

NORTHERN TERRITORY CANCER REGISTER

DATA COLLECTION, ANALYSIS AND REPORTING PROCEDURES

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1. Introduction

Cancer is a general term used to describe a range of diseases where cells grow and spread abnormally. Cells multiply in an uncoordinated way, independent of normal growth control mechanisms, to form a tumour. The tumour can be either benign or malignant. A benign tumour does not spread outside of the normal boundaries of the organ in which it developed and is not cancer. A malignant tumour is cancer, and can expand and spread by invading surrounding tissue, spreading to nearby organs, or spreading to other parts of the body by metastasis via the lymphatic or vascular systems.

Early changes can be detected in cells in some organs of the body which indicate that the behaviour of these cells has changed and they are growing abnormally but have not yet begun to spread in an invasive manner; these cells are not yet malignant tumours but may become malignant if left untreated. These pre-malignant cells are called 'in-situ' cancers.

The causes of many cancers are not known. Some cancers are caused by unhealthy lifestyle and environment. The major causes of cancer include smoking, sun exposure, diet, chemicals, infectious agents and radiation. Cancer causing substances are called carcinogens. People with a family history of some cancers, such as breast cancer, may have a higher risk of developing that cancer. Some cancers are caused by viruses, such as the Hepatitis B virus

that can cause primary liver cancer and the Human Papilloma Virus (HPV) which can cause cancer of the cervix. Cancer itself, however, is not infectious and cannot be passed to friends or relatives.

Each Australian state and territory has a Cancer Register which records information about all cases of invasive cancer which are diagnosed in residents of that state and notified to the state Registry. All cancers except non-melanotic skin cancers are recorded by Cancer Registries. Non-melanotic skin cancers are the very common cancers caused by sun damage which are so common in Australia that there are more cases of these cancers than all other cancers combined. They are easy to treat and are rarely fatal.

Cancer Registries also record information about in-situ cancers of the breast, bladder and melanoma of skin, but in-situ cancers are not usually included in analysis of cancer statistics as they are not yet malignant cancers. Cancer Registries do not record benign tumours.

When used in reports of the Northern Territory Cancer Registry, the term *cancer* refers to all invasive malignant tumours or neoplasms but does not include non-melanocytic skin cancer or in-situ cancers.

2. The Northern Territory Cancer Register

The Northern Territory Cancer Register is a register of all NT residents diagnosed with cancer, which is maintained by the Northern Territory Cancer Registry (NTCR), a population-based cancer registry operated by the NT Department of Health and Community Services. A ‘population-based’ registry aims to record information about all cases of cancer that occur in the population that is covered by the registry, which for the NTCR is the population of the Northern Territory. Many specialist cancer treatment centres in major hospitals also maintain a ‘clinical cancer register’ which records details of the diagnosis and treatment of all cancer patients treated in each centre; these registers provide information on cancer treatment, but do not provide information on the occurrence of cancer for the entire population because not all cases of cancer are included in clinical registers.

The functions of the NTCR are to provide reliable cancer statistics to inform cancer control programs in the areas of prevention, screening, treatment, rehabilitation and palliative care, and to assist in monitoring and evaluating the impact of these programs, by:

- collecting accurate and complete data on cancer occurrences and deaths in the NT population;
- publishing statistics on cancer incidence, mortality and survival for the NT population;
- contributing NT cancer data for national and international cancer statistics; and
- providing cancer data for cancer research (after approval by an ethics committee and the NT Chief Health Officer).

2.1 History

The NTCR was established in 1981 by the Statistics Branch of the NT Department of Health. Initially it relied on voluntary reporting of cases of cancer from doctors and hospitals. In 1988 the NT Legislative Assembly passed the NT Cancer (Registration) Act. This Act requires pathology laboratories to notify the NTCR of all cases of cancer diagnosed by each laboratory, and requires the Registrar of Births, Deaths and Marriages to notify the NTCR of all deaths registered with cancer mentioned on the

death certificate as either a cause of death or related condition. The Act came into effect when the related regulations were gazetted in 1991.

