

Notifying Cancer-Related Data to the NSW Cancer Registry

Summary This Policy Directive provides information on the procedures to be followed for the reporting of cancer-related data to the NSW Cancer Registry.

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Distributed to Ministry of Health, Public Health System, Private Hospitals and Day Procedure Centres

Audience Medical Records;Health Information Managers;Clinical Coders;Directors of Nursing;Radiation Oncology Treatment Centres;Data Managers;Pathologists;All Pathology Laboratory Staff

NOTIFYING CANCER-RELATED DATA TO THE NSW CANCER REGISTRY

POLICY STATEMENT

NSW Health is committed to reducing the burden of cancer in the NSW population and will do this by continuing to capture cancer-related data into the NSW Cancer Registry. The data captured will be used to report on incidence and mortality from cancer and support programs that utilise the data to reduce incidence and improve outcomes for people diagnosed and treated for cancer.

SUMMARY OF POLICY REQUIREMENTS

This Policy Directive outlines the requirements for submitting notifications to the NSW cancer registry and presents information on data quality, security, access, and dissemination.

Under the provisions of the Public Health Act 2010 and the Public Health Regulation 2012, public and private sector admitted and non-admitted patient facilities, and pathology laboratories are required to notify the NSW cancer registry of all cancer cases.

Under these same provisions, the registrar of births, deaths, and marriages is required to notify the NSW cancer registry of deaths due to cancer.

The provisions of the Cancer Institute (NSW) Act 2003 also allow for the NSW Cancer Registry to request and collect clinical data relating to cancer treatment from any facility providing care to cancer patients in NSW.

All data submitted to the NSW cancer registry undergo a series of quality checks and validations. If data quality issues are detected that require resolution at the source, an error report is generated and sent to the notifier.

The procedures outlined in the NSW Health privacy manual for health information and the Cancer Institute NSW Data Governance Policy are adhered to by NSW cancer registry staff in order to ensure that appropriate data security and governance safeguards are in place.

Data held within the NSW cancer registry can be used to support the functions of the Cancer Institute NSW:

- Monitor and record the number of new cases of notifiable cancers and deaths due to notifiable cancers in NSW;
- Produce regular and ad hoc reports on cancer incidence, treatment patterns, mortality, and survival;
- Evaluate the effectiveness of cancer screening programs;
- Assist in planning and monitoring services for cancer control and the care of cancer patients;
- Contribute cancer data to national and international agencies to assist in cancer control.

- Review adherence to best practice guidelines and optimal care pathways
- Assist in development and implementation of culturally safe cancer care for Aboriginal people across the optimal care pathways
- Review treatment outcomes of standards of care and also review clinical trial outcomes when transitioned into best practice care for a wider cohort.
- Inform reporting which supports quality improvements in cancer care.

REVISION HISTORY

Version	Approved by	Amendment notes
Month-Year (PD2022_008)	Chief Health Officer and Deputy Secretary, Population and Public Health	Initial Document

ATTACHMENTS

1. Notifying Cancer-Related Data to the NSW Cancer Registry: Procedures

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1 BACKGROUND

1.1 About this document

Under the provisions of the Public Health Act 2010 and the Public Health Regulation 2012, public and private sector admitted and non-admitted patient facilities, and pathology laboratories are required to notify the NSW Cancer Registry of all cancer cases.

Under these same provisions, the registrar of births, deaths, and marriages is required to notify the NSW Cancer Registry of deaths due to cancer.

The provisions of the Cancer Institute (NSW) Act 2003 also allow for the NSW Cancer Registry to request and collect clinical data relating to cancer treatment from any facility providing care to cancer patients in NSW.

1.2 Key definitions

Aboriginal person

An 'Aboriginal person' is a person who:

- is of Aboriginal descent
- identifies as an Aboriginal person and
- is accepted as an Aboriginal person by the community in which they live.

Active treatment

A clinical treatment intervention for a specific cancer at a single point in time where the cancer is the principal or an additional diagnosis for the episode of care. Active treatment refers to those under acute or palliative care.

Admitted patient

A person provided a health care service by a hospital, day procedure centre or multi-purpose service on an admitted patient basis.

Cancer

Cancer is a Category 3 Scheduled medical condition and is also a notifiable disease under Schedule 2 of the Public Health Act 2010. This document provides guidance regarding the procedures to be followed for the reporting of cancer-related data to the NSW Cancer Registry.

