Australian Government
Australian Institute of Health and Welfare

Cancer in adolescents and young adults in Australia 2023

AIHW

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Australian Institute of Health and Welfare
Canberra
Catalogue number CAN 151

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A complete list of the Institute's publications is available from the Institute's website www.aihw.gov.au.

ISBN 978-1-922802-71-2 (Online)
ISBN 978-1-922802-72-9 (Print)
DOI: 10.25816/ez1m-0803

Suggested citation

Australian Institute of Health and Welfare (2023) *Cancer in adolescents and young adults in Australia 2023*, catalogue number CAN 151, AIHW, Australian Government.

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Published by the Australian Institute of Health and Welfare.

Please note that there is the potential for minor revisions of data in this report. Please check the online version at www.aihw.gov.au for any amendments.

Contents

Summary

This is the third national report to present comprehensive national statistics on cancer in adolescents and young adults (people aged 15–24). It provides an overview of cancers in young Australians, as well as key summary measures, including incidence, treatment, survival, prevalence, mortality, and disease burden. It also includes a spotlight section focusing on second and subsequent primary cancers in young Australians.

Cancers in young Australians are rare, but have a large impact

In the period 2014–2018, 5,302 new cases of cancer (excluding basal and squamous cell carcinoma of the skin) were diagnosed in people aged 15–24 – an average of just under 3 cases per day.

In 2021, cancer accounted for 7.7% of all deaths of people aged 15–24, and in 2022, cancer was the 10th leading cause of overall disease burden in people aged 15–24 and the second leading cause of fatal burden. People aged 15-24 lost 6,848 disability-adjusted life years from cancer, with most (93%) of the burden due to dying prematurely.

Hodgkin lymphoma was the most common cancer, and bone cancers and central nervous system cancers were the leading causes of cancer mortality

In 2014–2018, Hodgkin lymphoma was the most commonly diagnosed cancer in people aged 15-24, accounting for 13% of all cancers diagnosed. Incidence rates for Hodgkin lymphoma increased from 25 new cases per 1,000,000 in 1984–1988 to 43 new cases per 1,000,000 in 2014–2018. Melanoma of the skin, testicular germ cell cancers, carcinoma of the thyroid and carcinoma of the colon and rectum were the next most common, at 12%, 12%, 11% and 10% of all cancers, respectively.

In 2013–2017, bone cancers and central nervous system cancers were the leading causes of cancer mortality in people aged 15-24, each accounting for 17% of all cancer deaths. Soft tissue sarcomas were responsible for 15% of all cancer deaths.

Cancer survival is high

In 2014–2018, people aged 15-24 diagnosed with cancer had, on average, a 90% chance of surviving for 5 years compared with other people their age. Relative survival from all cancers combined for people aged 15-24 rose from 79% in 1984–1988 to 90% in 2014–2018, though changes in 5-year relative survival varied between cancer types. As at 31 December 2018, there were 4,974 alive people who had been diagnosed with cancer within the previous five years while aged between 15 and 24 years.

Over 11,300 hospital admissions and at least 37,000 services at outpatient clinics

In 2020–21, there were 11,300 hospitalisations of people aged 15-24 due to cancer, as well as at least 37,000 services provided at hospital outpatient clinics.

The most common cancers associated with hospital admission were acute lymphoblastic leukaemia (16% of admissions), Hodgkin lymphoma (14%) and bone cancer (11%), as well as testicular cancer for males and acute myeloid leukaemia for females.

Almost 70% of hospitalisations were same-day admissions.

In 2020–21, an estimated 17,000 chemotherapy and 11,600 radiotherapy services were provided to people aged 15-24 in Australia.

Some subpopulations have poorer cancer outcomes

Adjusted 5-year relative cancer survival among people aged 15–24 was:

- 82% for Indigenous people and 89% for non-Indigenous people
- broadly similar across states and territories
- similar in Major cities (90%) and Inner regional areas (90%), but lower in Outer regional (87%) and Remote and Very remote areas (80%)
- lower in socioeconomically disadvantaged areas (87%) than in more advantaged areas (90%–92%).

