

DATA RELEASE GUIDELINES

Hospitals and laboratories in Tasmania are required by law to report any incidence of cancer to the Tasmanian Cancer Registry (the Registry). The Registry is responsible for collecting, collating and reporting on the incidence of cancer. Cancer registration is required in all Australian states and territories to assist efforts to understand the causes of cancer, to plan health services and assist prevention efforts and treatment decisions.

The Registry does not provide cancer support services or medical advice. These enquires are directed to medical practitioners or other agencies such as The Cancer Council Tasmania.

Confidentiality of information

Information held by the Registry is confidential and cannot be released unless authorised by the Director of Public Health. The procedures for making a request for information, which may be identifying data (personal information) or non-identifying data, are explained below.

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

Requests for identifying data

- Identifying data are data items that either singularly or collectively allow people to be identified.
- Written applications for identifying data require the approval of the Director of the Registry and the approval of the Director of Public Health.
- Requests for data to be used for research purposes also require the approval of the proposal by the researchers' own institutional ethics committee and the Human Research Ethics Committee (Tasmanian) Network
- Requests for access to Registry data held by the National Cancer Statistics Clearing House at the Australian Institute of Health and Welfare (AIHW) also require approval of the AIHW Ethics Committee. For such requests the Chair of the Human Research Ethics Committee (Tasmania) Network can approve the study based on a letter providing an overview of the study, along with a copy of the researcher's institutional ethics application and letter of approval. Prior to its release, the Registry will quality test the data matching done by the NCSCCH.
- Prior to contacting people named in the Registry, researchers must notify the person's medical practitioner and provide a form to be returned if the medical practitioner does not want the person to be approached. The Registry can provide researchers with templates and further information about this requirement.
- Researchers seeking access to identified data should apply to the Registry with the following documents:
 - a covering letter (detailing the purposes of the study and who is funding the study);

- two copies of the study protocol (including the approach letter to participants); and
- two copies of the relevant ethics committee approvals.

Requests for non-identifying data

- Non-identifying data are data that either singularly or collectively do not allow data subjects to be identified.
- Non-identifying cancer data are available upon request (preferably in writing).
- Data are usually released as incidence or mortality rates or number of cases or deaths for specific cancers, cancer morphologies, time periods or age groups.
- Requests that can be compiled using existing reporting systems have a turnaround of approximately 48 hours. If the information has not previously been released, authorisation from the Director of Public Health will be required.
- Requests requiring significant registry resources or input from a biostatistician may take longer to process and may incur a charge.
- Requests for de-identified unit record data (un-named information about an individual) must have the approval of the Director of Public Health. Prior to release of the data, the user is required to sign a confidentiality agreement.

Access to data about yourself

- A person may access personal data about themselves held by the Registry. Such access will be subject to:
 - Completion of an 'Access to Information' request form; and
 - Satisfactory proof of identity, such as driver's licence, health benefits card etc, preferably with a photograph.

If approval is given:

- A search will then be made to locate any personal information held about the applicant on the Registry. If information is located, the applicant will be provided with the relevant records. If no information is held on the Registry, the applicant will be advised in writing.

Access to personal data about someone other than yourself

- When an applicant wishes to access information from the Registry about someone, other than him/herself, the following procedure applies:
 - An 'Access to Information' request form must be submitted;
 - Satisfactory proof of identity, such as driver's licence, health benefits card etc (preferably with a photograph) must be provided. If the applicant is requesting the information by mail, two forms of identification witnessed by a Justice of the Peace must be provided with the application, and the documents forwarded by registered mail.

- If the applicant is requesting information about a person who is alive, the applicant must provide a letter of authority from the person stating they agree that information held about them by the Registry can be released to applicant.
- If the applicant is requesting information about a deceased person, the applicant must write to the Registry stating what information they wish to access and why they wish to access the information. The letter should also include the details required by the 'Access to Information' request form. Approval of the Director of Public Health is required.

If approval is given:

- A search will then be made to see if any information is held about the person concerned on the Registry database. If information is located, the applicant will be provided with the relevant records. If no information is held on the Registry, the applicant will be advised in writing.

Release of Published data

- The Registry provides annual reports on the number of new cancers and incidence and mortality statistics. Additional information is provided on selected cancer sites. Due to data matching and validation requirements, there is a two year interval from year of diagnosis to date of publication of incidence.
- The Registry supplies data to the National Clearing House for Cancer Statistics and to the International Association of Cancer Registries.

Contacting the Registry:

Enquires and applications should be directed to:

Tasmanian Cancer Registry
Menzies Research Institute
Private Bag 23
HOBART TAS 7001
Telephone: (03) 6226 7757
Fax: (03) 6226 7755