

Australian Cancer Database, 2019; Quality Statement

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Identifying and definitional attributes

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Data quality

Data quality statement summary:

Description

The 2019 version of the Australian Cancer Database (ACD) contains data on all cases of cancer diagnosed in Australia in the period 1982 to 2019 excluding squamous and basal cell carcinomas of the skin. It also contains data on some other kinds of neoplasms, as follows:

- all cases of melanoma in situ diagnosed since 2004
- all cases of breast carcinoma in situ diagnosed since 2002
- all cases of cervical carcinoma in situ diagnosed since 2001 in Victoria and Queensland
- all cases of benign and uncertain-behaviour neoplasms of the central nervous system diagnosed since 2003 in Victoria, Queensland and Western Australia.

All states and territories have legislation that makes cancer and certain other neoplasms notifiable diseases. Various institutions, for example hospitals and pathology laboratories, must report all cases of these diseases to their jurisdictional cancer registry. Each registry supplies the main elements of these data annually to the Australian Institute of Health and Welfare (AIHW) under an agreement between the registries and the AIHW. The data are compiled into the ACD, which is the only repository of national cancer incidence data.

To avoid excessive repetition in this quality statement, the word cancer is used to mean cancer excluding squamous and basal cell carcinomas of the skin. In most states and territories these cancers are not notifiable diseases and are not collected by cancer registries. Consequently, they are not in the scope of the ACD.

Institutional environment:	<p>The Australian Institute of Health and Welfare (AIHW) is an independent corporate Commonwealth entity under the Australian Institute of Health and Welfare Act 1987 (AIHW Act), governed by a management Board and accountable to the Australian Parliament through the Health portfolio.</p>
	<p>The AIHW is a nationally recognised information management agency. Its purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians.</p>
	<p>Compliance with the confidentiality requirements in the AIHW Act, the Privacy Principles in the Privacy Act 1988 (Cth) and AIHW's data governance arrangements ensures that the AIHW is well positioned to release information for public benefit while protecting the identity of individuals and organisations.</p>
	<p>For further information see the AIHW website www.aihw.gov.au/about-us, which includes details about the AIHW's governance (www.aihw.gov.au/about-us/our-governance) and our role and strategic goals (www.aihw.gov.au/about-us/our-vision-and-strategic-goals).</p>
	<p>All states and territories have legislation that makes cancer and certain other neoplasms notifiable diseases. Various institutions, for example hospitals and pathology laboratories, must report all cases of these diseases to their jurisdictional cancer registry. Each registry supplies the main elements of these data annually to the AIHW under an agreement between the registries and the AIHW. The data are compiled into the ACD, which is the only repository of national cancer incidence data. The jurisdictions retain ownership of the data and must approve any jurisdiction-level output before it is released. Jurisdictional approval is also required for national-level output if it is sufficiently fine-grained.</p> <p>The AIHW has been maintaining the ACD since 1986.</p>
Timeliness:	<p>A new version of the ACD is produced each year. Each version is referred to by the most recent year for which all the state and territory cancer registries have provided data. The 2019 ACD contains data on all cases of cancer diagnosed in Australia in the period 1982 to 2019.</p> <p>Each state and territory cancer registry supplies data annually to the AIHW. Once all the data have been received it takes several months to de-duplicate the ACD, link it to the AIHW's National Death Index and apply consistency checks and data standardisation processes. After these tasks are complete the ACD becomes available for analysis and reporting purposes and customised data requests.</p>
Accessibility:	<p>The AIHW website provides extensive cancer incidence and mortality data that can be downloaded without charge. The main online data product is Cancer data in Australia, which is updated every year. The main published report is Cancer in Australia, which is produced in odd-numbered years. This and other reports can be downloaded from the AIHW website without charge.</p> <p>Data not available online or in reports can be requested by lodging a customised data request. Further enquiries can be made by contacting the AIHW Cancer Data and Monitoring Unit on (02) 6244 1000 or via email to cancer@aihw.gov.au. Data requests are charged for on a cost-recovery basis.</p> <p>The ACD is also available for data linkage projects. Such projects must be approved by the AIHW Ethics Committee as well as the data custodians of the state and territory cancer registries and jurisdictional ethics committees.</p>
Interpretability:	<p>Information on the scope and content of the ACD is available on the AIHW website.</p> <p>The Cancer data in Australia product contains extensive material to assist users with interpretation of the data, comprising cancer data commentaries, answers to frequently asked questions, and technical notes.</p>

Relevance:

The 2019 ACD contains data on all cases of cancer diagnosed in Australia in the period 1982 to 2019.

