

Tasmanian Cancer Registry

Data Access Guidelines

Updated 9 February 2023

This document defines the type of data that can be obtained from the Tasmanian Cancer Registry (TCR), access requirements, and procedures to be followed when requesting data. The procedures are designed to protect against potential privacy breaches, as well as ensuring the ethical integrity and scientific merit of proposals seeking to access data collected by the TCR.

Fees are not generally charged for access to data held by the TCR unless significant resources are required to complete the request.

Types of data requests

You can request data for research or personal information. Always contact the TCR as the first step to discuss your data requirements and to request the relevant forms.

Requesting data for research

The application requirements will depend on whether the applicant is requesting non-identifiable, potentially identifiable, or identifiable data.

Non-identifiable data

Non-identifiable data include summary data that are acquired by aggregating individual level information, which prevents the identification of individuals in the Tasmanian population. Examples may include number of cancer cases by age group, sex, year of diagnosis, or statistical area.

Most of these data are publicly available via the TCR online statistics tool and published in annual reports. If the data you seek are not publicly available, please follow these steps:

1. Contact the TCR to discuss your request

Please contact the TCR (03 6226 4275 or menzies.tcr@utas.edu.au) to discuss your data requirements and request the relevant forms.

2. Submit a data request to the TCR

Send an email to menzies.tcr@utas.edu.au outlining your request, and include the following:

- Completed *Data Access Form (aggregated data)*

Potentially identifiable or identifiable data

Identifiable data include variables that can be used to identify an individual in the population, such as name and address. Potentially identifiable data do not include name and address but may contain other information that could be used to identify an individual. For example, data including a combination of sex, age, and residential area.

Potentially identifiable or identifiable data are protected by legislation and release is subject to approvals from an ethics committee, TCR Director and data custodian (i.e., the Tasmanian Director of Public Health or delegate).

To request identifiable or potentially identifiable data, follow these steps:

3. Contact the TCR to discuss your request

Please contact the TCR (03 6226 4275 or menzies.tcr@utas.edu.au) to discuss your research and data requirements, and to request the relevant form. The TCR will advise you on the feasibility of your request, ethics application and whether other institutions or organisations must be contacted (e.g., the Tasmanian Data Linkage Unit).

4. Submit a data request to the TCR

Send an email to menzies.tcr@utas.edu.au outlining your request, and include the following:

- Completed *Data Access Form (identifiable data)*
- Approved Ethics application*
- Research protocol†

* The TCR accepts approval from a National Mutual Acceptance (NMA) ethics committee; however, if the project is affiliated with the University of Tasmania you *must* obtain approval from the [Tasmanian Human Research Ethics Committee \(HREC\)](#) using the [Ethics Review Manager](#).

† The protocol must include the project title, background, research questions, methodology, statistical analysis plan, and a data management plan. Please ensure you provide specific details and justification for all the variables you are requesting.

5. Obtain approval from TCR Director and Director of Public Health (or delegate)

The TCR will seek approval from the TCR Director and the Director of Public Health or delegate on your behalf.

6. Release of data

The TCR will inform you of the outcome of your application via email. If successful, you will be asked to sign a *Data Release Agreement* and encrypted data will be released via secure message.

Request for personal information (self)

To request access to personal cancer information about yourself, follow these steps:

1. Contact the TCR

Please contact the TCR (03 6226 4275 or menzies.tcr@utas.edu.au) to request relevant form and provide your email or postal address.

2. Submit a request to the TCR

The TCR will send you an email via a file sharing platform with a link for you to securely upload the following documents:

- Completed *Access to Personal Information Form*
- Satisfactory proof of identity, preferably with a photograph (e.g., driver's licence, passport, etc.)

3. Release of data

A search will be made to locate any personal information held about you in the TCR. If information is located, relevant records will be released via secure email and encrypted files, or by arrangement. You will be notified if no information is held in the TCR.

Request personal information (others)

To request personal information about someone other than yourself, consent must be sought from person (if alive) or next of kin (if deceased). Please contact the TCR (03 6226 4275 or menzies.tcr@utas.edu.au) to discuss your request.

TCR acknowledgement

Please acknowledge access to TCR data in all publications and presentations. Suggested wording for print publications:

The authors would like to thank the Tasmanian Cancer Registry for the supply of Tasmanian cancer data.

The TCR kindly asks that any manuscripts published using TCR data be forwarded to menzies.tcr@utas.edu.au.

Contact the TCR

For further information, contact:

Tasmanian Cancer Registry

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