Because of the small size of the NTCR and the difficulty in maintaining specialist cancer coding expertise, in 1997 the NTCR contracted the South Australian Cancer Registry to perform data processing (including coding) and database maintenance functions for the NTCR. The NTCR remains directly responsible for data collection, analysis and statistical publications, and for approval of access to NTCR data for cancer research.

The NTCR is currently administered within the Health Gains Planning Branch of the NT Department of Health and Community Services (the successor to the Statistics Branch). A senior epidemiologist in the Health Gains Planning Branch is appointed under the Cancer (Registration) Act as the NT Cancer Registrar.

2.2 Legislation

The NT Cancer Registry operates under the provisions of the NT Cancer (Registration) Act 1988 (see Appendix One for a copy of the Act and Regulations). The Act established the statutory office of NT Cancer Registrar, who is required to maintain a register of all NT residents diagnosed with invasive cancer. The Act requires pathology laboratories operating in the NT to notify the Cancer Registrar of all people diagnosed with cancer in the NT, and requires the Registrar of Births, Deaths and Marriages to notify the Registrar of all people who die from cancer in the NT.

The Cancer Registrar is required to keep confidential all information recorded in the Register about individual people with cancer. The Act allows two uses of the information contained in the Register: publication of statistical reports on cancer and use for research projects. Access to NTCR data by researchers must be approved by the Chief Health Officer of the NT. Such approval will only be granted after each research project has been approved by a Human Research Ethics Committee.

2.3 Operation

The main sources of information about people with cancer are pathology laboratories and the Registrar of Births Deaths and Marriages, with additional information provided for some cases by hospitals, individual doctors, other State cancer registries and cancer screening programs. In 2003 there were only two pathology laboratories that perform histology and cytology testing in the NT: Western Diagnostic Pathology and the Royal Darwin Hospital pathology laboratory. These laboratories provide a copy of pathology reports that diagnose cancer to the NTCR on a regular basis. Pathology reports are also received from other cancer registries if an NT resident has received treatment interstate. Computerised death registration data are also obtained from the Registrar of Births, Deaths and Marriages on a monthly basis.

On receiving a report from a pathology laboratory, Cancer Registry staff check whether the person is already registered with this cancer; if already registered, the original notification is updated if necessary. If not already registered, a new cancer notification form is completed with details from the pathology report. If there are details missing from the pathology report further information is obtained from the laboratory, treating hospital and/or treating doctor as necessary.

Data recorded in the Cancer Register includes:

- name
- date of birth
- sex
- residential address
- country of birth
- indigenous status
- occupation
- date of diagnosis
- cancer site
- cancer histology
- treating doctor
- date, place and cause of death (for people who are deceased).

Cases that are found to be residents of another state at the time of diagnosis are not registered by the

NTCR; information of these cases is sent to the Cancer Registry in the person's state of residence. Conversely, when an NT resident is diagnosed with cancer in another state and notified to the cancer registry in that state, the information is forwarded by the interstate registry to the NTCR. A small number of NT residents who are diagnosed with cancer interstate may not be notified to the NTCR if they use a temporary interstate address as their place of residence.

Information on people who die from cancer in the NT is provided each month by the Registrar of Births, Deaths and Marriages. Cancer Registry staff record the date, place and cause of death on the Cancer Register. For deaths due to cancer which are not already registered, Registry staff check with the treating doctor and/or hospital to obtain information about the original diagnosis of cancer.

Some people who are diagnosed with cancer while resident in the NT, and thus recorded on the NT Cancer Register, die in another state after moving there for cancer treatment or for other reasons. These deaths are not registered with the NT Registry of Births, Deaths and Marriages. Once every 1-2 years the NTCR dataset is matched with the National Death Index to identify deaths of people on the NTCR that have not been previously identified. The National Death Index is a complete dataset of all registered deaths in Australia, maintained by the Australian Institute of Health and Welfare from information supplied by the Registry of Births, Deaths and Marriages in each state and territory.

A small number of people diagnosed with cancer in the NT may move overseas and die in another country. The NTCR has no means to identify such deaths. A small proportion of deaths may be missing from the Register for this reason.

To ensure as complete notification of cancer cases as possible, the NTCR performs an annual audit of hospital separations data from the five NT public hospitals. All people discharged from hospital with a diagnosis of cancer are identified and the NTCR checked to ensure that they are all registered. For

people who are not registered further information is obtained from the treating hospital to confirm the cancer diagnosis information, place of residence, etc, and all eligible cases are registered.

