ACT Cancer Registry (CR)

# Dataset Information

| **Aspect** |  | **Comment** |
| --- | --- | --- |
| Dataset Description |  | 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.    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. |
| Data Quality Statement | Duration of dataset | 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. |
| Breast & melanoma cancer | Researchers wishing to access information on in-situ breast and melanoma cancer should specifically state this in their application. |
| Record structure | The ACT Cancer Registry (ACT CR) is a case, rather than person-based registry. If two cancers occur in a person, the ACT CR counts this as two cases. The Registry 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. |
| Links & Resources |  | None provided. |

# Variable Information

## Category: Demography

|  | **Column** | **Column Description** | **Datatype** | **Code** | **Code Description** |
| --- | --- | --- | --- | --- | --- |
|  | CountryBirthCode | Country of birth (SACC) | VARCHAR |  |  |
|  | DeathAge | Death Age (dthage) | INT |  |  |
|  | DiagnosisAge | Diagnosis Age (diagage) | INT |  |  |
|  | SexCode | Sex | INT | 1 | Male |
| 2 | Female |
| 8 | Person |

## Category: Dates & times (events)

|  | **Column** | **Column Description** | **Datatype** | **Code** | **Code Description** |
| --- | --- | --- | --- | --- | --- |
| ▲ | DeathDate | Date of Death (dthdte) | DATE |  |  |
| ▲ | DiagnosisDate | Date of Diagnosis (diagdte) | DATE |  |  |
| ▲ | Degree of granularity subject to disclosure risk assessment | | | | |

## Category: Presentation details

|  | **Column** | **Column Description** | **Datatype** | **Code** | **Code Description** |
| --- | --- | --- | --- | --- | --- |
|  | DeathICDO3TopoCode4 | ICD-O-3 topographical code (4 characters) of cancer which caused death (cod) | VARCHAR | 0006 | Non-cancer death |
| 0007 | Unknown |
|  | DiagnosisBasisCode | Method of diagnosis (basis) | INT | 0 | Death certificate only |
| 2 | Clinical |
| 5 | Cytology |
| 7 | Histology performed |
| 9 | Unknown |
| 66 | Histopathology sighted at NSWCR |
|  | DiagnosisICDO3MorphCode5 | ICD-O-3 morphological code (5 characters) of diagnosed cancer (morph) | VARCHAR |  |  |
|  | DiagnosisICDO3TopoCode4 | ICD-O-3 topographical code (4 characters) of diagnosed cancer (topo) | VARCHAR |  |  |
|  | PrimarySiteCount | Number of primary sites (primsite) | INT |  |  |
|  | ThicknessSize | Breslow thickness of melanoma / Size of breast cancer (thick) | FLOAT | 888 | Size not recorded due to neoadjuvant therapy (breast cancer only) |
| 995 | Micro-invasion |
| 996 | Size < 0.1 mm |
| 997 | Size described as small |
| 998 | Size described as big |
| 999 | Unknown |

## Category: Geography

|  | **Column** | **Column Description** | **Datatype** | **Code** | **Code Description** |
| --- | --- | --- | --- | --- | --- |
| ▲ | DiagnosisPostcode | Diagnosis Postcode (postcode) | VARCHAR |  |  |
| ▲ | GCDiagnosisSA2Code2011 | Residential Statistical Area Level 2 code at time of diagnosis (using ASGS 2011 standard). Sourced from geocoding (rolled up from mesh block) | VARCHAR |  |  |
| ▲ | GCDiagnosisSA2Code2016 | Residential statistical area level 2 code at time of diagnosis (using ASGS 2016 standard). Sourced from geocoding (rolled up from mesh block) | VARCHAR |  |  |
| ▲ | GCDiagnosisSLACode2006 | Diagnosis Statistical Local Area code 2006 (ssla) | VARCHAR |  |  |
|  | StateID | State of Residence | INT | 1 | New South Wales |
| 2 | Victoria |
| 3 | Queensland |
| 4 | South Australia |
| 5 | Western Australia |
| 6 | Tasmania |
| 7 | Northern Territory |
| 8 | Australian Capital Territory |
| 9 | Other Territories |
| ▲ | Degree of granularity subject to disclosure risk assessment | | | | |

# General Enquiries

**Population Health Informatics**

Epidemiology Section

Data Analytics Branch

ACT Health Directorate

|  |  |
| --- | --- |
| **Email:** | [healthinfo@act.gov.au](mailto:healthinfo@act.gov.au) |
| **Linkage request submission portal:** | <https://act-health.atlassian.net/servicedesk/customer/portal/20> |

# Acknowledgment of Country

We acknowledge the Ngunnawal people as traditional custodians of the ACT and recognise any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region.

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