Young cancer survivors are at an increased risk of developing a second cancer

For cancer survivors who had been diagnosed as an adolescent or young adult, the risk of developing a second primary cancer was, on average, 1.9 times as high as for the general population, and varied from cancer to cancer.

Between 1984 and 2018, 1,009 second cancers were diagnosed among the 31,246 individuals who had been diagnosed with cancer when aged 15–24 since 1984. Of these, 76 were diagnosed with a third cancer in this period, and of these, 3 were diagnosed with a fourth cancer.

The risk of developing a second cancer appears to have remained broadly similar between 1984 and 2018.

Of subsequent cancers, 20% were in people who had been diagnosed with Hodgkin lymphoma when aged 15–24, while 19%, 8% and 6% were in people who had been diagnosed with melanoma of the skin, testicular germ cell cancer and thyroid carcinoma, respectively, when aged 15–24.

The percentage surviving after diagnosis has increased with each successive cohort.

1 Introduction

Cancers in adolescents and young adults (people aged 15–24) are uncommon, but can have far-reaching consequences and contribute a substantial disease burden. In 2022, cancers were the second leading contributor to fatal burden after injury and accounted for about 8% of the fatal burden in Australians aged 15–24 (AIHW 2022a).

There is also growing recognition that young people with cancer have distinct biological, psychosocial, and information needs (Bleyer 2009; Patterson et al. 2015). The unique health needs of young Australians with cancer are reflected in the Youth Cancer Services program (previously named Youth Cancer Networks). The program aims to improve services, support, and the coordination of care for young people aged 15–25 with cancer. Through the Youth Cancer Services program, Canteen and Cancer Australia developed a National Service Delivery Framework for young Australians with cancer.

The framework highlighted the importance of developing an evidence base to measure the effectiveness of health services in meeting the needs of young Australians with cancer, and to further policy development, planning, and service delivery (Cancer Australia and CanTeen Australia 2008). The Australian Institute of Health and Welfare (AIHW) contributed to this objective by producing a national report on cancers in young Australians in 2011, with input from the Clinical Oncological Society of Australia (AIHW 2011).

To inform ongoing and future policy development and service delivery in Australia, the continued monitoring of cancer in young Australians is essential. As the AIHW compiles and holds national cancer data for this population, it is in a unique position to provide updated information on the impact of cancer in young Australians nationally, with the aim of monitoring and helping to improve cancer outcomes for young Australians.

1.1 Purpose and structure of this report

This is the third national report focusing on cancers in young Australians.

The first national report was released in 2011, and examined cancer incidence, mortality, and survival in young Australians between 1983 and 2010 (AIHW 2011).

The second national report was released in 2018 and examined incidence, survival, mortality, disease burden, treatment, and the additional risk of developing another cancer sometime after a first cancer diagnosis (AIHW 2018).

This third report presents updated national incidence and survival data for young Australians with cancer for 2014–2018, with trends dating back to 1984–1988. National mortality data are presented for 2013–2017 (based on SEER recode), and for 2016–2020 (based on ICD-10 coding, with trends back to 1981–1985).

This report also presents data on cancer-related hospitalisations, cancer-related non-admitted patient activity and some Medicare Benefits Schedule (MBS) services in 2020–21, as well as trends in cancer-related hospitalisations for 2001–02 to 2020–21, and the burden of cancer in 2022. Bringing together the latest national cancer statistics and trend data, this report answers the following questions:

- How many young Australians were diagnosed with cancer each year, and what are the trends in cancer incidence? (Chapter 2)
- What are the survival figures for young Australians diagnosed with cancer, and is survival from cancer improving for young Australians? (Chapter 2)