After obtaining all necessary information, cancer notification forms are sent to the South Australian Cancer Registry (SACR), where information is coded, entered onto the register database and paper records stored. Data validation is carried out at the time of data entry, and again annually before using data for statistical analysis. Updated NT cancer data is then regularly sent back to the NTCR for data analysis and statistical reporting.

2.4 Data Confidentiality

Records maintained by the NTCR are strictly confidential (see Section 2.2). Access is restricted to staff of the NTCR and of the SACR who process NT data and maintain the NT Register under contract to the NT Department of Health and Community Services (see Section 2.1). Paper records are stored in locked storage and electronic records in password-protected databases stored on secure computer systems. Measures to ensure confidentiality are implemented in all stages of cancer registration ie data collection and entry, data storage, data transmission and reporting.

Data are de-identified for statistical analysis. Researchers who seek access to identifiable or potentially identifiable data must obtain approval from a research ethics committee and authorisation by the Chief Health Officer of the NT.

2.5 National and International Reporting

National cancer statistics

National cancer statistics for Australia are produced by the National Cancer Statistics Clearing House (NCSCH), part of the Australian Institute of Health and Welfare. The NTCR provides data on NT

cancer cases to the NCSCH each year for the compilation of national cancer data and publication of national cancer statistics. The national cancer dataset maintained by the NCSCH is held under the same strict requirements of confidentiality and security as at the NTCR. The NCSCH also assists state and territory cancer registries to identify and resolve duplicate registrations for people who are notified to a cancer registry in more than one state (a particularly important issue for the NTCR because many NT residents diagnosed with cancer are treated at interstate hospitals), and to identify people diagnosed with cancer in one state who subsequently die in another state. Further information about the NCSCH, and copies of national cancer statistical reports, may be found at:

www.aihw.gov.au/ncsch.

International cancer statistics

International cancer statistics are compiled by the International Agency for Research on Cancer (IARC), part of the World Health Organisation. The NTCR provides anonymous data on NT cancer cases to IARC every five years, for the five-yearly international report on cancer incidence and mortality 'Cancer in Five Continents'. The most recent international report, 'Cancer in Five Continents, 1993-1997' was published in 2003.

Australasian Association of Cancer Registries (AACR)

The AACR is the coordinating body for cancer registries in Australia and New Zealand, which determines data collection and reporting standards for cancer registries, publishes national cancer statistics jointly with the AIHW, and provides guidelines for access to and use of cancer registry data by medical researchers. The International Association of Cancer Registries and IARC perform similar standardisation and coordination functions for cancer registries internationally.

3. Cancer Incidence And Mortality Data

3.1 Classification and coding

NT cancer registrations are coded by staff of the SACR using the same coding systems as the SACR. Data items are coded in accordance with the Australian standards for coding of cancer registry data, as specified in the National Health Data Dictionary. Cancer primary site is currently coded using the Ninth Revision of the International Classification of Diseases (ICD9) (WHO, 1977). Cancer histology is currently coded using a modified version of the SNOMED coding system (SACR coding manual). The SACR plans to change to the Tenth Revision of the ICD coding system (ICD10) for primary site and to the International Classification of Diseases for Oncology, Third Edition (ICDO3), for histology, but no date has been set for this conversion.

3.2 Data quality assessment

Prior to the release of the previous report of the NTCR, *Cancer in the Northern Territory 1987–1993* (d’Espaignet ET et al 1996), the NTCR had only used passive surveillance to enumerate cancer in the NT. A retrospective audit of public hospital admissions for cancer during the period 1987–1993 detected an additional 125 cases of cancer. This indicates that cancer incidence reported in *Cancer in the Northern Territory 1987–1993* was under-enumerated by at least 6.7%. Audits of public hospital admissions are now conducted annually. Audit of public hospital admissions for the years 1994–1997 detected 220 additional cancer cases: 179 (81.4%) of these were diagnosed by histology but not reported; 27 (12.3%) were diagnosed by clinical history, and 14 (6.4%) by radiology. Complete audits of hospital records at Darwin Private Hospital are not conducted.

