



Guide to Applying for Linked Data

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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.

This guide has been prepared to assist researchers applying for linked data via the [Online Application System](#) and is structured to follow the sequence of information required. The application system is available to researchers seeking to apply for linked data for projects to be carried out in Tasmania only, as well as for cross- and multi-jurisdictional projects.

All projects requiring the use of linked data must have approval by three parties:

1. The data linkage unit;
2. a NHMRC-registered human research ethics committee (HREC); and
3. The data custodian responsible for each data set.

Further information on specific aspects of data linkage can be found via the following links:

- [TDLU's application process](#)
- [Data Linkage](#)
- [Datasets Available](#)
- [Researcher Agreements](#)
- [Terms & Conditions](#)
- [Legislative Framework](#)

Contact Details

Applicants for linked data services are encouraged to contact the TDLU prior to applying for data. All enquiries should be directed to:

Tasmanian Data Linkage Unit
Menzies Institute for Medical Research
University of Tasmania
17 Liverpool Street HOBART Tas 7000
Manager P | 03 6226 4717 E | menzies.tdlu@utas.edu.au
Client Services P | 03 6226 7752

Data Linkage Application Process

The process of applying for linked data requires applications and approvals from the Tasmanian Health and Medical Human Research Ethics Committee (HREC), the Tasmanian Data Linkage Unit and approvals from the data custodians of the datasets accessed via data linkage. It is the researcher's responsibility to submit applications to the Tasmanian HREC and the TDLU, and 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.

The TDLU's data linkage process is outlined below. The TDLU strongly recommends that you contact us prior to starting an application. The TDLU will provide advice and guidance on whether the data linkage is feasible and provide the relevant documents (data variable lists, data linkage protocol diagram, feasibility letter) to apply for data linkage. The timeframe to undertake a project is dependent on a number of factors, and the TDLU will assist as much as possible to provide an indicative timeframe for you to plan your project. Charges apply for the provision of linked data. A formal quotation will be supplied by the TDLU upon application, or an indication given prior to application where possible.

TDLU Data Linkage Overview

1 | Design

- ❖ Discuss project with TDLU
- ❖ Request a [quote](#)
- ❖ If project is technically feasible, TDLU will provide:
 - [Data linkage diagram](#)
 - Data linkage feasibility letter
- ❖ Supply draft ethics application for feedback
- ❖ Complete [data variable lists](#)

3 | Approvals

- ❖ Upload HREC application and approval to TDLU [online application system](#)
- ❖ TDLU will seek data custodian approvals
- ❖ Researchers to sign and upload:
 - [Deeds of Confidentiality and Compliance](#)
 - [TDLU Security Checklist](#)
 - [Researcher Agreement](#) (PI only)
- ❖ Once data custodian and ethics approvals received and researcher documents submitted, TDLU provides final approval and [Researcher Terms and Conditions](#)

5 | Data Provision

- ❖ Researcher receives researchable dataset from data custodians
- ❖ TDLU issues invoice to researcher
- ❖ Researcher provides research papers and publications to the TDLU per the [Researcher Terms and Conditions](#)

2 | Apply

- ❖ Apply to the TDLU [online](#)
- ❖ Submit an ethics application to the [Tasmanian HREC](#)
- ❖ Ensure the same information is supplied in both applications:
 - Requested datasets
 - Date ranges of datasets
 - Data variable lists
 - List of researchers

4 | Data Linkage

- ❖ TDLU negotiates the supply of data for linkage (if required)
- ❖ TDLU conducts data linkage, creates PPIDs and provides to data custodians
- ❖ Data custodians attach approved data variables to PPIDs and provide the linked de-identified dataset to researcher



It is important that information (eg datasets, data variables required, date ranges) supplied to the Tasmanian HREC is identical to that provided to the TDLU and vice versa. If the information differs, there may be significant delays in the approval or provision of data, as an ethics amendment or additional data custodian approvals may be required. A summary of documents when applying for data linkage with the TDLU is available [here](#).

Sections 1-9 provide step-by-step information on completing an application in the Online Application System (OAS).

1. OAS Registration

If you have not used the PHRN's online application system previously you will need to [register as a new user](#). Once registered you will be able to create a new application. If you are returning to the system to modify an existing application, you will need to go to the Home page and identify the project you want to edit, then click anywhere in its row to highlight the row and click on Edit at the bottom of the page.

