TCR data release guidelines

Is the request for identifying (e.g. named) data?

Yes

Is the request for research?

Yes

Does the study involve other State cancer registries?

Approval of the researcher’s institutional ethics committee and the Human Research Ethics Committee (Tasmania) Network must be gained. Named data are only released after approval of a formal application to Director of TCR, & with subsequent approval from Director of Public Health. Researchers must send a covering letter (purpose of study & name of funding body), two copies of the study protocol (including approach letter to participants if applicable) & two copies of the Ethics Committees approvals to the TCR.

No

To get access to your files you must:
- Complete an Access to Information request form.
- Satisfy proof of identity.

Is the request for personal information about you?

Yes

To obtain information on someone other than yourself you must:
- Complete an Access to Information request form.
- Satisfy proof of identity.

No

What if the research requires contact with cancer patients?

Prior to contacting persons named, researchers must notify the patient’s medical practitioner of their intent to contact & provide a form to be returned if he/she does not want the patient to be approached.

Is the request for personal information about someone other than you, e.g. relative?

Yes

The TCR requires a letter of authority from the relative stating they agree that information held about them by the TCR can be released.

No

If the relative is alive

The TCR requires a letter stating what information is sought, the reason why the information is being sought, and your relationship to the person you are requesting information about.

If the relative is deceased

The TCR requires a letter stating what information is sought, the reason why the information is being sought, and your relationship to the person you are requesting information about.

What if I want de-identified unit record data?

Requests for de-identified unit record data must have the approval of the Director of Public Health & the user must sign an agreement undertaking to observe information privacy and confidentiality requirements. The approval of the Human Research Ethics Committee (Tasmania) network may also be required.

Data are usually released as incidence or mortality rates or numbers of cases or deaths for specific cancers, cancer morphologies, time periods or age groups. If the information has not previously been released, authorisation from the Director of Public Health will be required.

Non-identifying summary data are available upon request (preferably in writing)

Yes

National studies requesting access to the TCR via the National Cancer Statistics Clearing House (NCSCH) at the Australian Institute of Health and Welfare (AIHW) also require approval of the AIHW Ethics Committee. Matching done by the NCSCH must be reviewed by the TCR prior to release of data to researchers. Any contact with patients requires prior notification of their medical practitioner.

No

Is the request for research?

Non

Data are usually released as incidence or mortality rates or numbers of cases or deaths for specific cancers, cancer morphologies, time periods or age groups. If the information has not previously been released, authorisation from the Director of Public Health will be required.

What if I want de-identified unit record data?

Requests for de-identified unit record data must have the approval of the Director of Public Health & the user must sign an agreement undertaking to observe information privacy and confidentiality requirements. The approval of the Human Research Ethics Committee (Tasmania) network may also be required.

Non-identifying summary data are available upon request (preferably in writing)

Yes

National studies requesting access to the TCR via the National Cancer Statistics Clearing House (NCSCH) at the Australian Institute of Health and Welfare (AIHW) also require approval of the AIHW Ethics Committee. Matching done by the NCSCH must be reviewed by the TCR prior to release of data to researchers. Any contact with patients requires prior notification of their medical practitioner.

No

Is the request for research?

Non

Data are usually released as incidence or mortality rates or numbers of cases or deaths for specific cancers, cancer morphologies, time periods or age groups. If the information has not previously been released, authorisation from the Director of Public Health will be required.

What if I want de-identified unit record data?

Requests for de-identified unit record data must have the approval of the Director of Public Health & the user must sign an agreement undertaking to observe information privacy and confidentiality requirements. The approval of the Human Research Ethics Committee (Tasmania) network may also be required.

Non-identifying summary data are available upon request (preferably in writing)