Information on cancer deaths is provided by the Registrar of Births, Deaths and Marriages. The NTCR has always conducted audits of death registrations at Registrar, Births, Deaths and Marriages, to detect cases of cancer diagnosed but not reported before death, and cases of cancer detected during post mortem examination but not diagnosed prior to death. For the period 1994–1997, an additional 110 cancer cases were detected: 56 (50.9%) had been diagnosed histologically, 20 (18.2%) had been diagnosed radiologically, and 29 (26.4%) had been diagnosed clinically; the

remaining 5 (4.5%) were detected during *post mortem* examination.

A detailed assessment of data quality in the NTCR has been conducted over the past two years: the results of this assessment have been published in a separate NTCR report (Condon 2004).

3.3 Mortality data time coverage

Reports of the NTCR generally include cancer mortality statistics from 1991, consistent with cancer incidence statistics. Cancer mortality data are obtained from the Australian Bureau of Statistics national deaths dataset, which is compiled from deaths registered by the Registry of Births, Deaths and Marriages in each state and territory. Death registrations are virtually complete in the NT from the late 1950s, when the last nomadic Aboriginal clans were settled in government or mission settlements. However, until the mid-1970s a high proportion of Indigenous deaths do not have a specific cause of death recorded, so that cancer mortality statistics prior to the mid-1970s probably underestimate cancer mortality in the NT.

3.4 Incidence data time coverage

Assessment of completeness of notifications to the NTCR indicates that notifications were only approximately 60% complete before 1987 and approximately 85% complete between 1987 and 1990. Cancer incidence rates published previously for these years therefore considerably under-estimate cancer incidence in the NT population. The NTCR now only publishes cancer incidence statistics from 1991.

3.5 Population data

Calculation of cancer incidence and mortality rates requires data on the number of people in the NT population, by age-group, sex, indigenous status and year. The mid-year Estimated Resident Population figures published by the Australian Bureau of Statistics are used for calculation of NT cancer incidence and mortality rates (ABS 2003). Population estimates are produced by the ABS for the NT Indigenous population (ABS 2002). Separate estimates for the non-Indigenous population are not produced by the ABS. The non-Indigenous population is estimated by subtraction of the Indigenous population estimates from the total population estimates, within age and sex groups.

4. Statistical Methods

This section describes the methods used to calculate cancer incidence and mortality rates, and other cancer statistics, presented in NTCR reports. The calculations in the examples, which are based on the data in Table 1, below are applicable to both incidence and mortality.

This section is based, with only minor modifications, on the explanation of statistical methods in the report 'Cancer in Australia 2000', jointly published by the Australian Institute of Health and Welfare and the Australasian Association of Cancer Registries (with permission).

4.1 Crude rates—all age groups

A crude incidence rate is defined as the number of new cases of cancer divided by the population at risk in a specified time period. A crude mortality rate substitutes deaths for new cases in this calculation. Both are conventionally expressed as annual rates per 100,000 population and may be

calculated for males, females or persons, or for subsets of the population such as Indigenous people only. The total rate calculated in this way without adjustment for age or other factors is known as the 'crude rate'.

The crude rate is calculated by dividing the total number of cases across all age groups by the total population, for example:

$$\begin{aligned} \text{Crude incidence rate for lung cancer} &= \frac{\text{Column 1 total}}{\text{Column 2 total}} \times 100,000 \\ &= \frac{5,278}{9,505,331} \times 100,000 \\ &= 55.5 \text{ per } 100,000 \end{aligned}$$

4.2 Age-specific rates

Age-specific rates are calculated by dividing the number of cases occurring in each specified age group by the corresponding population in the same age group expressed as a rate per 100,000 population. This rate may be calculated for

Table 1: Example table—Trachea, bronchus and lung cancer incidence (ICD-10 C33–34), males