2. Project Summary

In the OAS, researchers are to select the applicable application type:

Quote: Select this option if you would like a quote before applying for a grant or to scope your project.

- Charges apply to the provision of linked data by the TDLU. A formal quotation will be supplied by the TDLU upon application, or an indication given prior to formal application where possible.
 - The estimated data linkage cost is dependent on a number of factors including the number of datasets to be linked, the size of the datasets, and the technical complexity of the project. Quotes will also comprise a client servicing component and a fee covering the hardware and human resources to build and maintain the TDLU's Master Linkage Map. It is important to note that data custodians may charge a fee for extraction of data from their collections. This fee will be included in the total price for linkage.

Expression of Interest (EOI): Select this option when you are planning your project and would like feedback from the TDLU about your proposal. For Tasmanian projects, we recommend you contact the TDLU prior to your application to discuss your requirements and before HREC approval is sought. For multi-jurisdictional projects, nationally coordinated feedback will be provided from the PHRN.

Application: The TDLU and jurisdictional Data Linkage Units (DLUs) will advise you when your EOI is ready to transition to an application. An application indicates that your project is ready to be formally reviewed.

Amendment: Please select this option if you have an approved application and you would like to apply for access to additional linked data for the same project.

Project Title: Title must be the same as on relevant Ethics application

Project Duration

- The date entered here only needs to be an estimate. Note that longer lead times are required for datasets that are not currently linked or held by the Data Linkage Units (DLU/s). Dates are requested to assist with resource provisioning and have no impact on overall timeframes. Please be aware that it may take a number of months for ethics and data custodian approvals to be received after your application is finalised.

Are there any time-critical aspects of the research project you would like us to be aware of?

- This will provide an opportunity for the TDLU to let you know if your proposed linkage is feasible within your time restrictions. Examples of time-critical aspects may include funding deadlines, employment contracts, and student candidate requirements. Note that if you check this box the “*Please specify*” field becomes a required field for all application types.

Project Description: Provide a brief description of the linkage requirements.

Select type of organisation/institution responsible for the project.

- Enter the organisation that is legally responsible for the project.

Funding Source(s): Please specify funding source

Conflict of Interest

- Conflicts of interest in the area of research may arise from time to time and it is important that they are disclosed.
- The TDLU seeks to protect its integrity in relation to conflicts of interest that may arise in relation to the services it provides
- If you have a conflict of interest in areas covering finance, ethics, intellectual property or other, please list details in this section.
- Conflict of Interest declarations will be considered as part of the approval process

3. Researchers

Principal Investigator

- This must be the person who has immediate responsibility for the management of the project and must not be a student.

Access to data required:

- Check this box if the Principal Investigator will require access to linked data at any stage throughout the project. The Principal Investigator is required to sign the [TDLU Researcher Agreement](#), [Deed of Confidentiality and Compliance](#), and [TDLU Security Checklist](#).
- If you have entered an email address for the Principal Investigator upon saving or pressing the next button the Principal Investigator will receive an email notification to inform them that they are able to view the application. This email will provide a link directly to your project. If they are not a registered user already, they will need to register.

TIP: Leave the email address field for the Principal Investigator or Contact Person empty until you are ready for them to view the form.

Contact person for project

- If the contact person is the same as the Principal Investigator check the 'Contact Person is same as above' box. This will auto-fill all fields under the contact person. Note that if you check and then uncheck this box the details will remain in the contact person fields but will now be editable. This is useful if the Principal Investigator and Contact Person have similar details, ie work at the same organisation and have the same or similar contact details.
- All correspondence and communication with the TDLU will be undertaken with the person named as the contact person.

Please list all the project personnel, including students

- You will notice that the Principal Investigator and the Contact Person will show up in the table on the Researchers' page. If you need to edit the details of the Principal Investigator or Contact Person at any time, you will need to do this from the Summary page. All other researchers and students can be added and edited from the Researchers' page.
- All personnel added to the project and for whom you have provided an email address will receive an automated email via the online application system notifying them that they have been listed on the project upon saving. It is recommended that you enter email addresses when you are comfortable with having project personnel being notified about the project.

