

Data Quality Statement

Summary

Name	NSW Cancer Registry (NSWCR) - NSW Cancer Incidence and Mortality Data
Description	The NSWCR Incidence and Mortality dataset contains incidence and mortality data of people diagnosed with primary invasive cancer in NSW.
Date last updated	15 May 2025
Organisation	Cancer Institute NSW (Institute)
Sponsor	NSW Chief Cancer Officer and Chief Executive Officer, Cancer Institute NSW
Steward	<ul style="list-style-type: none"> • Manager, Data and Reporting, Cancer Institute NSW • Manager Registries and Data Collection, Cancer Institute NSW • Data Quality Officer, Cancer Institute NSW
Custodian	Lisa McCallum, Manager, Data Governance, Cancer Institute NSW
Legislation and authority	<ul style="list-style-type: none"> • Cancer Institute (NSW) Act 2003 • Public Health Act 2010 • Privacy and Personal Information Protection Act 1998 • Health Records Information Privacy Act 2002
Data reference period	<ul style="list-style-type: none"> • 1972-2022 (invasive primary cancer cases incidence and mortality) • 2002-2022 (in-situ cancer cases for breast and melanoma incidence and mortality) • 2013 (clinical episodes of care)
Scheduled data release	Annually
Data update frequency	Annually
Data type	<ul style="list-style-type: none"> • Unit record data • Aggregated data
Privacy and confidentiality	Data will be used and disclosed in accordance with the Privacy and Personal Information Protection Act (PPIPA), Health Records and Information Privacy Act (HRIPA) and Ministry of Health Policies.

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Data asset version number	Version 1.1
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Identifiers for linkage	<ul style="list-style-type: none">• Record ID• Hospital code (first admission to public or private hospital only)• Medical record number• Surname• Alias surname• Given names• Alias given names• Sex• Date of birth• Age at diagnosis• Address of residence at diagnosis• Locality of residence at diagnosis• Postcode of residence at diagnosis• Date of death• Diagnosis date• Patient ID

Abstract

The NSW Cancer Registry (NSWCR) is a population-based registry that maintains records of people with cancer in NSW. The data captured within the NSWCR provides useful insights into the impact of cancers, and how this has changed over time. Notification of new cancer cases and cancer deaths is required under the *Public Health Act 2010*.

The NSWCR contains demographic, incidence and death details for people diagnosed with cancer in NSW since 1972. It also includes these details for residents of NSW diagnosed with cancer in other Australian states and territories.

All primary malignant neoplasms (from 1972), and in-situ melanoma and breast cancer (from 2002-present) are included.

The NSWCR contains clinical data relating to episodes of care for NSW residents diagnosed with primary invasive cancer. Clinical data are currently available for 2013, with additional data to be added as they become available. The NSWCR does not currently have population coverage of clinical data.

Data are received from pathology laboratories, hospitals, radiotherapy and medical oncology departments, aged care facilities (until 2019) and the Registry of Births, Deaths and Marriages.

Key Metrics

This section covers the key areas of relevance, accuracy, and coherence.

Relevance

Scope and coverage

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Data collection purpose	The purpose of this data asset is to report incidence and mortality of people with cancer in NSW in order to improve outcomes for people diagnosed with cancer. The data provides useful insights into the impact of cancers and how this has changed over time.
Target population	The target population is residents diagnosed with cancer in NSW since 1972. Records are included for residents of NSW diagnosed with cancer in other Australian states and territories.
Data collection period	<ul style="list-style-type: none"> 1972-2022 (invasive primary cancer cases incidence and mortality) 2002-2022 (in-situ cancer cases for breast and melanoma incidence and mortality) 2013 (clinical episodes of care for primary invasive cancers)
Exceptions to data collection period	Data is currently available for episodes of care that occurred in 2013 only.
Geographic Detail	
Level of geographical data	Geographic data is available at multiple levels. Please see the NSWCR Incidence and Mortality Data Dictionary.
Geographical coverage	Data are provided for residents of NSW at the time of cancer diagnosis.
Standards used	<ul style="list-style-type: none"> International Classification of Diseases for Oncology (ICD-O-3) International Association of Cancer Registries' conventions International Classification of Diseases (ICD-9) International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) Australasian Association of Cancer Registries (AACR)
Aboriginality	<p>Permission is required from the Aboriginal Health and Medical Research Council when publishing reports utilising this data element.</p> <p>Aboriginality is incomplete on the NSW Cancer Registry (NSWCR). From 1999 to 2022, approximately 9% of all NSW invasive cancer cases recorded on the NSWCR, did not have Aboriginality recorded (unknown or not available).</p> <p>Aboriginality in the NSWCR is based on notifications received and uses in-built business rules for indigenous hierarchy status, so that the most descriptive value will overwrite a less descriptive value. (see data dictionary for the rules). Aboriginality is available from 1999 for incidence and since 1994 for mortality.</p>