Age group	No. of cases (column 1)	Australian 2000 male population* (column 2)	Age-specific rate per 100,000 population (column 3)	Australian 2001 Population Standard** (column 4)	Expected number of cases (column 5)
0–4	0	655,870	0	1,282,357	0
5–9	0	692,562	0	1,351,664	0
10–14	0	684,739	0	1,353,177	0
15–19	2	677,754	0.3	1,352,745	4
20–24	2	655,257	0.3	1,302,412	4
25–29	2	722,233	0.3	1,407,081	3.9
30–34	11	708,467	1.6	1,466,615	22.8
35–39	27	748,345	3.6	1,492,204	53.8
40–44	54	719,843	7.5	1,479,257	111
45–49	113	667,121	16.9	1,358,594	230.1
50–54	261	634,443	41.1	1,300,777	535.1
55–59	444	490,199	90.6	1,008,799	913.7
60–64	599	400,799	149.5	822,024	1,228.50
65–69	839	332,035	252.7	682,513	1,724.60
70–74	1,086	299,587	362.5	638,380	2,314.10
75–79	989	219,590	450.4	519,356	2,339.10
80–84	524	118,969	440.5	330,050	1,453.70
85+	325	77,518	419.3	265,235	1,112.00
Total	5,278	9,505,331		19,413,240	

* ABS 2001a.

** ABS 2002a.

particular age and sex groupings, for example:

$$\begin{aligned} \text{Age-specific lung cancer incidence rate in males aged 75-79} &= \frac{\text{Column 1 for this age}}{\text{Column 2 for this age}} \times 100,000 \\ &= \frac{989}{219590} \times 100,000 \\ &= 450.4 \text{ per } 100,000 \end{aligned}$$

Where rates are calculated for periods of more than one year, the number of cases diagnosed in several years is added and the mid-year population estimates for the same years are added before calculation of the rate.

4.3 Age-standardised rates (AS rate)

Cancer occurs more commonly in older than younger people. As a result, the number of cases of cancer will be less in a younger than an older population. The NT has a very young population, for both Indigenous and non-Indigenous people, so the number of cases of cancer in the NT population cannot be directly compared with the number of cases occurring in a similar-sized group of people elsewhere in Australia, where a higher proportion of people will be older.

Rates are adjusted for age to facilitate comparisons between populations that have different age structures, for example, between youthful and older communities. There are two different methods commonly used to adjust for age. In NTCR statistical publications the direct standardisation method is used, in which age-specific rates are multiplied against a constant population (the Australian 2001 Population Standard or the new WHO World Standard Population). This effectively removes the influence of age structure on the summary rate which is described as the age-standardised rate. The method may be used for both incidence and mortality calculations. The method used for this calculation comprises three steps which can be followed by reference to Table 1.

Step 1 Calculate the age-specific rate for each age group (column 3).

Step 2 Calculate the expected number of cases in each five-year age group by multiplying the age-specific rates (column 3) by the corresponding standard population (column

4) and dividing by 100,000, giving you the expected number of cases (column 5).

Step 3 To give the age-standardised rate, sum the expected number of cases in each age group (total column 5). Divide this sum by the total of the standard population used in the calculation and multiply by 100,000.

4.4 Confidence intervals (CI)

The age-standardised and crude incidence and mortality rates presented in NTCR reports also show 95% confidence intervals. These confidence intervals indicate the variation that might be expected in such estimates purely by chance. The confidence intervals are calculated using the methods presented in Holman et al. (1987).

A relatively simple approximation of the confidence limits that readers might use when examining state and territory age-standardised rates is as set out below.

$$95\% \text{ CI approximation} = \text{AS rate} \pm 1.96 \times \frac{\text{AS rate}}{\sqrt{\text{Number of cases}}}$$

4.5 Lifetime risk and cumulative rate

Lifetime risk is a measure that approximates the risk of contracting a particular cancer in a lifetime if the risks at the time of estimation remained throughout life. It is based on a mathematical relationship with the cumulative rate and is calculated in NTCR reports for ages 0–74 years.

Cumulative rate is a directly standardised rate calculated by summing age-specific rates from equal age groups, for example, 5–9, 10–14 years. An example is provided below.

$$\begin{aligned} \text{Cumulative rate} &= \frac{5 \times (\text{sum of the age-specific rates}) \times 100}{100,000} \\ &= \frac{5 \times 926.8 \times 100}{100,000} \\ &= 4.63\% \end{aligned}$$

The factor of 5 is used to indicate the five years of life in each age group and the factor of 100 is used to present the result as a percentage. As age-specific rates are presented per 100,000 population (column 3), the result is divided by 100,000 to return the age-specific rates to a division of cases by

population. Cumulative risk is related to cumulative rate by the expression:

$$\text{Cumulative risk} = (1 - e^{-\text{rate}/100})$$

where rate is expressed as a percentage.