- How many young Australians died from cancer each year, and what are the trends in cancer mortality? (Chapter 2)
- How many young Australians were hospitalised or attended hospital outpatient clinics with a cancer-related illness? (Chapter 3)
- What is the burden of cancer in young Australians? (Chapter 4)
- Does cancer incidence and mortality in young Australians differ across special population groups, including by Indigenous status, state and territory, socioeconomic group, and remoteness area? (Chapter 5)
- What is the risk of developing a second cancer for young Australians who survived their initial cancer diagnosis, how have previous cohorts tracked over the years since their initial diagnosis, and have outcomes improved? (Chapter 6).

Stage at diagnosis was not able to be reported, as only a few records have this information recorded at this time.

Box 1.1: Definitions and terminology in this report

Adolescent and young adult: An individual aged 15–24.

Older young adult: An individual aged 25–39.

Age-specific rate: A rate for a specific age group. The numerator and denominator relate to the same age group. In this report, rates for incidence and mortality are expressed per 1,000,000 (million) population.

Age-standardised rate (ASR): A rate that results from removing the influence of age, by converting the age-structures of the different populations to the same 'standard' structure. Age-standardised rates have been used infrequently in this report, as age structure is similar in all populations considered in this report.

Cancer: A primary tumour that is invasive (that is, malignant). It does not include secondary cancer, benign tumours, and non-invasive tumours. Basal and squamous cell carcinoma of the skin are not reportable by Australian cancer registries, so are excluded from this report.

Child: An individual aged 0–14.

Incidence: The number of new cancer cases diagnosed during a given period.

Late effects: A health condition that often follows months or years after a cancer has been diagnosed or cancer treatment has ended. In this report, late effects refer specifically to second cancers.

Mortality: The number of deaths that occurred during a specified period for which the underlying cause of death was recorded as cancer.

Relative survival: The ratio of observed survival of a group of people diagnosed with cancer to expected survival of those in the corresponding general population after a specified interval following diagnosis (for example, 5 years).

Second cancer: A new primary cancer that occurs in a person who has had cancer in the past.

Survival: The probability that individuals with cancer will still be alive at a specified point in time after diagnosis.

This report is accompanied by:

- online tables that provide detailed data supporting each of the chapters
- online interactive tables and graphs to aid visualisation of the data.

These resources can be accessed through the AIHW website, specifically through the webpage hosting this report (https://www.aihw.gov.au/reports/cancer/cancer-in-adolescents-young-adults-australia-2023/contents/summary).

1.2 What is cancer?

Cancer is a common term used to describe various diseases in which cells become abnormal, grow in an uncontrolled way, and form a mass called a neoplasm or a tumour. Tumours can be benign (not cancerous) or malignant (cancerous).

Benign tumours do not spread to other parts of the body, although they might interfere with other areas of the body as they expand. A malignant tumour is characterised by its ability to spread to other parts of the body through a process known as metastasis.

Cancers can develop from most cell types in the body and are usually classified according to their organ or tissue of origin and histological features. In this report, cancer refers to malignant tumours, unless otherwise stated.

1.3 Who are adolescents and young adults?

Adolescence is recognised as the developmental period of transition from childhood to early adulthood, which is characterised by cognitive, biological, and socioemotional changes (Santrock 2005). Cancer can have far-reaching and serious consequences during this stage of life, when young people are facing various life events, and decisions that affect their longer-term health and wellbeing (Peter MacCallum Cancer Centre n.d.).

There is no universally accepted age group to define adolescence and young adulthood (Geiger and Castellino 2011). Definitions of ‘young people’ have varied depending on whether they are based on age or developmental stage (Aubin et al. 2011).

