

Australian Cancer Database 2009 Data Quality Statement

Identifying and definitional attributes

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| METEOR identifier: | 500417 |
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Data quality

Quality statement summary:

Important note

To avoid excessive repetition in what follows, the word 'cancer' is used to mean 'cancer, excluding basal cell carcinomas of the skin and squamous cell carcinomas of the skin'. In most states and territories these two very common skin cancers are not notifiable diseases and as such are not in the scope of the Australian Cancer Database (ACD).

Summary of Key Issues

- All states and territories maintain a population-based cancer registry to which all cancer cases and deaths must be reported
- The AIHW compiles the ACD using information from state and territory registers
- Some duplication may occur where the same person and cancer have been registered in two or more jurisdictions. The AIHW provisionally resolves these instances and notifies the relevant states and territories of possible duplicates. Full resolution has usually occurred by the following year's version of the ACD.
- The level of duplication is small, about 0.17% of all records
- Cancer registry databases change every day, adding new records and improving the quality of existing records as new information becomes available. Information on ACD records may therefore change from year to year.

Description

All states and territories have legislation that makes cancer a notifiable disease. All hospitals, pathology laboratories, radiotherapy centres and registries of births, deaths and marriages must report cancer cases and deaths to the state or territory population-based cancer registry.

Each registry supplies incidence data annually to the AIHW under an agreement between the registries and the AIHW. These data are compiled into the ACD, the only repository of national cancer incidence data.

Institutional environment: The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act 1987 to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent statutory authority established in 1987, governed by a management board, and accountable to the Australian Parliament through the Health and Ageing portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The Institute also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The Institute works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national datasets based on data from each jurisdiction, to analyse these datasets and disseminate information and statistics.

The Australian Institute of Health and Welfare Act 1987, in conjunction with compliance to the Privacy Act 1988 (Commonwealth), ensures that the data collections managed by the AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.

For further information see the AIHW website www.aihw.gov.au.

The AIHW has been maintaining the ACD since 1986.

Timeliness: This data quality statement refers to the 2009 version of the ACD, which contains data on all cancer cases diagnosed between 1982 and 2009. However, the number of cases in 2009 for NSW and the ACT was estimated (see 'Accuracy' section below).

Each jurisdictional cancer registry supplies data annually to the AIHW. Because each jurisdiction operates on its own data compilation and reporting cycle, the ACD cannot be fully compiled until the final jurisdiction supplies its data.

It generally takes a year or more for the state and territory cancer registries to fully process and release their latest full-year of cancer data to the AIHW. Once the AIHW receives all the data sets from cancer registries, time is needed to check for data consistency and to deduplicate the data before the new version of the ACD is available for reporting purposes.

Accessibility: The AIHW website provides cancer incidence and mortality data that can be downloaded without of charge. Numerous reports, including the biennial Cancer in Australia, are published and are available on the AIHW website where they can also be downloaded without charge. Users can request data not available online or in reports via the Cancer and Screening Unit of the AIHW on (02) 6244 1000 or via email to cancer@aihw.gov.au. Requests that take longer than half an hour to compile are charged for on a cost-recovery basis. General enquiries about AIHW publications can be made to the Communications, Media and Marketing Unit on (02) 6244 1032 or via email to info@aihw.gov.au.

Researchers following a cohort of people enrolled in a longitudinal study of health outcomes can request the AIHW to undertake data linkage of their cohort to the ACD. Such requests must be approved by the AIHW Ethics Committee as well as the ethics committees governing access to the state and territory cancer registries.

Interpretability: Information on the ACD is available on the AIHW website.

While numbers of new cancers are easy to interpret, other statistical calculations (for example, calculations of age-standardised rates and confidence intervals) are more complex and their concepts may be confusing to some users. In most publications there is an appendix on statistical methods as well as technical notes.

Relevance:

The ACD is highly relevant for monitoring trends in cancer incidence. The data are used for many purposes, such as by policy makers to evaluate health intervention programs and as background data for health labour force planning and health expenditure; by pharmaceutical companies to assess the size of the market for new drugs; by researchers to explore the epidemiology of cancer; by insurance companies to evaluate the risk of people being diagnosed with cancer.