Lifetime risk is expressed as a '1 in n' proportion by taking the inverse of the above formula:

$$n = \frac{1}{(1 - e^{-\text{rate}/100})}$$

For lung cancer in men, the cumulative rate was 4.63%, therefore:

$$\begin{aligned} n &= \frac{1}{(1 - e^{-4.63/100})} \\ &= 22.10 \end{aligned}$$

That is, for men, the lifetime risk (0–74 years) of developing lung cancer is 1 in 22, providing they remain at risk for the whole period and the 2000 age-specific rates apply throughout their lives. Note that no account has been taken of specific cancer risk factors, for example, the risk for men who smoke would be higher than that for those who have never smoked.

4.6 Per cent of all cancers

The 'per cent of all cancers' measure is the proportion of all cancers accounted for by a particular cancer. The measure may be computed for cancer incidence or mortality. Using an incidence example, the measure is calculated by taking the number of new cases of a particular cancer, for example, lung cancer, and dividing that by the total number of all new cancer cases and multiplying by 100 to express it as a percentage. This is undertaken for each sex and for total persons. Note that in NTCR reports the incidence and mortality of skin cancers other than melanoma are not included in total new cancer cases.

4.7 Sex ratio

This measure indicates the relative incidence or mortality between the sexes. It can be calculated on the basis of observed numbers, crude rates, age-

standardised rates or cumulative rates per cent. In NTCR reports it is calculated using the age-standardised rates where the male rate is divided by the female rate for each cancer. Ratios greater than 1 indicate an excess in males while ratios less than 1 indicate an excess in females.

It is preferable to use either the age-standardised rates or the cumulative rate as these both adjust for age variations between male and female populations. In addition, the use of cumulative rate per cent discounts the occurrence of cancer in people aged over 75 years. This gives more emphasis, therefore, to early cancer diagnosis or death, and diminishes the impact of variable diagnostic investigation of the elderly.

4.8 Person-years of life lost

Person-years of life lost is a concept that attempts to measure the number of years of life lost per annum due to death as a result of a specific cause, for example, lung cancer, given life expectancies at specific ages. Age groups 0–4 years up to 70–74 years were used for the calculations, as deaths before age 75 years are regarded as premature for both men and women. The method used in NTCR reports for the calculation of person-years of life lost is an aggregation of years between age at death and 75 years for each person for each cancer, for example, a person dying at age 50 contributes 25 years to the measure of person-years of life lost.

4.9 Average annual rates of change

To indicate the extent of change in age-standardised rates over time, a linear line of best fit is calculated for the time frame in question. Average annual rates of change are then calculated using the geometric formula:

$$\text{Average rate of change} = ((P_n/P_o)^{1/N} - 1) \times 100$$

where P_n = rate at later year n

P_o = rate at earlier year o

$N = n - o$.

This process averages out variations in the actual annual changes that may have occurred between the two points in time.

4.10 Standard population

From 2003, all standardised rates published by the NTCR are calculated using the 2001 Australian Estimated Resident Population as the standard population, unless otherwise stated (Table 2). This

is the standard population recommended by the Australian Institute of Health and Welfare and the Australian Bureau of Statistics for calculation of directly standardised rates, replacing the previously recommended standard (the Australian 1991 ERP).

Table 2: Australian Standard Population (2001)

Age-group	Number	Proportion (%)
0-4	1,282,357	6.6
5-9	1,351,664	7.0
10-14	1,353,177	7.0
15-19	1,352,745	7.0
20-24	1,302,412	6.7
25-29	1,407,081	7.2
30-34	1,466,615	7.6
35-39	1,492,204	7.7
40-44	1,479,257	7.6
45-49	1,358,594	7.0
50-54	1,300,777	6.7
55-59	1,008,799	5.2
60-64	822,024	4.2
65-69	682,513	3.5
70-74	638,380	3.3
75-79	519,356	2.7
80-84	330,050	1.7
85+	265,235	1.4
Total	19,413,240	100.0

5. Interpretation Of Rates

Cancer incidence rates include all patients who were residents of the NT at the time of diagnosis, irrespective of where the diagnosis was made. Cancer death rates include all residents of the NT who died from cancer, whether they died in the NT or interstate. Deaths overseas are not included as no deaths data is available for such deaths.