Internationally, reporting on cancer in adolescents and young adults tends to start at age 15, but the upper limit of what constitutes adolescence and young adulthood varies considerably. The European members of EUROCARE define it as individuals aged 15–24 (Gatta et al. 2013). This is similar to the definition used in Australia, with the Youth Cancer Services program providing treatment and support for those aged 15–25. Other organisations report on broader age groups for adolescents and young adults; for example, the National Cancer Institute reports on ages 15–39 (Adolescent and Young Adult Oncology Progress Review Group 2006).

In determining the appropriate age ranges to use for this report, the following factors were considered: the patterns of cancer diagnosis and mortality; the need to inform service delivery in Australia; and comparability with other Australian and international data sources. Consequently, in this report, ‘adolescents and young adults’ refers to individuals aged 15–24, ‘children’ refers to individuals aged 0–14, and ‘older young adults’ refers to individuals aged 25–39.

Box 1.2: A profile of adolescents and young adults in Australia

In June 2022, there were estimated to be almost 3.2 million adolescents and young adults (people aged 15–24) in Australia, representing about 12% of the total population (ABS 2022a). Males (52%) made up a slightly higher proportion than females (48%). Those aged 20–24 accounted for 52% of the total population of adolescents and young adults in Australia, slighter more than those aged 15–19 (48%).

In 2021, the majority of adolescents and young adults in Australia lived in *Major cities* (74% compared with 73% for the total population) (Public Health Information Development Unit 2022).

The number of adolescents and young adults increased by just over 600,000 between 2001 and 2022, but with more than two-thirds of this increase in the first half of that period and with less than one-third of this increase in the second half of that period (ABS 2022a).

1.4 Why is examining cancer in adolescents and young adults important?

There is growing evidence that cancers in young people have a unique biology (Bleyer 2009; Tricoli et al. 2011), as well as recognition that young people with cancer have distinct medical, psychosocial, and information needs (Peter MacCallum Cancer Centre n.d.). For example, young people are diagnosed with cancer during periods associated with higher education, and the impact on educational outcomes and future employment can be significant (CanTeen Australia 2018).

Additionally, as relative survival from all cancers combined tends to be high for this population (90% 5-year relative survival in 2014–2018 for those aged 15–24), the number of years lived post-cancer is higher than many other age groups, resulting in a higher lifelong impact from cancer. For those aged 15–25 who were diagnosed with cancer in Australia in 2016, the total lifetime costs were estimated to be $1.4 billion (CanTeen Australia 2018).

In addition to the economic costs associated with cancer care, post-cancer treatment can be difficult for young people, as they move from intensive cancer care services into more general or primary care settings (Patterson et al. 2015). Post-cancer care is particularly important for young people who survive their first cancer, as they have an increased risk of developing a second cancer when compared with adult cancer survivors (Lee et al. 2016). Adolescents and young adults who survive their first cancer are also at increased risk of other late effects, such as impaired fertility, hormone deficiencies, heart or lung problems, and hearing or vision problems (ACS 2019).

1.5 How are cancers in adolescents and young adults classified?

In this report, the revised Surveillance, Epidemiology and End Results (SEER) adolescent and young adult site recode (NCI 2020) was used as the basis to classify and report incidence, survival and, where possible, mortality statistics. The 10th revision of the International Statistical Classification of Disease and Related Health Problems (ICD-10)

was used to classify and report treatment and burden of disease statistics, and mortality if SEER categorisation was not possible (Box 1.3).

SEER adolescent and young adult site recode

The SEER adolescent and young adult site recode was developed to describe the major cancers affecting individuals aged 15–39 and designed to report cancer incidence rates and trends (NCI 2008). To ensure comparability with cancers in young Australians in this report, cancers in children are also reported according to the SEER recode rather than the International Classification of Childhood Cancer, third edition (Steliarova-Foucher et al. 2005).

Since the 2018 edition of *Cancer in adolescents and young adults in Australia* ((AIHW 2018) was released, the AYA SEER recode has been revised (AYA Site Recode 2020 Revision (NCI 2020)). This revised recode has then been adjusted to Australian conditions (see Appendix A1), and it is this categorisation which has been used in this report to define cancer types when reporting incidence, survival and, where possible, mortality.