The ACD contains information on all reported cancer cases and deaths in Australia. Data can be provided at state and territory level and at Remoteness Area level.

The 3rd edition of the International Classification of Diseases for Oncology (ICD-O-3) is used to classify cancer cases. Data can also be classified according to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10).

The ACD also contains the name and date of birth of each person diagnosed with cancer. This allows researchers who have enrolled people in a study to link their database to the ACD to find out which of their study subjects have been diagnosed with cancer, what kind of cancer, and when. (Such data linkage can only be undertaken after receiving approvals from various ethics committees.) This kind of research gives insight into cancer risk factors. Data linkage is also undertaken when a researcher has been contracted to investigate a potential cancer cluster in a workplace or small area.

Accuracy:

The 1982–2009 data files for NSW and the ACT were not available for inclusion in the 2009 version of the ACD. An extended delay of the receipt of mortality data has meant that NSW and the ACT have not been able to close off their 2009 data sets. As a consequence, 2009 cancer data for these jurisdictions are not available for reporting purposes. The 2009 incidence data for NSW and the ACT were estimated by the AIHW in consultation with the NSW and ACT cancer registries. The estimates were combined with the actual data supplied by these two jurisdictions for the 2008 ACD to form their 1982–2009 data sets for inclusion in the 2009 ACD. Although the estimation procedure has been shown to be reasonably accurate for estimating overall cancer incidence, its accuracy with respect to individual cancers will vary. As NSW and ACT make up about a third of Australia's population, the national incidence data for 2009 is likely to be somewhat inaccurate for some individual cancers—which cancers these are is not predictable.

It is anticipated that future versions of the ACD will include 2009 actual data for NSW and ACT and the data will then be made available in subsequent cancer publications.

The publication *Cancer incidence in five continents* is issued about every 5 years as a collaborative effort by the International Agency for Research on Cancer (IARC) and the worldwide network of cancer registries. Australia's cancer registries continue to pass IARC's numerous tests for data quality. Details of the tests and Australia's cancer registries' results in them can be found in the above-mentioned book and the registries' annual incidence reports.

Each year, when all the registries' new data have been compiled into the new ACD, a data linkage process called the national deduplication is undertaken. 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. All such instances that are found are provisionally resolved at the AIHW by removing one record while the relevant jurisdictions are notified of the situation so that they can determine in which jurisdiction the person was a usual resident at the time of diagnosis. Their resolution will flow through to the ACD in the next year's data supply. In recent years the national deduplication has resulted in the removal of about 3,500 records from the ACD, which is about 0.17% of all records supplied by the jurisdictions.

While all state and territory cancer registries collect information on Indigenous status, in some jurisdictions the level of identification of Indigenous Australians is considered to be insufficient to enable analysis. Data for four states and territories—New South Wales, Queensland, Western Australia and the Northern Territory—are considered suitable for analysis.

Cancer registry databases change every day, and not just because new records are added. Existing records are changed if new, more precise, information about the diagnosis becomes available. Also, any typographical errors that are discovered by routine data checking procedures are corrected by referring to the source documentation. Finally, existing records can be deleted if it is discovered that the initial diagnosis of cancer was incorrect (for example, the tumour was in fact benign) or the person is found to be not a resident of that state or territory. As a result of all these issues, the number of cancer cases reported by AIHW for any particular year may change slightly over time, and data published by a cancer registry at a certain point in time may differ slightly from what is published by the AIHW at a different time.

Coherence:

Cancer data are reported and published annually by the AIHW. While there are sometimes changes to coding for particular cancers, it is possible to map coding changes to make meaningful comparisons over time.

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

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

Relational attributes

Related metadata references:

See also [Australian Cancer Database 2008 Data Quality Statement](#)

- [AIHW Data Quality Statements](#), Standard 20/07/2012

See also [Australian Cancer Database 2010 Data Quality Statement](#)

- [AIHW Data Quality Statements](#), Standard 14/05/2014