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Typical Use and Analyses	<p>The NSWCR incidence and mortality data have been, and continue to be used, for reporting on manifold aspects of cancer including diagnosis, treatment, survival, patient outcomes, and other measures. The data is a rich store and is the best source for data relating to cancer in NSW.</p>
Other Cautions	<p>In-situ cases for breast cancer and melanoma are collected by the NSWCR but are not included in any statistical reporting and are not validated.</p> <p>The data asset has the following caveats:</p> <ul style="list-style-type: none"> • Preliminary Incidence Data <ul style="list-style-type: none"> ◦ Preliminary cancer incidence for a given year may be made available periodically. Preliminary cancer incidence data is incomplete due to missing “Death Certificate Only” cancer cases. • Place of Death <ul style="list-style-type: none"> ◦ Place of death is only available for persons that had a cancer case diagnosed in NSW and/or died of cancer and/or died in NSW. Place of death will be missing if they died of causes other than cancer or if they died outside NSW. ◦ https://www.cancer.nsw.gov.au/getmedia/619912c4-0168-4991-8143-a19a451018b2/Place-of-death-caveat-may-2015.pdf • Degree of Spread <ul style="list-style-type: none"> ◦ by the NSW Cancer Registry (NSWCR). We advise that any analysis done using degree of spread data or any derived variables (stage at diagnosis or stage at first presentation consider the caveat for the period 1993-1998. ◦ https://www.cancer.nsw.gov.au/getmedia/1d6bf5fd-eea3-48a4-b800-f794a1e8495e/Degree-of-spread-caveat-may-2015.pdf • Day of Diagnosis <ul style="list-style-type: none"> ◦ Day of diagnosis was coded from 1972–2011 to the 15th day of the month. In 2013 a review of this practice resulted in a change to actual date of diagnosis and historical data was reviewed ◦ A new date of diagnosis validity code was created, to identify which dates of diagnosis contain actual dates, estimated days and/or months, and which dates were unknown. ◦ We advise that analysis using date of diagnosis before 2011 consider the caveat for the period 1972-2011 ◦ https://www.cancer.nsw.gov.au/getmedia/d502fff3-4ecd-4b90-a16e-dae7f766d2eb/Day-of-diagnosis-caveat-NSWCR-Mar2016.pdf <p>For more information on current caveats relating to this data asset see https://www.cancer.nsw.gov.au/research-and-</p>

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[data/cancer-data-and-statistics/data-available-on-request/request-unit-record-data-for-research#Accordion](https://data.cancer-data-and-statistics/data-available-on-request/request-unit-record-data-for-research#Accordion)

Accuracy

Data Collection Methods	Data are received from pathology laboratories, hospitals, radiotherapy and medical oncology departments, aged care facilities (until 2019) and the Registry of Births, Deaths and Marriages and Cause of Death Unit Record File. The majority of data is provided electronically with a small volume of paper notifications.
Coverage	<p>The NSWCR has population coverage of cancer cases with exceptions of episodes of care.</p> <p>1-2% of cases are death certificate only cancer cases, where notification of a case only occurs after the individual's death.</p>
Error Types	Country of birth is incomplete on the NSWCR. Country of birth is updated from hospital inpatient records if it is available. Particular cancer sites like melanoma, where a person does not always have a hospital visit and the pathology report is the main source of notification, will have a larger proportion of unknown country of birth. For the most recent 5-year period of data available (2018-2022), approximately 13% of diagnoses had unknown country of birth.
Steps to minimise processing errors	<p>Data in the NSWCR undergoes stringent quality assurance processes to ensure highest accuracy of all data elements available except for the Episodes of Care (EOC) variables. EOC data may be incomplete and contain duplicates.</p> <p>We advise using the NSW All Radiotherapies Data where radiotherapy is of importance.</p>