Select Researcher/Select Student

- It is worthwhile checking to see if the researcher already exists in the system. Start typing the person's name in the 'Select an option' text box or scroll through the list that appears when you click in the text box. If the researcher already exists select them by clicking on their name. Details that are available for them will auto fill however will be editable. If they do not already exist in the system, simply type their details in the fields below.
- **Access to data required:** Check this box if the researcher will require access to linked data at any stage throughout the project. Data are to be accessed only by named people who have signed the TDLU's [Researcher Deed of Confidentiality and Compliance](#) and the TDLU [Security Checklist for Researchers](#). Please ensure that the same co-investigators and researchers are listed on the corresponding Ethics application submitted to Tas HREC.
- **Allow access to form:** The allow access check box enables you to invite other researchers involved in the project, supervisors or colleagues to view the application. They will not be able to edit the application, but they will be able to view the form and add comments throughout. If they have rewritten a section or provided suggested replacement text you will be able to copy and paste from the comments modal directly into the relevant section. Note that you must open the comment (by pressing the edit button) before you will be able to copy.
- If you check this box, the next time you save the application an email will be automatically sent to the researcher to inform them that they are able to view the application. This email will provide a link directly to your project. If they are not a registered user already, they will need to register.
- It is recommended that you check this box when you are comfortable having the co-investigators being able to view your form.

4. Cohort Selection

- Please provide a concise description of your cohort and how your study population is defined. List datasets which should be used for selection of your cohort and whether the cohort will be selected from specific disease or procedure groups.
- Please estimate the number of people that are expected to be in the cohort.
- If a control group is required, please provide a description of how it will be selected and used. List datasets which should be used for selection of your controls.

5. Datasets


Jurisdictions to be involved






- This field allows you to select the jurisdiction(s) from which you are requesting data. The 'Other' jurisdiction should be selected if you intend to link international datasets.
- For some national datasets you are able to obtain one approval from the national data custodian (i.e. the National Death Index). For other national datasets you will need to obtain approval from each of the contributing (state) data custodians of the jurisdictions from which you require the data (i.e. Australian Cancer Database). Please contact the TDLU for advice if required.

Datasets to be provided

Add required dataset:

- The TDLU provides a range of data linkage services that include the linkage of one or more Master Linkage Map (MLM) datasets, one-off linkage from a MLM dataset, or linkage to external datasets.
- For some projects, researchers may have Ethics approval to link TDLU MLM datasets to an existing data source.
- Access to data is subject to relevant legislative requirements and restrictions, policy and operational considerations, approval by HREC and the relevant data custodians.
- A list of routinely or commonly-linked datasets (referenced datasets) is available online once you select the jurisdiction/s for your project. For referenced datasets only, it is the responsibility of the DLU to complete fields filled with grey. The researcher cannot complete these fields. These may be filled out by the DLU after you submit your form via the DLU information tab.
- TDLU commonly-linked datasets are listed below. Only request datasets that are **essential** to answering your research questions. If you are uncertain about this, please discuss with TDLU Client Services.