Data custodian

The data custodian is incumbent to the position responsible for day-to-day management and oversight of the data asset, approval of access to data, and the overall quality and security of the data asset.

Non-admitted patient

A person provided a health care service by a hospital, day procedure centre or multi-purpose service on a non-admitted patient basis.

Notifiable diseases

A medical condition listed under Schedule 2 of the Public Health Act 2010 (NSW)

Palliative treatment

Treatment aimed at providing pain and symptom relief in order to improve the patient's quality of life

Pathology laboratory

A Pathology Laboratory is a Laboratory where tests are carried out on clinical specimens to obtain information about the health of a patient to aid in diagnosis, treatment, and prevention of disease.

Note: In NSW pathology laboratories include services provided by Pathology NSW, Institute of Forensic Medicine, NSW private sector pathology services providers and interstate pathology laboratories.

Radiology services

Any accredited premises in which radiology services are provided within NSW to diagnose or stage a notifiable cancer or response to cancer treatment, or where interventional radiology treatments for cancer are provided.

Scheduled condition

A medical condition listed under Schedule 1 of the Public Health Act 2010 (NSW).

Tabulated data

Summary data produced from analyses of unit record data using broad categories (e.g. age group) and presented in a way that it is not possible to identify any individual.

Unit record data

Data relating to an individual person, which may be presented in an identified (containing identifying information such as name and address) or re-identifiable (identifying information removed) format

1.3 Legal and legislative framework

The Public Health Act 2010, Public Health Regulation 2012, and Cancer Institute (NSW) Act 2003 give authority to the Policy Directive relating to the collection of cancer-related data and the NSW Cancer Registry.

The Public Health Act 2010 outlines the mandatory requirement to notify cancer cases and cancer-related deaths to the NSW Cancer Registry and describes the penalties for non-compliance. The Cancer Institute (NSW) Act 2003 allows for clinical data relating to cancer treatment to be provided to the NSW Cancer Registry.

The Health Records and Information Privacy Act 2002 outlines the requirements for managing health information, including data collection, storage, use, disclosure, and retention.

The NSW Health [Privacy Manual for Health Information](#) provides information to these legislative obligations and outlines procedures to support compliance.

1.4 The NSW Cancer Registry

The NSW Cancer Registry, formerly known as the NSW Central Cancer Registry, is a population-based, central repository of data relating to cases of notifiable cancers, deaths due to notifiable cancers, and clinical treatment data for residents of NSW.

Data is also held in the NSW Cancer Registry for residents of other Australian states and territories who were diagnosed or treated for cancer in NSW. The NSW Cancer Registry also processes all notifications received for the ACT cancer registry.

The Cancer Institute NSW acts as the manager of the NSW Cancer Registry and custodian of the data held within the NSW Cancer Registry on behalf of the Secretary of the NSW Ministry of Health.

1.5 Aboriginal and Torres Strait Islanders

NSW Health Policy Directive *Aboriginal and Torres Strait Islander Origin – Recording of Information of Patients and Clients* ([PD2012_042](#)) outlines the requirements for collecting and recording accurate information on whether clients of NSW Health services are Aboriginal and/or Torres Strait Islander.

Aboriginal and Torres Strait Islander people are under-reported in many health-related data collections in NSW. Self-report in response to the standard Australian Bureau of Statistics question about a person's Aboriginality is the most accurate means of ascertaining whether a client is Aboriginal and/or Torres Strait islander.

The standard question must be asked of all clients of NSW Health services, and the information needs to be recorded accurately according to national standards.

2 MANDATED NOTIFIERS

Sections 82 and 83 of the Public Health Act requires hospital Chief Executive Officers and medical practitioners to notify each case of cancer if they work for certain health entities including:

- Public hospitals within the meaning of the Health Services Act 1997
- Private health facilities, within the meaning of the Private Health Facilities Act 2007
- Any other types of institutions declared by the Public Health Act regulations to be a hospital.

Section 55 of the Public Health Act requires pathology laboratories to notify each case of cancer where the result for a pathology test for cancer, carried out at the request of health practitioner, is positive.

To meet the cancer notification requirements, the notification must be sent to the NSW Cancer Registry either via the NSW Health data warehouse (public hospitals only), or via direct submission in the prescribed format to the NSW Cancer Registry.

