Tasmanian Data Linkage Unit
Menzies Institute for Medical Research
17 Liverpool Street
Hobart, Tasmania, 7000

TDLU RESEARCHER TERMS AND CONDITIONS

Data Access Agreement

Prior to final project approval by the TDLU, the Principal Investigator of the study must sign the TDLU Data Access Agreement. All researchers involved in the project should be provided with a copy of the agreement to ensure that they are aware of and comply with all conditions outlined in the Data Access Agreement.

Researcher Data Access Conditions

All researchers accessing linked data facilitated by the TDLU must:

- Comply with all conditions outlined in the TDLU's Data Access Agreement;
- Comply with all relevant privacy regulations and legislation applicable to the research activities, including all applicable National Health and Medical Research Council guidelines and the Australian Code for the Responsible Conduct of Research;
- Only use the data provided in accordance with the Project Description/Protocol approved by the Tasmanian Human Research Ethics Committee (HREC);
- Abide by any conditions placed on the approval and supply of data by the Data Custodians;
- Ensure the safeguarding of data, information and assets by adhering to the ethically approved Data Management Plan;
- Report all information security breaches, violations of trust, and incidents to the TDLU and to the Tasmanian HREC; and
- Acknowledge the TDLU and Data Custodians in publications.

Sensitive Data and Confidentiality

The Australian Research Data Commons (ARDC) has published an online guide to the ethical and legal considerations surrounding sensitive data for research. Researchers must be aware of the risks and mitigation strategies when working with sensitive data and take all practical measures to maintain confidentiality of linked data.

The Australian Bureau of Statistics defines a breach of confidentiality as "when a person, group or an organisation is re-identified through a data release or when information can be attributed to them." (Australian Bureau of Statistics, Five Safes Framework, 2021)

To aid in preserving confidentiality of data, the TDLU recommends that all researchers familiarise themselves with the Five Safes Framework published by the Australian Bureau of Statistics.

Core principles of the five safes framework are:

1. Safe people – all researchers must be appropriately authorised to access and use the data
2. Safe projects – projects must have a valid research aim and outline the public benefit of the research. Data should not be used for any purpose other than that outlined in the ethically approved data linkage application and protocol

3. Safe settings – research must be carried out in a secure environment that prevents unauthorised sue.
4. Safe data – at a minimum, all identifiers must be removed from the data before access is granted. Other measures should be applied as appropriate for the type of data being accessed.
5. Safe outputs – all data should be checked for confidentiality before it is published to ensure that statistical results do not inadvertently identify individuals

Avoiding accidental reidentification

Steps that can be taken to ensure that individuals cannot be reidentified include:

- Not publishing any results where there are less that 5 individuals in a category (small cell rule)
- Using caution when analysing small subgroups of the population such as geographical areas with a low population or rare disease groups
- Being aware that release of some combinations of variables that are not individually identifying may result in increased risk of reidentification. Examples include:

  Postcode or SA2
  Date of birth/death
  Ethnicity
  Medical conditions
  Event date

PROJECT AMENDMENTS

Throughout the duration of the project, any amendments to the project must be submitted to the Tasmanian HREC and the TDLU. *All* amendments require approval from an Ethics Committee, and in some cases data custodians, *before* any changes are made to the project. A summary of common types of changes and the actions required is detailed below.

Additional research personnel or changes in research personnel

1. Ethics amendment and approval required.
2. Ethics amendment and approval provided to the TDLU.
3. In most cases Data Custodians are not informed of changes in research personnel.

New hypotheses, research questions, aims or analysis not covered in the scope of the original ethics application and approval

1. Ethics amendment and approval required.
2. Ethics amendment and approval provided to the TDLU. TDLU will send project revisions to all Data Custodians for their approval.
3. The TDLU will advise the researcher of Data Custodian approval.

Additional time periods of data required

1. Ethics amendment and approval required.
2. Ethics amendment and approval provided to the TDLU. TDLU will seek approval from Data Custodians for the additional data.
3. The TDLU will advise the researcher of Data Custodian approval.

New dataset to be added to the project and linked

1. Discuss with TDLU in the first instance to determine the feasibility.
2. Ethics amendment and approval required.
3. If feasible, provide TDLU with Ethics amendment and approval. TDLU will seek approval from the new Data Custodian.
4. The TDLU will advise the researcher of Data Custodian approval.

Acknowledging the TDLU and Data Custodians in Publications

The TDLU and all Data Custodians must be acknowledged in all publications arising from the linked data. The acknowledgment may vary according to the individual project, however the following example is provided as a guide:

> *The authors would like to thank the following organisations: the Department of Health, Tasmania for the supply of Tasmanian Public Hospital Admitted Patient and Emergency Department Presentations data; and the Registries of Births, Deaths and Marriages, the Coroners and the National Coronial Information System for Cause of Death Unit Record File data; and the Tasmanian Data Linkage Unit for undertaking the linkage of these datasets.*

If in doubt, please contact the TDLU for advice on how to correctly acknowledge data custodians.

Journal Articles or Publications

The TDLU requires that journal articles or publications pertaining to the data linkage project are emailed to menzies.tdlu@utas.edu.au at least two weeks prior to submission. The TDLU reviews the wording relating to data linkage methodology and checks for appropriate acknowledgement of data custodians and the TDLU. In accordance with relevant data exchange agreements, the TDLU may forward manuscripts to data custodians to provide them with the opportunity to review and provide feedback.

The TDLU requests researchers provide a copy of the final published manuscript for TDLU reporting purposes.

Cause of Death Data – Researcher Terms and Conditions

Specific conditions apply to the use of Cause of Death Unit Record File (COD URF) data. It is a condition of use that all journal articles containing COD URF data are to be emailed to BDM.CODURF@justice.qld.gov.au for approval prior to publishing.

Confidentialisation Guidelines

All published outputs resulting from use of the COD URF must not disclose information that is likely to enable the identification of any individual. If spontaneous recognition was to occur, the output data must not include additional information about an individual which would not already be known.

Confidentialisation Parameters

1. No identifying information, such as names or registration numbers, can be published.
2. Combinations of variables should not be published together, where doing so would significantly increase the risk of identification of an individual, e.g. publishing combinations such as a person's date of birth, date of death and place of death may allow for easy identification of the particular individual.
3. Ensure extra care is taken when publishing any information below the national level, particularly in smaller States/Territories or for sub-population groups.
4. Steps must be taken to confidentialise the data. Refer to the following link on confidentiality: https://toolkit.data.gov.au/Confidentiality.html

COD URF Confidentialisation Rules

All outputs derived from COD URF data must apply general confidentialisation techniques and use one or all of the rules as outlined below and any additional requirements as indicated in the treatment columns of the Output Risk table.

Small Cell Size rule:

Cell sizes that have between 1 and including 5 (≤5) contributors must not be published – apply confidentialisation techniques. Note: This is sometimes referred to as a cell frequency rule.

Attribute disclosure rule:

Data must not be published where the identification of an individual would enable other details (attributes) of the individual to be revealed.

Cell Dominance rule:

The cell dominance rule (also called the cell concentration rule) is used to identify cells where a small number of individuals contribute a large proportion of the overall population. If this occurs, further confidentialisation actions will need to be undertaken.