In most reports age-specific and age-adjusted rates are presented for cancer incidence and cancer mortality. Because cancer incidence and mortality rates are very different for Indigenous compared with non-Indigenous people, separate statistics are provided for the Indigenous and non-Indigenous populations of the NT. Separate statistics are also provided for males and females for the same reasons.

The NTCR has in the past intermittently produced detailed and comprehensive statistical reports on cancer incidence and mortality in the NT. A revised publication strategy is now being implemented to improve the timeliness and usefulness of cancer reports. The NTCR is now producing a series of more frequent, smaller reports including a biennial summary of cancer statistics and a regular series of reports on the more common cancer sites, including incidence, mortality and survival statistics and information on the prevalence of cancer risk factors in the NT population and cancer screening programs for relevant cancers.

Many of the rates presented in NTCR reports are based on small numbers of cases or deaths. When rates are derived from small numbers of cases or deaths, a small change in the number of new cases or deaths will result in a substantial change in the rate. Differences between rates based on small numbers of cases or deaths should be interpreted with caution. Paradoxically, the reader may find the death rate to be higher than the incidence rate for some cancers, because of the instability of rates based on small numbers of cases or deaths, and the effects of age-adjustment on rates in populations with different age structures.

The NT population is a much younger population than the total Australian population or the population of other states and territories; only 4% of the NT population are aged over 65 years, compared to 13% of the total Australian population. Because cancer is predominantly a disease of older people, fewer cases of cancer would be expected to occur in the NT population than in a similar sized population elsewhere in Australia, which would have a higher proportion of older people. The crude incidence rate, which takes no account of the age-distribution of the population, would thus be lower for the NT population than for other Australian populations because of the different age structure. To adjust for the difference in age structure, age-standardised incidence rates are used.

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Appendix One: NT Cancer Registration Act

The NT Cancer (Registration) Act 1988
NORTHERN TERRITORY OF AUSTRALIA
CANCER REGISTRATION ACT

As in force at 10 December 1997

TABLE OF PROVISIONS

Section

1. Short title
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CANCER REGISTRATION ACT
NORTHERN TERRITORY OF AUSTRALIA

This reprint shows the Act as in force at 10 December 1997. Any amendments that may come into operation after that date are not included.

CANCER REGISTRATION ACT

An Act to provide for the registration of cancer and for related matters

1. Short title

This Act may be cited as the *Cancer (Registration) Act*. (See back note 1)

2. Commencement

This Act shall come into operation on a date to be fixed by the Administrator by notice in the *Gazette*. (See back note 1)

3. Definitions

In this Act, unless the contrary intention appears –

“cancer” means a neoplasm of human tissue that is malignant, that if unchecked invades adjacent tissues or extends beyond its site of origin, and that has the propensity to recur either locally or remotely in the body;

“Registrar” means the person appointed Registrar for the purposes of this Act.

4. Appointment of Registrar to maintain cancer register

(1) The Minister shall appoint a person to act as Registrar for the purposes of this Act.

(2) The Registrar shall establish and maintain a register of persons in respect of whom he has been provided with details in pursuance of this Act.

5. Details to be provided to Registrar

(1) The person in charge of a place where specimens of human origin are accepted for pathological examination (whether the examination is to take place within the Territory or outside it) shall, within 7 days of receiving a report which indicates that the person from whom a specimen was taken is or was suffering from cancer, provide the Registrar with the prescribed details (so far as available to him) in respect of that person.

(2) The Registrar of Births, Deaths and Marriages shall, in every case where the registration of a person's death shows cancer as the cause of death, provide the Registrar with the details contained in that registration.

(3) A person who –

(a) fails to comply with subsection (1); or

(b) knowingly provides details pursuant to subsection (1) that are false or misleading, is guilty of an offence.

Penalty: \$100.