Box 1.3 provides more information on how the SEER adolescent and young adult recode differs from the International Classification of Childhood Cancer, third edition. The SEER classification is based on topography (the anatomic location of the tumour) and histology (the type of cell from which the cancer arose), as coded by the third edition of the International Classification of Diseases for Oncology (ICD-O-3).

The classification system used in this report defines 9 major (Tier 1) cancer groups, which are:

- blood cancers
- central nervous system cancers
- bone cancers
- soft tissue sarcomas
- germ cell and trophoblastic cancers
- melanomas
- carcinomas
- miscellaneous specified neoplasms
- unspecified cancers.

This differs from the categorisation in the previous report, in that leukaemias and lymphomas are reported together as blood cancers. There are also some other adjustments at a finer level.

All but one of these major cancer groups are divided further into (Tier 2) subgroups. The codes for each group and subgroup are presented in Appendix A1. Further information about each of the 9 major cancer groups is provided in this section.

Blood cancers

Blood cancers refer to a wide group of cancers that occur when blood cells develop abnormally (Cancer Council Victoria 2021a). The majority of blood cancers form in blood cells in the bone marrow (American Society of Hematology n.d.). Blood cancers are predominantly leukaemias or lymphomas.

Leukaemias are cancers arising in the blood-forming cells within the bone marrow, leading to an uncontrolled overproduction of abnormal white blood cells (Leukaemia Foundation

2017a). Leukaemias are grouped based on how quickly the disease develops (acute or chronic), and which type of white blood cell is involved (lymphoid or myeloid).

Lymphomas are cancers arising in the lymphatic cells of the immune system. They often present as solid tumours, originating in one or more lymph nodes, or in other organs such as the liver, spleen, bowel, or bone marrow (Leukaemia Foundation 2017b). Lymphomas can be divided into 2 main groups: Hodgkin lymphoma and non-Hodgkin lymphoma. This division is based on the different features of the cancer cells that can be seen under a microscope.

Central nervous system cancers

Central nervous system (CNS) cancers are cancers that originate in the brain or spinal cord.

CNS cancers consist of a heterogeneous set of invasive tumours arising from different types of cells in the central nervous system. They can occur anywhere in the central nervous system, including in the brain, meninges, spinal cord, cranial nerves, pituitary gland, pineal gland, or craniopharyngeal duct (Bleyer et al. 2006). Tumours of the central nervous system differ widely in terms of pathologic appearance, behaviour, and prognosis (Youlden et al. 2009).

Bone cancers

Bone cancers are malignant tumours starting in the bone. Generally, bone cancers develop around the knee, wrist, shoulder, and pelvis. There are many different types of bone cancer, named according to the area of bone or surrounding tissue that is affected, and the types of cells forming the tumour. Common types of bone cancer include osteosarcoma, chondrosarcoma, and Ewing tumour (Cancer Council NSW 2019; NCI 2018).

Soft tissue sarcomas

Soft tissue sarcomas develop in soft tissues (such as muscles, tendons, fibrous tissues, fat, blood vessels, nerves, and synovial tissues) that connect, support, or surround other structures and organs of the body. They can be found almost anywhere in the body, with common sites including arms and legs (ACS 2021). There are many types of soft tissue sarcoma named after the type of tissue in which they begin. Similar types of soft tissue sarcoma are grouped based on microscopic features, symptoms, and treatment.

Germ cell and trophoblastic cancers

Germ cell cancers develop in germ cells (that is, reproductive cells that develop into sperm in males, and eggs in females) in the testicles or ovaries, or in germ cells that have settled in other parts of the body, such as the bottom of the spine, brain, abdomen, and chest (Cancer Research UK 2022).