3 REPORTING METHODS

3.1 Incidence Cancer cases

Sections 55 and 83 of the Public Health Act 2010 and the Public Health Regulation 2012 requires chief executives of hospitals and laboratories operated by public sector or the private sector within NSW to notify each case of cancer to the NSW Cancer Registry. A separate notification is required for each primary site of cancer.

Lists of notifiable cancers and exclusion criteria can be found in Appendix 1 and 2.

3.1.1 Hospitals

For admitted patients, a cancer notification must be reported at each episode of care where a notifiable cancer is the principal or additional diagnosis and/or where active or palliative treatment has been provided. These notifications are to be provided within 6 weeks of the admission date.

For non-admitted patients, a cancer notification must be reported following a consultation where a diagnosis of a notifiable cancer is first diagnosed and notated in the patient’s medical record and following the start of each course of treatment.

Complete and accurate notifications must be reported within 12 weeks of the consultation or course of treatment start date.

An episode of care refers to an admission, or a treatment sequence from commencement to completion (Course).

The data items to be provided may include, but are not limited to:	
Demographics	name, sex, address, date of birth, country of birth, Aboriginality status
Episode of care information	facility ID, AMO/AHPRA registration number of treating clinician, admission date, separation date, status at separation
Diagnostic information	date of diagnosis, primary site, morphology, best basis of diagnosis

For an up-to-date list of notification data items please refer to the *current notification specification*.

NSW health public hospitals, multi-purpose services and affiliated health organisations are required to report cancer notifications through the NSW Health data warehouse via the admitted patient data collection extract formats, or the non-admitted patient and supplementary services data collection extract format.

The data extract requirements for reporting through the NSW data warehouse are issued by the Ministry of Health systems information and analytics branch. Requests for information can be sent to: MOH-SIA-HIE@health.nsw.gov.au

Where reporting cancer notifications via the NSW Health data warehouse has not been established cancer notifications must be submitted via data extracts sent directly to the NSW Cancer Registry. [The extract requirements](#) for these direct submissions are issued by the Cancer Institute NSW. Submissions must be made via the [cancer notification portal](#).

Private sector hospitals must report cancer notifications directly to the NSW Cancer Registry either via the batch data extract format, or as individual notifications. These submissions must be made via the [cancer notification portal](#).

3.1.2 Pathology laboratories

Public and private sector operated pathology laboratories are required to notify all cases reported as cancer, as well as benign and uncertain-behaviour neoplasms of the central nervous system, to the NSW Cancer Registry.

A pathology report with a confirmed diagnosis of cancer is regarded as the definitive source for determining a cancer case for NSW Cancer Registry. These notifications are to be provided within 6 weeks of the pathology collection date.

Pathology reports for the diagnosis of notifiable cancers may come from histopathology, cytology, cytogenetics, haematology, or molecular diagnostic tests.

The following qualifiers used in pathology reports are regarded as acceptable for a diagnosis of cancer:

consistent with	compatible with	comparable with
diagnostic of	equivalent to/of	extension into
in keeping with	indicative of	invasion of
supports a diagnosis of	(the features) are those of	typical of

Pathology laboratories must provide a copy of each complete and final pathology report that confirms the diagnosis of a notifiable cancer or contributes to the staging or grading of a cancer and associated prognostic factors to the NSW Cancer Registry.

Supplementary reports detailing the results of additional tests and expert reviews, must also be provided, especially when the diagnosis has been revised to a benign condition.

Pathology laboratories can provide notifications in hard copy (paper format) or soft copy (electronically). Hard copy reports must be marked “Private and Confidential” and can be sent to the mailing address provided in Section 5.

3.2 Cancer deaths

Under the provisions of the Public Health Act 2010 and the Public Health Regulation 2012, the NSW Registrar of Births, Deaths, and Marriages is required to notify the NSW Cancer Registry of deaths due to notifiable cancers and the department of forensic medicine where cancer was an incidental finding at post-mortem. These notifications are to be provided within 6 weeks of the date of death or final determination of the cause of death.

The Australian Bureau of Statistics manages the collation of coded cause of death data from state and territory registrars and the National Coronial Information Service and the consolidated data are sought from the Australian Coordinating Registry (ACR) and provided to the NSW Cancer Registry.