<p>Public Hospital Admitted Patient Data Collection</p> <p>Administered by the Department of Health Tasmania. Administrative data collection containing morbidity data on admitted patients from all public hospitals in Tasmania. Contains demographic, administrative and clinical data for each admitted patient separation.</p> <p>Date range: Jan 2007 – Dec 2019 <i>Updated annually in 2nd quarter</i> Data variable checklist & metadata</p> 	<p>Public Hospital Emergency Department Presentations</p> <p>Administered by the Department of Health Tasmania. Administrative data collection covering the EDs of all public hospitals in Tasmania. Contains demographic, administrative and clinical data specific to each presentation.</p> <p>Date range: Jan 2000 – Dec 2019 <i>Updated annually in 2nd quarter</i> Data variable checklist & metadata</p> 
<p>RBDM Death registrations</p> <p>The Register of Deaths includes any person who died in Tasmania; stillbirths and foetal deaths are not recorded in the Deaths Register. Where there is sign of life at birth, but the neonate subsequently dies, the birth is recorded in the Births Register and the death is recorded in the Deaths Register.</p> <p>Date range: Jan 1970 – Feb 2019 <i>Updated annually</i> Data variable checklist: contact TDLU</p> 	<p>Cause of Death (Tasmania)</p> <p>The dataset is a compilation of death records from each of the State and Territory Registries of Births, Deaths and Marriages and from the State and Chief Coroners through the National Coronial Information System. The TDLU can link to Tasmanian registered deaths only. The dataset contains a number of attributes of an individual including the International Classification of Disease codes (currently version 10) relating to the causes of death, which are added by the Australian Bureau of Statistics. The dataset contains deaths registered in Tasmania and is not dependent on the place of usual residence.</p> <p>Date range: 2006-2015 (final); 2016 (revised); 2017 (preliminary) <i>Updated annually</i> Data variable checklist</p> 
<p>RBDM Birth registrations</p> <p>Administered by the Registrar of Births, Deaths and Marriages. The register includes all children born and registered in the State of Tasmania, including stillbirths, or deaths in utero, occurring after 20 weeks gestation, or with a body mass of at least 400 gm at birth.</p> <p>Date range: Jan 2000 – Mar 2019 <i>Updated annually</i> Data variable checklist</p> 	<p>Perinatal Data Collection</p> <p>Public & private hospitals, birthing centres and home births.</p> <p>Administered by the Department of Health Tasmania. Administrative data collection recording all births in Tasmania. Information in this collection is specific to pregnancy care, services and outcomes, including demographic, medical and obstetric information about the mother, and information on the labour, delivery and condition of the infant.</p> <p>Date range: Jan 2005 – Dec 2018 <i>Updated annually</i> Data variable checklist Data variable metadata</p> 
<p>Tas Cancer Registry (TCR)*</p> <p>The TCR provides population-based statistics about cancer incidence and mortality for Tasmanian residents, collecting for each cancer case information on residence, sex, date of birth, date of diagnosis, cancer topography and morphology, means of diagnosis, multiple primary sites, race, country of birth, place and cause of death, where applicable.</p>	<p>Australian Early Development Census (AEDC)</p> <p>The AEDC is a full population census of children's health and development in their first year of formal full-time schooling. AEDC datasets have near-total national coverage of school entrants. Teachers complete the AEDC Checklist in the first year of formal full-time school, and are completed based on teachers' knowledge and observations of the children in their class. Participation in AEDC is not compulsory.</p> <p>Dates: 2009, 2012, 2015, 2018</p>

<p>Date Range: Jan 1982 – Dec 2017 <i>Updated annually</i> Data variable checklist & metadata</p> 	<p><i>Updated every 3 years</i> Data variable checklist: contact TDLU</p> 
<p>Ambulance Tasmania Emergency Incidents* This dataset contains Tasmanian emergency ambulance care incidents extracted from the Victorian Ambulance Clinical Information System (VACIS). The VACIS captures the electronic patient care record including information on patient symptoms, diagnoses and treatment.</p> <p>Date range: Jan 2010 – Dec 2015 <i>Updated on an ad hoc basis</i> Data variable checklist: contact TDLU</p> 	<p>Tas Community Mental Health Data Collection Contains Tasmanian state government-provided ambulatory episodes of mental health care. Data contains information specific to the assessment, treatment, recovery and care of child and adolescent, adult and older persons in non-admitted settings. Episodes of care represent services provided in community mental health centres to individuals or groups, as part of crisis assessment and response, outreach services or home visits. Records occasions of services provided by clinicians to patients.</p> <p>Date range: Jan 2000 – Dec 2015 <i>Updated on an ad hoc basis</i> Data variable checklist: contact TDLU</p> 
<p>Australia New Zealand Dialysis and Transplant Registry (ANZDATA)* Data is contributed from all adult and paediatric Renal Units in Australia and New Zealand. This encompasses all patients receiving renal replacement therapy (RRT), either dialysis or kidney transplantation, for the treatment of end stage kidney disease (ESKD). Survey data is collected nearest to the 31-December every year for the previous twelve months. Real time data is collected on all new incident patients commencing RRT, changes of RRT modality, changes in treating centre, death and other major events such as new cancer diagnoses.</p> <p>Date range: Jan 1963 – Dec 2016 <i>Updated annually</i> Data variable checklist: contact TDLU</p> 	

**Subject to additional approval*

Add other dataset: Other datasets may include researcher/clinical cohorts, State government datasets, or information collected from any other organisation. They may also include Commonwealth Datasets such as Medicare Benefits Scheme (MBS) or Pharmaceutical Benefits Scheme (PBS).

In such instances, relevant Ethics Committee approvals must be sought. The TDLU will work with an approved Integrating Authority to negotiate linkage of Commonwealth data.

