process. Note that conversion of the Expression of Interest to an Application does not imply final approval by the TDLU.

OPTIONAL: APPLYING FOR COMMONWEALTH GOVERNMENT HELD DATASETS

Applicants requesting Commonwealth Government held datasets, including National Death Index (NDI), Australian Cancer Database (ACD), Medicare Benefits Schedule (MBS) or Pharmaceutical Benefits Scheme (PBS) must include these datasets on the Online Application System and complete an application to the [AIHW Ethics Committee](#). Researcher resources for data linkage to Commonwealth datasets are available [here](#).

3 | APPROVALS PHASE

All projects using linked data provided by the TDLU must be approved by the Tasmanian HREC and the custodian of the requested datasets before the TDLU provides final approval. While it is the applicant's responsibility to obtain ethics approval, the TDLU is happy to assist and will provide documents required to complete the ethics application.

The TDLU will manage approvals with data custodians based on the information supplied in ethics and TDLU documentation. This phase includes formal correspondence with data custodians, documentation management, researcher support, a cohort request (if required) and final TDLU approval.

TASMANIAN HREC APPROVAL

Applications for access to linked data are carefully considered and reviewed by the [University of Tasmania Human Research Ethics Committee \(HREC\)](#) to ensure that only the information necessary for the fulfilment of the research project is provided. Applications can be lodged online in the University of Tasmania's [Ethics Review Manager \(ERM\)](#). As a minimum, the ethics application should include:

1. A study protocol
2. A data linkage feasibility letter (provided by the TDLU)
3. Completed data variable lists (as attachments, not embedded within the protocol)
4. Any other documents stipulated in the HREC application

For single jurisdictional projects (Tasmania only) a data linkage protocol diagram provided by the TDLU is also required.

Note that in some cases an ethics application may be submitted prior to applying to the TDLU, or during the application process. In this situation, an ethics amendment may be required at this point to ensure consistency with the Online Application.

It is very important that the following information is identical on the TDLU Online Application and HREC applications:

- Researchers
- Datasets
- Date ranges of datasets
- Data variable lists
- Cohort description

The TDLU will only supply data as approved in the ethics application. Failure to ensure that these details are the same in both applications may lead to significant delays in the approval or provision of data, as ethics amendments or additional data custodian approvals may be required.

The Prior Approval pathway: for cross/multi-jurisdictional projects only

The Tasmanian HREC is not part of the National Mutual Acceptance (NMA) scheme. However, if a cross/multi-jurisdictional project has already received approval from a NHMRC registered HREC in a different jurisdiction, it may be eligible for the Tasmanian HREC Prior Approval pathway. Please see the Tasmanian HREC [website](#) for more information.

Upload approvals to the Online Application System

Once your HREC application is approved, upload your HREC application and approval notification to the [online application system](#) (under Approvals/Ethics Committees)

DATA CUSTODIAN APPROVAL

The TDLU will apply for Data Custodian approval on behalf of the applicant. To do this, the TDLU requires:

1. A finalised Expression of Interest that has been converted to an Application on the Online Application System
2. A copy of the approved Tasmanian HREC application
3. The approval letter issued by the Tasmanian HREC
4. Completed variable lists in the official format provided by the TDLU
5. A data linkage diagram (provided by the TDLU)

If the Tasmanian HREC approval was obtained through the prior approval pathway, the TDLU will also require:

1. A copy of the source/head HREC application
2. The approval letter issued by the source/head HREC

Please note that it typically takes several weeks at minimum to obtain data custodian approvals.

TDLU APPROVAL

The TDLU will issue its final approval once HREC and Data Custodian approvals are obtained and a data access agreement is signed. The data access agreement must be signed by the principal investigator. A revised quote for data linkage will be provided at this stage.

4 & 5 | DATA LINKAGE AND DATA PROVISION PHASES

Data linkage and data provision are undertaken by the TDLU and data custodians. These phases generally do not require action from the applicant.