Cancer death data and coded cause of death data are provided to the NSW Cancer Registry via encrypted electronic notification files. Aboriginal status must be recorded.

Lists of notifiable cancers and exclusion criteria can be found in Appendix 1 and 2.

3.3 Clinical data

The provisions within the Cancer Institute (NSW) Act 2003 allow the NSW Cancer Registry to request clinical data relating to cancer treatment from any facility providing treatment for cancers in NSW, including private sector health organisations.

The data that must be reported describes the clinical aspects treatments provided to patients with a notifiable cancer. The treatments include radiotherapy, systemic therapies, interventional radiology and other day procedures which aim to remove, control or prepare the cancer for further treatments, or to treat recurrent and metastatic disease.

Clinical data can be provided via extracts from electronic medical record systems used by oncology services or centralised data repositories, via electronic secure data transfer in the form prescribed by the Cancer Institute NSW. Clinical data must be reported within 12 weeks of treatment completion or cancellation, with a minimum frequency of quarterly supply.

Requests for the data extract format requirement specifications for each type of treatment, and details about the data submission process for clinical cancer treatment data, must be sent to [CINSW- ClinicalData@health.nsw.gov.au](mailto:CINSW-ClinicalData@health.nsw.gov.au).

4 DATA QUALITY

4.1 Errors

Staff at notifying facilities are to review notifications prior to submission and address any errors detected in source systems where possible.

All data submitted to the NSW Cancer Registry via any of the reporting mechanisms undergo a series of quality checks and validations. If data quality issues are detected that require resolution at the source, an error report is generated and sent to the notifier.

These error reports are to be checked and corrections made by the notifier within 10 working days.

4.2 Requests for further information

Where a notification is received for an equivocal or unconfirmed cancer diagnosis, further information may be requested before the case is registered. In these instances, the NSW Cancer Registry may contact the notifier, or any medical practitioner involved in the treatment of the person concerned to obtain clarification of test results or the results of any additional tests performed, as well as other information concerning the person's medical condition, transmission and risk factors.

It is a requirement that clarification or further information is provided upon request to NSW Cancer Registry staff. Responses to requests for further information are required within 10 working days.

5 DATA STORAGE AND SECURITY

NSW Cancer Registry data are stored on secure servers located on eHealth's infrastructure hosted in the GovDC with access restricted to authorised personnel only.

The procedures outlined in the [NSW Health privacy manual for health information](#) and the Cancer Institute NSW Data Governance Policy are adhered to by NSW Cancer Registry staff in order to ensure that appropriate data security and governance safeguards are in place.

6 DATA ACCESS AND DISSEMINATION

Data held within the NSW Cancer Registry can be used to support the functions of the Cancer Institute NSW:

- Monitor and record the number of new cases of notifiable cancers and deaths due to notifiable cancers in NSW;
- Produce regular and ad hoc reports on cancer incidence, treatment patterns, mortality, and survival;
- Evaluate the effectiveness of cancer screening programs;
- Assist in planning and monitoring services for cancer control and the care of cancer patients;
- Contribute cancer data to national and international agencies to assist in cancer control.
- Review adherence to best practice guidelines and optimal care pathways
- Assist in development and implementation of culturally safe cancer care for Aboriginal people across the optimal care pathways
- Review treatment outcomes of standards of care and also review clinical trial outcomes when transitioned into best practice care for a wider cohort.
- Inform reporting which supports quality improvements in cancer care.

Tabulated data from the NSW Cancer Registry can be made available upon request and may require approval from the data custodian.

Unit record data held within the NSW Cancer Registry can be utilised for epidemiological research upon approval from the data custodian, NSW population and health services research ethics committee, and the NSW Ministry of Health. Depending on the research question and data requested, additional ethics approvals may be required.

Further information on data access and the approvals required can be found at Cancer Institute NSW [website](#).

7 CONTACT INFORMATION

Requests for further information about the mandatory reporting requirements of the NSW Cancer Registry must be directed to the cancer notifications manager, NSW Cancer Registry.

Requests for further information about the provision of clinical data related to cancer treatment must be directed to the manager, registries and data collection.