It is recommended that the following variables for linkage of external datasets (eg those provided by the researcher) are provided where available:

- First name, middle name, surname;
- Alternative names/aliases;
- Date of birth;
- Gender;
- Address, and
- a date that is associated with the address at a point in time (e.g. diagnosis date, admission date).

The TDLU will provide further advice on linkage variables and data specifications for new datasets.

TIP: Please ensure the datasets and data variable lists are included in your ethics application.

Data Items Required

- For each dataset that you are requesting, you will need to specify each data variable you require.
- Lists of data variables for all core TDLU datasets can be accessed at the [TDLU website](#) or by clicking on the dataset names in the above table.
- For multi-jurisdictional projects please contact the relevant DLUs to obtain their data variable lists.

Data Extraction

Are you requesting a once-off data extraction?

- *Yes. We only require a one-off data extraction:* Select *Yes* and press the Next button
- *No. We will require more than one data extraction:* Select *No* and a "please specify" box field becomes a required field. Please specify:
 - the number of expected updates
 - frequency of updates/timing/dates
 - if the current data custodian and ethics approvals cover ALL updates, and
 - any changes to, or expansion of your cohort or datasets requested or project funding/resourcing.

6. Consumer Participation

Have you sought consumer participation?

Whilst fields in this section are not mandatory, they have been included to encourage researchers to consider the benefits of involving consumers in all aspects of their project.

The PHRN is committed to the principles of best practice consumer and community participation in all its activities. It recognises and supports the central role of consumers and community members in the development, governance, and operations of the PHRN as well as the planning, design and dissemination of results of all research projects conducted using the PHRN infrastructure. The PHRN strongly encourages researchers to involve consumers in all stages of their research.

For more information about involving consumers in research:

[NHMRC Statement on Consumer and Community Participation in Health and Medical Research](#)

Interest of maintaining public confidence

The statement pertaining to maintaining public interest in research is a mandatory field for all application types. This box must be checked for the successful submission of a quote, EOI or formal application.

7. Privacy

Personal information

Personal information is information about an individual where the identity of the individual or institution is apparent or can reasonably be ascertained from the information itself. Information is also personal information if it is reasonably possible for the person receiving the information to identify the individual by using other information that they already hold.

Select 'Yes' if you require any of the following information for your research and provide an explanation for why personal information is required.

- Participant / Patient names
- Participant / Patient location (postcode/suburb)
- Participant / Patient full address
- Participant / Patient full date of birth (NB: ddmmyyyy not mmyyyy)
- Patient identifiers (e.g. MRN)
- Clinician or health service provider identifications
- Individual hospital or healthcare institution identifications
- Geo-coded points (longitude or latitude)

Consent

- It is recognised that in some situations there may be datasets collected and used with consent being linked with datasets collected and/or used without consent. To accommodate this, this section allows you to select both *Yes* and *No* if required.
- The Manage Documents button has been provided to allow researchers to upload any contact letters, information sheets or consent forms etc. that may be used for the project.

8. Data Management

Location

If you are expecting to use the Secure Unified Research Environment (SURE), tick the box. Note that if linkage to Commonwealth datasets is requested, the linked data can only be stored and analysed through SURE.

The Secure Unified Research Environment (SURE) is a remote-access computing environment that allows data users to access and analyse linked health-related data files for approved studies in Australia. SURE has been developed by the Sax Institute as part of the Population Health Research Network.

SURE aims to:

- Minimise the risk of privacy and/or confidentiality breaches when conducting research using linked, de-identified health and other data, by supplying a remote-access computing environment with comprehensive security features which replaces a researcher's local computing environment;
- Improve the accessibility of linked data to accredited researchers undertaking ethics committee-approved population health, health services and related research;
- Make collaboration between researchers from different institutions easier and more efficient;
- Provide researchers with a high-performance computing environment with enhanced speed, storage and cutting-edge analytic software and tools to researchers.

In Tasmania data custodians will upload data directly into SURE, but some data custodians in other jurisdictions will not upload data directly, in which case it is the researcher’s responsibility. If this applies in your case, please include details of where the data will be stored prior to going into SURE. For more information, please see the [SURE introduction](#), or visit the [SURE website](#). Use of the SURE attracts fees.

List all locations

List all the locations where the data will be stored and analysed. When listing locations please include departments at institutions (including buildings and room numbers if appropriate). If the only place your data will be stored and analysed is SURE, type SURE only into this field to enable your form to be submitted.