Trophoblastic cancers are very rare and occur when tumours develop in the uterus during pregnancy (Cancer Research UK 2019). However, these cancers are distinct from uterine and endometrial cancers. Trophoblastic cancers have an extremely high survival rate.

Melanomas

Melanomas are malignant tumours of melanocytes (cells that produce the dark pigment, melanin, responsible for the colour of skin). They predominantly occur in the skin but are also found in other parts of the body, including the bowel and eye (Cancer Council NSW 2021).

Carcinomas

Carcinomas are cancers arising in the epithelial cells covering the outside of the body and the body's organs and cavities (Cancer Research UK 2020).

Miscellaneous specified neoplasms, not otherwise specified

This group largely consists of embryonal tumours that typically occur in children and are less prevalent in adolescents and young adults (Barr et al. 2006).

Unspecified malignant neoplasms

This group consists of cancers that have a specific histology code but are too uncommon to be listed among the 8 specific groups of cancers. It also includes cancers that are so poorly differentiated that it is not possible to classify them.

Box 1.3: Differences between the SEER adolescent and young adult site recode, the International Classification of Childhood Cancers, and the ICD-10

Because the distribution of cancers affecting adolescents and young adults differs from that found in childhood, the scheme of classifying cancers is also different.

The SEER adolescent and young adult site recode contains more detailed classification of carcinomas and central nervous system cancers than the International Classification of Childhood Cancer, third edition (Steliarova-Foucher et al. 2005), and a less detailed classification of lymphomas and reticuloendothelial neoplasms. It also has a separate group for germ cell cancers. Cancer Council Queensland presents detailed statistics on childhood cancer sourced from the Australian Childhood Cancer Registry (ACCR) classified according to the International Classification of Childhood Cancer, third edition (Cancer Council Queensland 2021).

Mortality data in the National Mortality Database (NMD), treatment data in the National Hospital Morbidity Database (NHMD), and burden of disease data in the Australian Burden of Disease Study are coded according to the ICD-10, and not to the ICD-O-3.

As a result, the SEER adolescent and young adult site recode could not be used as the basis for reporting treatment and burden of disease statistics, or for reporting mortality trends using the NMD. Treatment, burden of disease statistics, and mortality time trend presented in this report are instead based on the ICD-10.

Cancer groups with similar names in the incidence and survival chapters will not necessarily be identical to those in the treatment, and burden of disease chapters. As a result, care should be taken in comparing cancer types across incidence, treatment, mortality, burden of disease, and survival data.

1.6 Data interpretation

Ranking of cancer groups

For the purpose of ranking cancers (for example, when compiling a table of the 10 most common cancers), the ranking can contain a mixture of Tier 1 cancer groups and Tier 2 cancer subgroups.

When ranking cancers, the following Tier 1 cancer groups (rather than their Tier 2 cancer subgroups) have been reported:

- central nervous system cancers
- bone cancers
- soft tissue sarcomas
- unspecified cancers.

When ranking cancers, Tier 2 cancer subgroups have been reported for the following Tier 1 cancer groups:

- blood cancers (7 Tier 2 groups)
- germ cell and trophoblastic cancers (5 Tier 2 groups)
- melanomas (2 Tier 2 groups)
- carcinomas (15 Tier 2 groups)
- miscellaneous specified cancers (2 Tier 2 groups)

See Appendix A1 for further detail.

Periods for reporting

This report presents:

- incidence and survival, and trends for 1984–2018
- mortality for 2013–2017 (SEER recode) and mortality trends for 1981–2020 (ICD-10)
- cancer-related hospitalisations, outpatient activity and some MBS activity for 2020–21, and hospitalisation trends from 2001–02 to 2020–21,
- burden of disease (BOD) data for 2022, and BOD trend from 2003 to 2022.

These periods were chosen based on the availability of data, and consistency in presenting trends for cancer incidence, survival, and mortality in combined 5-year periods. The use of combined 5-year periods was chosen due to the small number of cancer diagnoses and deaths in individual years.