The cancers in the ACD are coded using the 2nd revision of the 3rd edition of the International Classification of Diseases for Oncology (ICD-O-3.2). The ICD-O-3.2 codes can be mapped to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10).

The ACD allows for cancer statistics to be stratified by many variables, for example sex, Indigenous status, country of birth, state/territory, age at diagnosis, and the histology code of the cancer. The geographic unit Statistical Area Level 2 (SA2) is available for all jurisdictions and the smaller Statistical Area Level 1 (SA1) is available for all except NT. This allows statistics to be compiled by geographic areas such as Remoteness Area and Socioeconomic Area. Requests for data at or below the state/territory level require the approvals of the data custodians of the state and territory cancer registries and potentially the jurisdictional ethics committees.

The ACD contains the name, sex and date of birth of each person diagnosed with cancer. This allows [data linkage](#) to be undertaken. For example, researchers who have enrolled people in a study can link their cohort to the ACD in order to determine which of their study subjects have been diagnosed with cancer, which type of cancer, and when. This kind of research gives insight into cancer risk factors. Data linkage might also be conducted when a researcher has been contracted to investigate a potential cancer cluster in a workplace or small area. Note that data linkage can only be undertaken after the researchers have received approvals from all relevant data custodians and ethics committees.

Accuracy:

The publication [Cancer incidence in five continents](#) is updated about every five years in a collaborative effort between the International Agency for Research on Cancer (IARC) and the worldwide network of cancer registries. All data sets are assessed for quality by the application of various tests (see publication for details). Each of Australia's cancer registries' data sets is assigned the highest quality grade in the scale.

During compilation the ACD undergoes a data linkage process called the national de-duplication. This process detects instances where the same person and cancer have been registered in two or more jurisdictions. This could happen, for example, when a person attends hospitals in different jurisdictions for the same cancer. Instances of cancer record duplication are provisionally resolved at the AIHW by removing all but one of the duplicate records. The relevant jurisdictions are notified of the duplication and they decide which one owns the case. This is determined by the person's place of usual residence at the time of their diagnosis. The resolution of duplicates flows through to the next ACD in the following year's data supply.

All state and territory cancer registries collect information on Indigenous status but the accuracy and completeness of Indigenous status is not considered of high enough quality for reporting for all jurisdictions or time periods. The data which are considered suitable for analysis are as follows: WA and NT for 1982 onwards, QLD for 1997 onwards, NSW for 1999 onwards and VIC for 2008 onwards.

Coherence:

The cancers in the ACD are coded using the 2nd revision of the 3rd edition of the International Classification of Diseases for Oncology (ICD-O-3.2).

Changes to the ICD-O code set can have an impact on trends in time series but usually only at quite a fine level of detail, involving one or a small cluster of histology codes. These issues are known to the cancer registries and AIHW and relevant advice is provided to any client who requests data at a fine-enough level of detail for this to be a potential issue. For impacts that occur at a larger scale, the cancer data commentaries (see the interpretability section) provide information on interpreting the time series.

Cancer registry databases change every day. The main type of change occurs when new records are added. However, existing records can change if:

- new information about the person or their cancer is provided to the registry
- errors are discovered by quality assurance processes
- the person is found not to be a resident of that state or territory (these records are deleted).

Because these factors can affect historical data, the cancer registries supply the AIHW each year with a completely new snapshot of their database going back to 1982. Therefore, for years prior to 2019 the number of cases reported by AIHW based on the 2019 ACD may differ from the number reported for the same year based on previous versions of the ACD.

The data supplied by each cancer registry to the AIHW come from a snapshot of its database taken at a specific point in time. Consequently, the number of cases reported by AIHW for a given jurisdiction may differ from the corresponding number published by that jurisdiction in its own reports if the numbers are derived from different snapshots of the jurisdictional database.

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Steward: [Australian Institute of Health and Welfare](#)