Security Plan

It is a requirement when supplying linked data that it will be stored securely in accordance with [Section 2 of the NHMRC Code for Responsible Conduct of Research, ‘Ensure security and confidentiality of researcher data and primary materials’](#).

The Security Plan should specify the measures to be taken to protect the information from misuse, loss or unauthorised access during the research project.

It is expected that the Security Plan will address elements such as those described below.

Element	Description
Physical security	<p>Should describe the measures put in place to physically protect the de-identified data and prevent access by unauthorised people, such as:</p> <ul style="list-style-type: none"> • locked filing cabinets • clear desk policies • door keypads • restricted access to workspace / office • security monitoring • both physical and technological protection should be used in transporting information.
Protection of identity	Such as the separation of identifying information and content information and statistical disclosure control in publication of results
Data transfer measures	<p>Should describe the processes put in place to ensure the safe transfer of de-identified data, including:</p> <ul style="list-style-type: none"> • encryption of data • method of transfer • who will manage <p>It is recommended that this element of the plan be discussed with the TDLU who will advise appropriate data transfer methods.</p>
Technological security	<p>This element of the plan should describe what technological measures will be put in place to ensure safe management of de-identified data, and include:</p> <ul style="list-style-type: none"> • limiting access to only those people assessed to be suitable and whose work responsibilities specifically require them to access these resources • use of passwords, password rules, password change frequency • protected directories, protected network drives • standalone or personal computers • timed out lockable screen savers • firewalls, network measures

Element	Description
	<ul style="list-style-type: none"> • encryption of data • use of removable media.
Organisational measures	This section should outline measures in place to limit access to information imposed by the organisation represented in the data-linkage application.
Training & administrative security measures	This part of the security plan should identify what measures are in place to ensure researchers are adequately trained in the handling of personal information. The response should be constructed in accordance with appropriate codes of conduct, policies, procedures, standards, guidelines, security training, risk assessments, protocols or legislative requirements applicable to the organisation or jurisdiction completing the application.
Other	Any other information deemed applicable to safe storage of data

Data Retention and Disposal Plan

The Data Retention and Disposal Plan must be in line with the relevant jurisdictional policies and take into account professional standards, legal requirements and contractual arrangements. Refer to the [NHMRC](#), [ANDS](#), the [TDLU website](#) for relevant institutional policies.

- The destruction of data is a specific requirement for TDLU Linkage Projects, unless agreed as part of the approval to supply linked data for the specific project
- Transparent and secure arrangements should be made for the retention and final destruction of the data after the project is complete.
- The TDLU, PHRN and other DLUs and Ethics Committees must be notified of data destruction.
- There is, however, a requirement for the Researchers to engage with the data custodians in considering conditions specific to the retention and destruction of data in accordance with Ethics approval and the overall aims and objectives of the research project.
- The Data Retention and Disposal Plan specifies the retention and destruction conditions required for de-identified data provided for this project, including 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 data destruction expectations and the destruction date.
- Data must be securely stored and available only to researchers named on this application.
- If agreed as part of conditions of data supply by Data Custodians, on completion of the project a *Certificate of Destruction* attesting to the destruction of the data associated with this project, including original data supplied and value-added unit record data derived must be completed.
- The *Certificate of Destruction* must be returned to TDLU within 10 working days of the data destruction.

Analytical tools

- Providing the DLU with information about the software packages and analytical tools you will use for the project may allow them to prepare the data to meet your requirements.

9. Approvals

Data linkage requires the use of personal information to make the initial link between data collections. This is usually done without consent and therefore significant legal and ethical issues arise. In Australia, research projects using linked data must be approved by three groups:

1. The data linkage unit/s
2. All participating data custodians/data stewards
3. All relevant Human Research Ethics Committee/s

Data Custodian Approvals

The data custodians listed in the Data Custodian Approvals table are determined by the datasets that you have selected under the datasets tab and have been provided for your information.