When reporting for subpopulations, longer (typically 10 year) periods have been used, so as to avoid volatility as much as possible.

Crude rates

This report presents information on the number of cancer cases and deaths, together with crude rates. Because of the narrow age range (15–24 years) reported, age-standardisation makes little difference to calculated rates and has not been used in this report. The effect of using crude and age-standardised rates was compared and negligible difference was identified between the 2 approaches (see Appendix E3). For simplicity in calculation and interpretation, crude rates have been used throughout the report.

Rates are expressed per 1,000,000 population (or per 10,000 population when reporting for cancer treatment, or per 1,000 population when reporting for disease burden).

Data variability

The numbers of cancer diagnoses/deaths for any given year in young Australians are small. These small numbers can lead to random fluctuations in rates and make it difficult to interpret trends in cancer over time or to compare differences across cancer types. To manage these potential fluctuations, the following steps were applied:

- The number of new cancer diagnoses/deaths, and rates for cancer incidence, survival, and mortality have been presented for 5-year periods. When reporting for small (for example, Indigenous or regional) populations, 10-year periods have been used.
- Larger categories have been used to present for small groups (for example, combining *Remote* and *Very remote* geographic areas in Chapter 5).
- Reporting for small populations has been restricted to persons.
- Incidence, mortality, and survival have been presented with confidence intervals in the online tables associated with this report. Confidence intervals have been used to guide the interpretation of statistics reported in the text of this report.
- Where data for small populations are available for preceding time periods, these have been presented so as to help interpret data for those areas in the most recent time period.

Confidence intervals and their use are discussed in Chapter 5.

Privacy

The AIHW operates under a strict privacy regime which has its basis in Section 29 of the Australian Institute of Health and Welfare Act 1987 (AIHW Act). Section 29 requires that confidentiality of data relating to persons (living and deceased) and organisations be maintained. The Privacy Act 1988 governs confidentiality of information about living individuals.

The AIHW is committed to reporting that maximises the value of information released for users while being statistically reliable and meeting legislative requirements described above.

The abbreviation ‘n.p.’ is used in tables to denote the suppression of data. Data (cells) in tables may be suppressed to maintain the privacy or confidentiality of a person or organisation, or because a proportion or other measure is related to a small number of events and may therefore not be reliable.

Data may also be suppressed to avoid attribute disclosure. Where necessary, other cells in the table may also be suppressed to prevent calculation of the confidential information. Unless otherwise noted, the totals in these tables include the suppressed information. Suppression rules differ between data sources. No suppression is necessary for cancer incidence, mortality and survival data. Cells describing hospitals data containing fewer than 5 counts must be suppressed along with any other cells that could be used to back-calculate suppressed cells. For MBS data, cells containing fewer than 6 counts must be suppressed. Cells containing a count of zero are not required to be suppressed.

2. Cancer incidence, mortality and survival

Key findings

Incidence

- In 2014–2018 there were an average of 1,060 new cases of cancer diagnosed in adolescents and young adults (people aged 15–24) each year.
- Incidence rates for all cancers combined in people aged 15–24 have been relatively steady since 1994–1998, with between 315–335 cases per 1,000,000.
- In 2014–2018 cancer incidence was distributed more evenly between sexes in the population aged 15–24 compared to the general population.
- From 1984–1988 until 2009–2013, melanoma of the skin was the most common cancer in people aged 15–24; in 2014–2018, melanoma of the skin fell to the second most common cancer replaced by Hodgkin lymphoma.
- The proportion of colorectal carcinomas located in the appendix was 85% for people aged 15–24 compared to only 3% in people older than 24. Colorectal carcinomas were the fifth most common cancer in people aged 15–24 in 2014–2018.

