

Caveat on use of **2019 NSW preliminary cancer incidence data**

Date updated

5 April 2022

Data set

NSW Cancer Registry (NSWCR) - 2019 NSW preliminary cancer incidence data

Data element

All data elements

Definition of data element

N/A

Caveat 1 – Missing Death Certificate Only (DCO) cancer cases

Data for 2019 cancer incidence in the 2019 NSW preliminary cancer incidence release are incomplete due to missing "Death Certificate Only" DCO cancer cases. This release does not contain mortality data for 2019 year of death. Please see details below regarding impacts when using these data for analysis.

Background

The Australian Bureau of Statistics (ABS) is the National body responsible for compiling and coding mortality data (including cause of death) from source agencies: Registrars of Birth Deaths and Marriages (RBDM) for each state and territory and the National Coronial Information System.

These data are available through the Australian Coordinating Registry (ACR) and the NSW Cancer Registry receives a Cause of Death Unit Record File (CODURF) as part of its process to code mortality. These data are by year of death registration and are available once a year, usually between May and July. To produce complete mortality for a reporting year, we require receipt of two years of CODURF death registrations.

Cancer cases that are only identified and coded as new cases on receipt of the CODURF data are known as DCO cases.

To provide researchers with the most relevant and up to date cancer information available there are two planned releases of data from the NSWCR for each reporting year, depending on the timing and receipt of the COD URF data:

- **Preliminary cancer incidence data**
 - Incidence data for current reporting year coded, but not complete due to missing DCO cancer cases.
 - Mortality data for current reporting year not available.
- **Final cancer incidence and mortality data**
 - Incidence data coded and complete for current reporting year.
 - Mortality data coded and complete for current reporting year.

Impact on 2019 cancer incidence counts

As 2019 mortality has not been processed and coded for this release, there is an expected undercount of new invasive primary cancer case of approximately 1.6% of all cancers. This represents the average annual proportion of DCO cases, based on historical final coded incidence and mortality data. This proportion varies by cancer type and age group.

The following tables provide a breakdown of the proportion of DCO cancer cases identified from death information over the five-year period from 2014 to 2018, by cancer type (ICD-9) and five-year age group. Cancer of unknown primary and age at diagnosis over 85 are most impacted by missing DCO cases, with approximately 16% (Table 1a) and 10% (Table 1b) of cases identified from coding death data respectively.

Table 1a: Proportion of NSW DCO cancer cases, by cancer type (ICD-9), 2014–2018

Cancer type (ICD-9)		Number of DCO cases (#)	Proportion of DCO cases (%)
Code	Description		
C920	Acute myeloid leukaemia	20	1.2%
C67	Bladder	99	2.2%
C401	Bone	4	0.9%
C71	Brain	47	1.7%
C50	Breast	152	0.5%
C98	Cancer unknown primary	846	16.1%
C72	Central nervous system	2	1.1%
C53	Cervical	4	0.3%
C18	Colon	155	0.9%
C479	Connective tissue, peripheral nerve	8	0.7%
C69	Eye	1	0.2%
C234	Gallbladder	35	2.0%
C648	Kidney	112	1.7%
C32	Laryngeal	6	0.6%
C00	Lip	2	0.1%
C22	Liver	170	4.3%
C334	Lung	570	2.8%
C43	Melanoma of skin	17	0.1%
C45	Mesothelioma	30	2.3%
C036	Mouth	14	1.3%

C8890	Multiple myeloma	58	1.8%
M96	Myelodysplasia	96	3.7%
C301	Nasal & sinus	2	0.6%
C11	Nasopharyngeal	4	1.4%
C82	Non-Hodgkins lymphoma	69	0.8%
C15	Oesophageal	44	1.8%
C0910	Oropharyngeal	3	0.3%
C745	Other endocrine gland	7	2.4%
C59	Other female genital	13	1.6%
M95	Other lymphatic haematopoietic	54	2.1%
C919	Other lymphoid leukaemias	39	1.3%
C6360	Other male genital	3	1.1%
C929	Other myeloid leukaemias	14	1.2%
C14	Other oral cavity & pharyngeal	8	9.6%
C94	Other specified leukaemias	1	0.7%
C378	Other thoracic	7	2.6%
C567	Ovarian	45	1.7%
C25	Pancreatic	267	4.5%
C61	Prostate	245	0.7%
C1921	Rectal	70	0.8%
C078	Salivary gland	8	1.5%
C17	Small intestinal	5	0.5%
C16	Stomach	59	1.5%
C62	Testicular	2	0.2%
C73	Thyroid	9	0.1%
C012	Tongue	13	0.8%
C95	Unspecified leukaemias	80	46.8%
C545	Uterine	26	0.6%
All cancer cases		3545	1.6%

Table 2: Proportion of NSW DCO cancer cases, by five-year age group at diagnosis, 2014–2018

Five year age group	Number of DCO cases (#)	Proportion of DCO cases (%)
0-4 years	0	0.0%
5-9 years	0	0.0%
10-14 years	0	0.0%
15-19 years	0	0.0%
20-24 years	1	0.1%
25-29 years	0	0.0%
30-34 years	0	0.0%
35-39 years	1	0.0%
40-44 years	4	0.1%
45-49 years	11	0.1%
50-54 years	18	0.1%
55-59 years	46	0.2%
60-64 years	86	0.3%

65-69 years	136	0.4%
70-74 years	211	0.7%
75-79 years	325	1.2%
80-84 years	580	2.8%
85+ years	2126	9.8%
All cancer cases	3545	1.6%

Caveat 2 – Incomplete facility notifications impacting cancer incidence in Central Coast and Northern NSW Local Health Districts (LHDs)

At the time the 2019 preliminary incidence data was extracted from the NSWCR for reporting, some facilities were incomplete for 2019 notifications. This has impacted the coding of new cancer cases in Central Coast and Northern NSW LHDs. Overall impact on the number of cases and age-standardised incidence rates are shown below.

Table 2a: Trend of cancer cases in Central Coast and Northern NSW LHDs, 2015-2019

Local health district	2015	2016	2017	2018	2019	2019 change on 2018	
						Cases	%
Northern NSW LHD	2341	2461	2148	2384	1709	-675	-28%
Central Coast LHD	2447	2608	2569	2693	2425	-268	-10%
NSW	44087	45282	45077	46952	45530	-1422	-3%

Table 2b: Trend of age-standardised incidence rates in Central Coast and Northern NSW LHDs, 2015-2019

Local health district	2015	2016	2017	2018	2019	2019 change on 2018	
						Rate	%
Northern NSW LHD	534	536	471	502	363	-139	-28%
Central Coast LHD	537	562	547	568	499	-68	-12%
NSW	498	502	488	497	474	-23	-5%

Estimated proportion of missing cancer cases in NSW overall

Overall, the NSW 2019 cancer incidence data is estimated* to be missing up to 2% of cancer cases due to missing DCO cases and up to an additional 3% of cancer cases due to incomplete cancer notifications. This varies by area, cancer type and age group.

* Missing cancer cases were estimated using 2019 cancer incidence projections estimated by Cancer Institute NSW: Cancer incidence and mortality projections, based on NSW annual cancer incidence and mortality dataset, 2018 (sourced from the NSWCR) and 2019 preliminary populations (sourced from Australian Bureau of Statistics).

Recommendation

Users of the 2019 preliminary* cancer incidence data release should take these caveats and estimates into account when using the 2019 preliminary release in their research and analysis.

**Official reporting of cancer incidence statistics for 2019 by the Cancer Institute NSW, will occur from the NSW 2019 final cancer incidence and mortality data release in the 2nd half of 2022.*

For more information contact

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