- In Tasmania the TDLU will liaise with the data custodians direct, to seek the necessary approvals once all relevant ethics committee approvals have been received for your study. A copy of your application will be provided to data custodians along with your ethics application and approval letter.
- For multi-jurisdictional projects, the DLUs will release your application to the data custodians on your behalf once they have determined that your project is well conceived, feasible and your application is complete. You will receive an automated email via the online application system notifying you when this occurs. You may be responsible for seeking data custodian sign off independently for external datasets but each DLU will advise if this is necessary.
- Each data custodian's nominated (authorised) representative must provide final approval of this application before it can proceed.
- The data custodian nominated delegate for each dataset may be involved in the negotiation stage of the development of this application and is entitled to impose reasonable conditions regarding the use of their data.
- These include the right to review the published research to verify that privacy has been maintained and that the data have been accurately analysed.
- The data custodians are also entitled to charge for the production and delivery of data to researchers on a cost-recovery basis.

Data Release Conditions (TDLU to supply to researcher)

- All applicants/researchers involved in the project are required to comply with the conditions listed in the relevant agreements in place between the TDLU and data custodians.
- Conditions imposed by data custodians will be provided to the researcher by the TDLU.

Human Research Ethics Committees:

- Human Research Ethics Committees (HREC) approvals are undertaken external to the PHRN online application system. Every linkage project must receive approval from at least one NHMRC registered HREC. In Tasmania this is either or both of the [Health & Medical](#) or [Social Sciences Ethics Committee](#). Applicants wishing to apply for data linkage in Tasmania must apply through the [Ethical Review Manager](#) online system.
- All HRECs registered with the NHMRC in Australia are listed in the HREC dropdown box. The jurisdiction field relates to the jurisdiction that requires the particular HREC's approval which may be different to the jurisdiction in which the HREC is situated. Note that both researchers and the DLU can add required Ethics Committees to this table.
- You are responsible for submitting your ethics application to all HRECs listed in your HREC approvals list. You will receive an email notification from the data linkage unit(s) via the online application system informing you when to submit your project for ethical review.

- The TDLU requires copies of your HREC applications, research protocols and HREC approval letters prior to seeking data custodian approval. You can upload these documents after the application has been submitted by pressing the *Manage Documents* button directly beneath the HREC Approvals table. Subsequent HREC amendments and approval letters will also be required to be provided.
- In other jurisdictions it is a requirement that HREC approval be sought after this application has been submitted (it is common for the HREC to require the technical feasibility letter from the DLU and the Data Custodians in-principle approval as part of their review). Submission of a formal application to the DLU can therefore occur without any HREC approvals.

All Other Approvals:

Depending on the jurisdiction in which you are requesting data, you may be required to obtain approvals in addition to data custodians and HRECs such as required by the Public Health Act in Queensland. For a list of additional approvals your project requires, please contact the [client services officer](#) of the Data Linkage Unit that will be linking your data.

Submit: The submit button allows you to submit your application to all DLU(s) involved upon completion of all mandatory fields. The form will not be successfully submitted until all mandatory fields are complete. You can use the 'submit' button to determine what the mandatory fields of each application type are.

Note: the system does not validate as you move through the pages. It will only validate on submission. This is for convenience and ease of use, allowing you to move through the form in any order and move between pages with sections incomplete.

Once submitted, you will receive an email generated from the online application system confirming successful submission for the project, and advising that you will be notified once your application has undergone review by DLUs.

10. TDLU Researcher Agreements

It is a condition of applying for, and releasing data linked by the TDLU that the following agreements are completed, signed and submitted once HREC and data custodian approvals have been received. These agreements can be loaded to the online application system after your application has been submitted.

Researcher Agreement

- The [Researcher Agreement](#) must be completed by the **Principal Investigator** (nominated in the online application, and who has immediate responsibility for the management of the project and must not be a student).
- It is the responsibility of the Principal Investigator to ensure that all researchers/co-investigators involved in this project and identified in the application comply with all the conditions and policies. This includes access to, storage, management and use of data, review of publication of findings, and retention and destruction of data.
- The applicant is required to acknowledge that the de-identified data provided for the project by the data custodians, and linkage keys provided by the TDLU, are confidential information and that the applicant is responsible for ensuring that the information remains confidential.
- If supervising a student undertaking research using linked data provided by the TDLU, the supervisor is required to acknowledge that training is provided to enable the project to be undertaken skilfully and ethically.
- It is a requirement that the Head of Department/school/research organisation representing the Principal Investigator certifies they are familiar with the project, that the institution they represent approves the project and that researchers have the necessary skill and expertise to undertake the project.

Researcher Deed of Confidentiality and Compliance

- The [Researcher Deed of Confidentiality and Compliance](#) must be signed by the Principal Investigator and **all** researchers/co-investigators involved in the project who will have access to the requested data, and be co-signed by the Principal Investigator.