6. Confidentiality of information

(1) Subject to subsections (2) and (3), it is an offence for a person to disclose to another, except for a purpose related to the carrying out of this Act or where the disclosure is required by law, any information provided under section 5 which has come to his knowledge in the performance of a function connected with or incidental to the carrying out of this Act.

Penalty: \$1,000.

(2) The Registrar may in his discretion make information provided under section 5 publicly available in a statistical form that does not identify those to whom the information relates.

(3) Subject to subsection (4), the Registrar may in his discretion disclose specific information provided under section 5 to a person authorized in writing by the Chief Health Officer appointed under the *Public Health Act* to undertake scientific research in accordance with guidelines established by the National Health and Medical Research Council continued in existence by the National Health and Medical Research Council Order made by the Governor-General on 21 December 1987 and published in the *Commonwealth of Australia Gazette* No. GN2 dated 20 January 1988.

(4) The consent in writing of the Registrar of Births, Deaths and Marriages is required for the disclosure by virtue of subsection (3) of information provided by him.

7. Regulations

The Administrator may make regulations prescribing matters –

(a) required or permitted by this Act to be prescribed; or

(b) necessary or convenient to be prescribed for carrying out or giving effect to this Act.

Notes

1. The *Cancer Registration Act* comprises the *Cancer Registration Act 1988* and amendments made by other legislation, the details of which are specified in the following table:

<u>Act</u>	<u>Number and year</u>	<u>Date of assent by Administrator</u>	<u>Date of commencement</u>
<i>Cancer Registration Act 1988</i>	No. 64, 1988	15 Dec 1988	1 Mar 1991
<i>Statute Law Revision Act 1997</i>	No. 17, 1997	11 Apr 1997	s. 16: 10 Dec 1997; Remainder: 1 May 1997

Table of Amendments

6. Amended by No. 17, 1997, s. 17

**NORTHERN TERRITORY OF AUSTRALIA
CANCER (REGISTRATION) REGULATIONS**

As in force at 1 March 1991

TABLE OF PROVISIONS

Regulation

1. Citation
2. Commencement
3. Prescribed details

Notes

**Cancer (Registration) Regulations
Northern Territory of Australia**

This reprint shows the Regulations as in force at 1 March 1991. Any amendments that may come into operation after that date are not included.

CANCER (REGISTRATION) REGULATIONS

Regulations under the Cancer (Registration) Act

1. Citation

These Regulations may be cited as the Cancer (Registration) Regulations.

2. Commencement

These Regulations shall come into operation on the commencement of the *Cancer (Registration) Act 1988*.

3. Prescribed details

For the purposes of section 5(1) of the Act, the prescribed details in respect of the person from whom the specimen was taken are -

- (a) the following personal details:
 - (i) surname;
 - (ii) former surname or alias, if any;
 - (iii) given names;
 - (iv) usual address;
 - (v) sex;
 - (vi) date of birth;
 - (vii) country of birth;
 - (viii) duration of residence in Australia;
 - (ix) ethnic group;
 - (x) occupation;
- (b) the following details in respect of the diagnosis of the cancer:
 - (i) name of hospital where that person attended;
 - (ii) hospital registration number of that person in respect of that hospital;
 - (iii) pathology examination reference number;
 - (iv) date of the diagnosis;
 - (v) primary site of the cancer;
 - (vi) histology type of the cancer;
 - (vii) if no histology type, the basis of diagnosis;
 - (viii) if a malignant melanoma, the Clarke level and thickness;
 - (ix) if human tissue or a specimen was sent out of the Territory, the name of the institution to which the tissue or specimen was sent;
 - (x) previous history of cancer, if any;
 - (xi) name of the doctor in charge of that person; and
- (c) the following details in respect of the death of that person:
 - (i) date of final admission to hospital;
 - (ii) date of death;
 - (iii) underlying cause of death.

Notes

1. The Cancer (Registration) Regulations, in force under the *Cancer (Registration) Act*, comprise the Regulations 1990, No. 57 as amended by the other Regulations specified in the following table:

<u>Year and number</u>	<u>Date made</u>	<u>Date notified in the <i>Gazette</i></u>	<u>Date of commencement</u>
1990, No. 57	20 Dec 1989	16 Jan 1991	1 Mar 1991