Contact details for the NSW Cancer Registry are provided below:

Physical address	Cancer Institute NSW Level 4, 1 Reserve Road St Leonards NSW 2065
Secure postal address	Locked Bag 2011 St Leonards NSW 1590 Must be marked: "Private and Confidential"
Phone	(02) 8374 5749
Secure fax	(02) 8374 3644
Email	CINSW-CCR@health.nsw.gov.au
Website	https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/request-unlinked-unit-record-data-for-research/nsw-cancer-registry
Cancer Notification Portal email	CINSW-CNP@health.nsw.gov.au
Cancer Notification Portal website	https://cnp.cancer.nsw.gov.au/Account/Login
Clinical Data notification email	CINSW-ClinicalData@health.nsw.gov.au

8 APPENDIX LIST

1. List of notifiable cancers
2. Cancers to be excluded from notifications
3. [List of notifiable ICD-10-AM 12th Edition topography codes for use by NSW Health public hospital notifiers](#)
4. [Cancer Notification Data Specification](#)

Appendix 1: List of notifiable cancers

Description	ICD-10-AM 12 th Edition ⁽¹⁾	
	Topography	Morphology
Human immunodeficiency virus (HIV) disease resulting in malignant neoplasms[2]	B21	Ending with /3
All cases of invasive cancer except those specified in Appendix 2	C00.0 to C97	Ending with /3
All cases of unequivocally malignant conditions (haematological[3])	D45-47	
Benign, uncertain-behaviour and malignant neoplasms of the central nervous system	C70.0–C72.9 and C75.1–C75.3	Ending with /0, /1 and /3
Squamous cell carcinoma of the vermillion surface and border of the lip	C00	M805X/3 to M808X/3
Squamous cell carcinoma of skin of anus	C44.5 ([4])	M805X/3 to M808X/3
Squamous cell carcinoma of skin of vulva	C51.9	M805X/3 to M808X/3
Squamous cell carcinoma of skin of penis	C60.9	M805X/3 to M808X/3
Squamous cell carcinoma of skin of scrotum	C63.2	M805X/3 to M808X/3
Carcinoma in-situ of bronchus and lung	D02.2	Ending with /2
Melanoma in-situ	D03	Ending with /2
Carcinoma in-situ of breast	D05	Ending with /2
Carcinoma in-situ of bladder	D09	Ending with /2

Notes:

1. ICD-10-AM codes taken from the International Statistical Classification of Diseases and Related Health Problems, 12th Revision, Australian Modification (12th Edition, 01/07/2022), published by the Independent Health and Aged Care Pricing Authority (<https://www.ihacpa.gov.au/resources/icd-10-amachiacs-twelfth-edition>).
2. When notifying a Topography= B21, the topography of the primary site of the cancer arising from HIV disease must also be notified.
3. Diseases with ICD-10-AM commencing with 'D' were reclassified in ICD-O-3 with a malignant morphology code. Despite being classified under 'Neoplasms of uncertain or unknown behaviour' in ICD-10-AM, these diseases are notifiable when paired with the corresponding morphology codes in this table. The NSW Cancer Registry commenced collection of these notifications for cases diagnosed from 2003 onwards. Cases diagnosed prior to 2003 may also be notified, and if the exact date of diagnosis is unknown a default date of 01/01/2001 should be reported.
4. C44.5 with morphology M805X/3 to M808X/3 also covers squamous cell carcinomas of skin sites other than the anus, which are not notifiable.

Appendix 2: Cancers to be excluded from notifications

Description	Topography	Morphology	Exception
In-situ cancers and intraepithelial neoplasia with no mention of invasion	C00.0 to C97	Ending with /2	Carcinoma in-situ of bronchus and lung (D02.2); Melanoma in-situ (D03.0 to D03.9); Carcinoma in-situ of breast (D05.0 to D05.9). Carcinoma in-situ of bladder (D09*)
Benign and uncertain behaviour tumours		Ending with /0 and /1	Benign, uncertain-behaviour neoplasms of the central nervous system (topography codes C70.0–C72.9 and C75.1–C75.3)
Basal cell carcinomas of the skin	C44*	M8090/3	
Squamous cell carcinomas of the skin	C44*	M805X/3 to M808X/3	Vermilion surface and border of lip (C00.0 to C00.9); Anus (C44.5); Vulva (C51.9); Penis (C60.9); Scrotum (C63.2).
Pre-cancerous conditions.			
Cases where there is an unclear or equivocal diagnosis of cancer and a definitive diagnosis has not been made radiologically, cytologically, or histologically; and the clinician does not regard the patient as having cancer.			