TDLU Security Checklist for Researchers

- The [TDLU Security Checklist for Researchers](#) must be signed by the Principal Investigator and **all** researchers/co-investigators involved in the project who will have access to requested data.

	Principal Investigator	Researcher
Researcher Agreement	✓	
Deed of Confidentiality & Compliance	✓	✓
Security Checklist for Researchers	✓	✓

11. Researcher Checklist

Please ensure all the following actions have been completed prior to submitting your data linkage application.

Complete	Action	Responsibility
<input type="checkbox"/>	Read information contained on TDLU website	Researcher
<input type="checkbox"/>	Discussed proposed data linkage project with TDLU	Researcher/TDLU
<input type="checkbox"/>	Expression of Interest or request for Quote lodged via the online application system . Once complete this will transition to an application.	Researcher
<input type="checkbox"/>	Obtained a data linkage feasibility letter from the TDLU to include with HREC application	TDLU/Researcher
<input type="checkbox"/>	Obtained a data linkage protocol diagram from the TDLU to include with HREC application	TDLU/Researcher
<input type="checkbox"/>	All applicants/researchers listed are the same in both the HREC application , and online data linkage application	Researcher
<input type="checkbox"/>	Datasets, date ranges, and data variable lists provided in HREC application match those requested in online data linkage application	Researcher
<input type="checkbox"/>	Ethics application submitted to Tas Health & Medical HREC via the Ethics Review Manager (ERM). If the project has been granted approval from a NHMRC-registered Australian HREC in another state/territory, you may be eligible to apply via the Prior Approval pathway.	Researcher

Once you have received Ethics approval please ensure the following are completed and uploaded to the online application system:

<input type="checkbox"/>	Provide TDLU with a copy of your HREC original application or amendment, and notification of approval	Researcher
<input type="checkbox"/>	Principal Investigator to sign the TDLU Researcher Agreement , authorised by Head of School/Organisation	Researcher
<input type="checkbox"/>	Researchers to sign the Researcher Deed of Confidentiality and Compliance , authorised by Principal Investigator	Researcher & PI
<input type="checkbox"/>	All Researchers to sign the TDLU Security Checklist for Researchers , witnessed	Researcher

The TDLU will liaise on your behalf and provide the following:

<input type="checkbox"/>	Data Custodian approvals for selected datasets and data variables for the dates requested	TDLU
<input type="checkbox"/>	Final Data Linkage Approval letter provided to Researcher with Researcher Terms & Conditions	TDLU
<input type="checkbox"/>	Where a study cohort is to be linked, TDLU will supply the Researcher with a Cohort request specifying variables, file format and data transfer	TDLU

GLOSSARY

Acronyms

AIHW.....	Australian Institute of Health & Welfare
DLU.....	Data linkage unit, jurisdictional nodes of the Population Health Research Network
EOI.....	Expression of Interest
ERM.....	Ethics Review Manager, a University of Tasmania secure web-based system that manages ethics application life cycles
HREC.....	Human Research Ethics Committee
MRN.....	Medical Record Number
OAS.....	Online application system
NHMRC.....	National Health & Medical Research Council (Australian Government)
PHRN.....	Population Health Research Network
SURE.....	Secure Unified Research Environment, a remote-access computing environment that allows data users to access and analyse linked health-related data files for approved studies in Australia. SURE has been developed by the Sax Institute as part of the PHRN
TDLU.....	Tasmanian Data Linkage Unit
Data Custodians.....	The people who look after the data collections. Data custodians work within an organisation or agency (such as a government department) and are responsible for the secure collection, use and disclosure of data. Data custodians collect and store personal information (eg name, address, date of birth) and also content information (eg health information such as diagnosis and treatment details).
Data Linkage.....	A method of bringing together information, from different sources, but relating to the same individual or event. PHRN data linkage units link existing information from different health and health related data collections to provide data for approved research. This is done using methods which minimise the risks to individual privacy.
Master Linkage Map (MLM).....	The MLM, Master Linkage Map, groups together records for individuals in a population. Each individual within the Map has their own unique 'key'.
Master Linkage Key (MLK).....	Refers to an individual's unique ID, otherwise known as a 'key'.
Project Person Identifier (PPID)	A project-specific, unique pseudo identifier that is supplied to researchers