ACT Cancer Registry

ACT Government, Health Directorate

### Background

The ACT Cancer Registry (ACT CR) receives notifications of cancer in the ACT. It is managed by the ACT Government Health Directorate, and operates under the authority of the *Public Health Act 1997*. The Registry maintains a record of all cases of cancer diagnosed in ACT residents since 1994 except basal cell carcinomas and squamous cell carcinomas.

The ACT CR is a case-based registry in which all notifications relating to a particular case of cancer are linked to form a single record. A case of cancer is the occurrence of a malignant neoplasm in a particular person. Therefore a case of malignant melanoma in a particular person counts as one case. If the same person subsequently develops leukaemia, the leukaemia counts as a second case.

### Coverage

* The ACT CR maintains records of people with cancer in ACT and reports on the impact of cancer in the community
* Since 1994, all public and private pathology laboratories, hospitals, radiation oncology clinics and nursing homes in the ACT have been required by law to notify the ACT CR of cancer in people or human tissues
* Information collected about patients with cancer includes:
	+ Name, address, date of birth and sex
	+ Country of birth and aboriginal status
	+ Clinical details about the cancer
	+ Information about the notifying institution and doctor

### Tips for using ACT Cancer Registry data in linkage studies

* The CHeReL has incorporated ACT CR data from 1994 into the Master Linkage Key
* It is possible to obtain ACT CR data back to 1982, but the CHeReL and ACT CR data custodian recommend using data from 1994 for linkage studies. From 1982 to 1994 the quality of the linkage is likely to be compromised by missing or estimated dates of birth, and incomplete pathology reports. Researchers should therefore exercise caution if interpreting results including pre 1994 data
* Researchers wishing to access information on insitu breast and melanoma cancer should specifically state this in their application
* The ACT Cancer Registry (ACT CR) is a case- rather then person-based registry. If two cancers occur in a person, the ACT CR counts this as two cases
* The ACT Cancer Registry (ACT CR) records new cancer cases. Cancer recurrences are not captured as part of the ACT CR.
* When linking ACT CR to treatment data (e.g. hospitalisations) note that treatment may occur many years after the original diagnosis and may be associated with a cancer recurrence rather than the original notification.

### General Enquiries

Population Health Informatics

Epidemiology Section

Data Analytics Branch

ACT Health Directorate

Email: healthinfo@act.gov.au

Please submit Data Linkage Request via:

[Data Analytics Branch - Jira Service Management (atlassian.net)](https://act-health.atlassian.net/servicedesk/customer/portal/20)

### Variable information

| Variable | Description/Notes | Codes |
| --- | --- | --- |
| Age at diagnosis (years) |  |  |
| Sex |  | 1 – Male2 – Female |
| Country of Birth |  | Codes are according to the Standard Australian Classification of Countries (SACC) issued by the Australian Bureau of Statistics – see link below |
| AHS of residence at diagnosis | Area Health Service of residence at diagnosis | All records are Australian Capital Territory |
| Postcode of residence at diagnosis |  | 4 digit Australia Post code with preceding zeros. |
| SSLA of residence at diagnosis | State and Statistical Local Area of residence at diagnosis | Codes are according to the Australian Standard Geographical Classification (ASGC) issued by the Australian Bureau of Statistics – see link below |
| Date of diagnosis | The month and year in which the diagnosis was made | MMYYYY |
| Cancer type | The type of cancer according to the reporting categories for cancer | See Attachment 1 – Reporting Categories for Cancers |
| ICD-0-3 Topography Code | The site of the cancer | Coded according to the WHO International Classification of Diseases for Oncology (third edition) – see link below |
| ICD-0-3 Morphology Code | Morphology codes are only recorded for malignant neoplasms and insitu breast and melanoma cases | Coded according to the WHO International Classification of Diseases for Oncology (third edition) – see link below |
| Best Basis of Diagnosis |  | 0 - Cytology (including FNA, smears, washing, sputum) 1 - Clinical/imaging/biochemical2 - Histopathology performed3 - Confirmed by post-mortem (obsolete code)4 - Found at post-mortem5 - Death certificate only6 - Histopathology sighted at CCR |
| Degree of spread |  | A - In-situB - Localised to tissue of originC - Invasion of adjacent tissuesD - Regional lymph nodes involvedE - Distant metastasisJ - Invasion of adjacent organs and regional lymph nodes |
| Thickness of melanomas | Thickness of skin melanomas in mm |  |
| Size of breast cancer | Size in mm |  |
| Date of death | The month and year of death for persons diagnosed with cancer who have since died | MMYYYY |
| ICD-0-3 Cause of death | The cause of death according to the reporting categories for causes of death (cancer cases) | Coded according to the WHO International Classification of Diseases for Oncology (third edition) – see link below |

### Useful Links

Country of birth: [http://www.abs.gov.au/ausstats/abs@.nsf/mf/1269.0](http://www.abs.gov.au/ausstats/abs%40.nsf/mf/1269.0)

State and Statistical Local Area: [http://www.abs.gov.au/ausstats/abs@.nsf/mf/1216.0](http://www.abs.gov.au/ausstats/abs%40.nsf/mf/1216.0)

WHO International Classification of Diseases for Oncology: <http://www.who.int/classifications/icd/adaptations/oncology/en/>

## Attachment 1 – Reporting Categories for Cancer

Code Description

 C00 Lip

 C012 Tongue

 C036 Mouth

 C078 Salivary glands

 C0910 Oropharynx

 C11 Nasopharynx

 C123 Hypopharynx

 C14 Other oral cavity & pharynx

 C15 Oesophagus

 C16 Stomach

 C17 Small intestine

 C18 Colon

 C1921 Rectum, rectosigmoid, anus

 C22 Liver

 C234 Gallbladder

 C25 Pancreas

 C301 Nose, sinuses, etc

 C32 Larynx

 C334 Lung, bronchus

 C378 Other thoracic organs

 C401 Bone

 C43 Melanoma of skin

 C44 Skin cancer (non-melanocytic)

 C45 Mesothelioma

 C46 Kaposi's sarcoma

 C479 Connective tissue, peripheral nerves

 C50 Breast

 C53 Cervix

 C545 Uterus, Body & NOS

 C567 Ovary

 C58 Placenta

 C59 Other female genital organs

 C61 Prostate

 C62 Testis

 C6360 Other male genital organs

 C648 Kidney, etc

 C67 Bladder

 C69 Eye

 C71 Brain

 C72 Central nervous system

 C73 Thyroid

 C745 Other endocrine glands

 C81 Hodgkin's disease

 C82 Non-Hodgkin's lymphoma

 C8890 Multiple myeloma

 C910 Acute lymphoblastic leukaemia

 C919 Other lymphoid leukaemias

 C920 Acute myeloid leukaemia

 C929 Other myeloid leukaemia

 C94 Other specified leukaemias

 C95 Unspecified leukaemias

 C98 Il-defined & unspecified site

 M95 Other lymphatic haematopoietic

0005 Death from cancer not diagnosed in ACT

 0006 Non Cancer Death

 0007 Unknown cause of death