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Data revision or correction	<p>Routine data quality control measures include:</p> <ul style="list-style-type: none"> • Use of the International Association of Cancer Registries' conventions • Data checks from the International Agency for Research on Cancer program • Monitoring of notifications • Validation of data entry • Periodic audits of coding accuracy • Reconciliation of information from multiple sources • Examination of multiple registrations • Validation using the NSW Electoral Roll data • Collaboration with medical experts and other cancer registries. • Review and analysis of cancer incidence and mortality trends <p>Existing records are updated if new, more precise information about the treatment procedure is obtained and any typographical errors that are discovered by routine data checking procedures are corrected.</p> <p>Data are provided to AIHW for national incidence and mortality reporting. As part of this process AIHW deduplicates the data as cancer diagnoses can be duplicated between state registries. Data is validated at the time it is uploaded to AIHW servers and any additional data issues are identified and rectified by state registries.</p>
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Coherence / Change Notes

Changes to Data Items / Data Collection	<p>The NSWCR data have been collected since 1972. This data quality statement covers data released until 2022. Significant changes by year are available on request.</p> <ul style="list-style-type: none"> • 2022 <ul style="list-style-type: none"> ◦ https://admin.cancer.nsw.gov.au/getmedia/81cd21bc-36f2-49c8-9bab-271b21ec57fd/Changes-relating-to-the-2022-NSW-cancer-incidence-and-mortality-dataset.pdf
Comparison across data items	<p>See the section "Other Cautions" for additional information.</p>
Comparison with other products available	<p>See the section "Other Cautions" for additional information.</p>

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User Notes

This section covers the key areas of interpretability and accessibility.

Interpretability

Data Sources	NSWCR Incidence and Mortality data are part of the NSW Cancer Registry. Data are received from pathology laboratories, hospitals, radiotherapy and medical oncology departments, aged care facilities (until 2019) and the Registry of Births, Deaths and Marriages.
Elements	Refer to the NSWCR Incidence and Mortality data dictionary for the complete list of data elements.
Elements with interpretation issues	None.
Completeness	In general, the completeness of information for cancer incidence and mortality is very high, apart from episode level data (EOC), Aboriginality and Country of Birth as noted in this document and Data Dictionary. Exact completeness will be released in the future.
Additional data context	None.
Data delays	None.

Accessibility

Relevant publications and reports	Reporting for Better Cancer Outcomes (RBCO) Reports – the statewide reports are available at the link below https://www.cancer.nsw.gov.au/what-we-do/supporting-cancer-care/reporting-for-better-cancer-outcomes-program/rbco-reports
Relevant and related data sets	Tabulated summary dashboard data is available on the Cancer Statistics NSW website at: https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-now/cancer-statistics-nsw/cancer-incidence-mortality-survival NSWCR data is included in the Enduring Cancer Data Linkage (CanDLe). Further information about access to CanDLe is available at: https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request/candle-program
How to access data	Unlinked data requests can be made at:

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	<ul style="list-style-type: none">• https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/data-available-on-request <p>Data for linkage to NSW Health datasets is available at:</p> <ul style="list-style-type: none">• https://www.cherel.org.au/datasets <p>General enquiries about NSWCR data can be made to CINSW-DARenquiries@health.nsw.gov.au</p>
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References

Australian Bureau of Statistics, ABS Data Quality Statement Checklist, Australian Bureau of Statistics, Canberra, accessed 11 May 2022, <https://www.abs.gov.au/websitedbs/D3310114.nsf/home/ABS+Data+Quality+Statement+Checklist>.