

Australian Cancer Database 2011 Data Quality Statement

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Identifying and definitional attributes

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Data quality

Data quality statement summary:

Important note

To avoid excessive repetition in this data quality statement, 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 skin cancers are not notifiable diseases, and in any case are not collected, and as such are not in the scope of the Australian Cancer Database (ACD).

Summary of Key Points

All states and territories have legislation that makes cancer a notifiable disease. Various institutions such as hospitals, pathology laboratories and registries of births, deaths and marriages must report cancer cases and deaths to their jurisdictional 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.

2010 and 2011 incidence data for NSW and ACT were not available for inclusion in the 2011 version of the ACD. These data have been estimated by the AIHW. 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 2010 and 2011 are likely to be somewhat inaccurate for some individual cancers; which cancers these are is not predictable. Until the actual data are available from these jurisdictions caution should be exercised when comparing the 2010 and 2011 NSW, ACT and Australian data with data from previous years.

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 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 data sets based on data from each jurisdiction, to analyse these data sets 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 <http://www.aihw.gov.au/home/>.

All states and territories have legislation that makes cancer a notifiable disease. Various institutions such as hospitals, pathology laboratories and registries of births, deaths and marriages must report cancer cases and deaths to their jurisdictional cancer registry. Each registry supplies incidence data annually to the AIHW under an agreement between the registries and the AIHW. These data are checked, standardised and compiled into the ACD, 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. The agreement and processes for operating the ACD are detailed in the National Cancer Statistics Clearing House Protocol which can be accessed from <http://www.aihw.gov.au/national-cancer-statistics-clearing-house/>.

The AIHW has been maintaining the ACD since 1986.

Timeliness:

This data quality statement refers to the 2011 version of the ACD, which contains data on all cancer cases diagnosed between 1982 and 2011. However, the number of cases in 2010 and 2011 for NSW and ACT has been estimated by the AIHW because the actual data were not available in time for inclusion (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 charge. The main online product is the set of Australian Cancer Incidence and Mortality (ACIM) books, available at <http://www.aihw.gov.au/acim-books/>. Numerous published reports, including the biennial *Cancer in Australia*, are available on the AIHW website where they can also be downloaded without charge. Users can request data not available online or in reports by lodging a customised data request at https://datarequest.aihw.gov.au/_layouts/AdHocDataRequest/LodgeRequest.aspx/ and can ask questions via the Cancer and Screening Unit of the AIHW on (02) 6244 1000 or via email to cancer@aihw.gov.au. Data requests 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.

Interpretability:

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.

Information on the content and scope of the ACD is available on the AIHW website at <http://www.aihw.gov.au/australian-cancer-database/>.

While numbers of new cancers are easy to interpret, other statistics, e.g. age-standardised rates, are more complex and their concepts may be confusing to some users. In most cancer 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 for the period 1982–2011 except for 2010 and 2011 for NSW and ACT (see 'Accuracy' section below). Data can be provided at state and territory level though this requires approval from the state and territory cancer registries.

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 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 cohort to the ACD to determine 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 book *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. The data from each of Australia's cancer registries are classified by IARC as 'A', which is the highest data quality grade in their scale. Details of IARC's 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 following 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, the level of identification of Indigenous Australians is not considered adequate 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.

2010 and 2011 incidence data for NSW and ACT were not available for inclusion in the 2011 version of the ACD. The development of the new NSW Cancer Registries system has resulted in a delay in processing incidence data for 2010 onwards and therefore the most recent NSW data available for inclusion in the ACD are for 2009. Full details about this situation are given on the web page <http://www.cancerinstitute.org.au/data-and-statistics/accessing-our-data/availability-of-nsw-central-cancer-registry-data>. As the coding of ACT cancer notifications is contracted to the NSW Cancer Registry, the most recent data available for the ACT are also for 2009. The 2010 and 2011 incidence data for NSW and ACT were estimated by the AIHW. Although the estimation procedure has been shown to be reasonably accurate for estimating overall cancer incidence, it is likely to be somewhat inaccurate for some cancer types; which cancers these are is not predictable. The estimates were combined with the actual data supplied by the other six state and territory cancer registries to form the 2011 ACD.

As NSW and ACT make up about a third of Australia's population, the national incidence data for 2010 and 2011 are likely to be somewhat inaccurate for some individual cancers; which cancers these are is not predictable. Until the actual data are available from these jurisdictions caution should be exercised when comparing the 2010 and 2011 NSW, ACT and Australian data with data from previous years.

The 2009 incidence data for NSW and ACT provided to the AIHW excluded the provisional death-certificate-only (DCO) cases. The reason these cases were not available is explained on the web page <http://www.cancerinstitute.org.au/data-and-statistics/accessing-our-data/availability-of-nsw-central-cancer-registry-data>. The AIHW has estimated the number of provisional DCO cases in 2009 for each cancer, sex and age group based on the numbers observed for 2004–2008. Overall, about 1.7% of NSW cases and 1.9% of ACT cases in 2009 are estimated provisional DCO cases.

Coherence: The ACD contains information on all reported cancer cases and deaths in Australia for the period 1982–2011 except for 2010 and 2011 for NSW and ACT (see 'Accuracy' section above).

Cancer diagnosis data are classified according to the International Classification of Diseases for Oncology (ICD-O). Sometimes updated codes are issued to align with new understandings of cancer types, and about every ten years an entirely new edition of ICD-O is issued. Updates and new editions can cause trend breaks in time series for particular cancers, but only at quite a fine level of detail. These trend-break issues are known to the 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.

The data supplied annually by each cancer registry to the AIHW come from a snapshot of their database at a specific point in time. 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 or person becomes available. Also, any typographical errors that are discovered by routine data checking procedures are corrected. 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 factors, for years prior to 2011 the number of cancer cases reported by AIHW based on the 2011 ACD may differ from the corresponding number reported based on previous versions of the ACD. Similarly, the number of cases in a given jurisdiction when based on the 2011 ACD 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

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