

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 than 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.

Data custodian

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Variable information

Variable	Description/Notes	Codes
Age at diagnosis (years)		
Sex		1 – Male 2 – 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
ARIA	Accessibility/Remoteness Index of Australia. Can be calculated using postcode, SSLA or AHS	ASGC remoteness structure – see link below
SEIFA	Socio-Economic Indexes for Areas. Can be calculated using postcode, SSLA or AHS	Codes as per Australian Bureau of Statistics products – 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

Variable	Description/Notes	Codes
Best Basis of Diagnosis		0 – Cytology including FNA, smears, washing, sputum 1 – Clinical/imaging/biochemical 2 – Histopathology performed 3 – Confirmed by post mortem (obsolete code) 4 – Found at post mortem 5 – Death certificate only 6 – Histopathology sighted at CCR
Degree of spread		1 – Localised to tissue of origin 2 – Regional spread – adjacent organs and/or regional lymph nodes 3 – Distant metastases 9 – Unknown **OTHER** - Invalid data
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>

State and Statistical Local Area: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/1216.0>

ARIA: <http://www.abs.gov.au/websitedbs/D3310114.nsf/home/remoteness+structure>

SEIFA: http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Seifa_entry_page

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

Attachment 1 – Reporting Categories for Cancer

<i>Code</i>	<i>Description</i>		
C00	Lip	C8890	Multiple myeloma
C012	Tongue	C910	Acute lymphoblastic leukaemia
C036	Mouth	C919	Other lymphoid leukaemias
C078	Salivary glands	C920	Acute myeloid leukaemia
C0910	Oropharynx	C929	Other myeloid leukaemia
C11	Nasopharynx	C94	Other specified leukaemias
C123	Hypopharynx	C95	Unspecified leukaemias
C14	Other oral cavity & pharynx	C98	Il-defined & unspecified site
C15	Oesophagus	M95	Other lymphatic haematopoietic
C16	Stomach	0006	Non Cancer Death
C17	Small intestine	0007	Unknown cause of death
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		