Between 1984–1988 and 2014–2018:

- Incidence rates in people aged 15–24 increased almost fourfold for carcinomas of colon and rectum (9 to 33 cases per 1,000,000); and almost threefold for carcinomas of thyroid (13 to 35 cases per 1,000,000) and chronic myeloid cancer (4 to 9 cases per 1,000,000). The rate of mature non-Hodgkin lymphoma more than doubled (8 to 18 cases per 1,000,000).
- Incidence rates more than halved for cervical carcinoma (6 to 3 cases per 1,000,000), carcinoma of sites in the head and neck (5 to 2 cases per 1,000,000) and melanoma of the skin (92 to 42 cases per 1,000,000).

(continued)

Key findings (continued)

Survival

In the period 2014–2018:

- 5-year relative survival was 90% for all cancers combined in people aged 15–24.
- Of the most commonly diagnosed cancers in people aged 15–24, 5-year relative survival was highest for those diagnosed with thyroid carcinoma and Hodgkin lymphoma and lowest for those diagnosed with bone cancers and soft tissue sarcomas.
- People aged 15-24 had a higher overall 5-year relative survival compared with children (0–14 years) and older young adults (25–39 years).

Between 1984–1988 and 2014–2018:

- 5-year relative survival for all cancers combined in people aged 15–24 gradually increased from 79% to 90%.
- Survival was consistently higher for females than males from 1984–1988 to 2014–2018, however the difference has narrowed over time.

Mortality

In the period 2013–2017 (reporting from the Australian Cancer Database):

- There was an average of 100 cancer deaths per year in people aged 15–24.
- Despite similar incidence rates, males contributed more cancer-related deaths (56%) than females.
- Bone cancer and central nervous system cancer were the leading causes of cancer death among people aged 15–24, followed by soft tissue sarcoma, acute lymphoblastic leukaemia/lymphoma, and acute myeloid leukaemia.
- Mortality tended to increase with age, however, people aged 15–24 had higher mortality rates than people aged 25–39 for acute lymphoblastic leukaemia and bone cancer.

In the period 2016–2020 (reporting from the National Mortality Database), there was an average of 92 cancer deaths per year in people aged 15–24.

2.1 Introduction

This chapter describes cancer incidence, survival and mortality for adolescents and young adults (people aged 15–24) in Australia in the 5-year periods for which data are most recently available.

Some data are also presented for children (people aged 0–14) and older young adults (people aged 25–39).

Specifically, the chapter provides:

- a description of statistics for 'all cancers combined' (Section 2.2)
- a comparison of statistics for a range of specific cancer groups (Section 2.3)
- a detailed description of statistics for each of 7 major cancer groups (Section 2.4).

Detailed data are available in the online tables associated with this report.

Box 2.1: Definitions and data sources

Incidence

In this report, incidence refers to the number of new cancer cases (not the number of people) diagnosed during a specified time period. Only cases of primary, invasive tumours are counted.

The main data source for this chapter was the Australian Cancer Database (ACD) 2018. It consists of data provided to the AIHW by the members of the Australasian Association of Cancer Registries through the National Cancer Statistics Clearing House. The most recent version of the ACD contains data on all primary, invasive tumours (excluding basal cell and squamous cell carcinoma of the skin) diagnosed in Australia from 1982 up to and including 2018. Late 2018 data are estimated, these estimations may not be whole numbers, as such case totals are rounded to the nearest unit.

The cancer classification used in this chapter was based on the revised SEER adolescent and young adult site recode (NCI 2020), (see Chapter 1 for further detail). This recode has been adjusted to suit the Australian context and is described in Appendix A1.

This chapter presents incidence for cancer in people aged 15–24 in the period 2014–2018, including differences by sex and comparisons with other age groups. Trends in incidence rates from 1984–1988 are also presented.

(continued)

Box 2.1 (continued): Definitions and data sources

Survival

Data for this section are sourced from the 2018 ACD and focus on 5-year relative survival. Data from the National Death Index (NDI) on deaths (from any cause) that occurred up to 31 December 2018 were used to determine which people with cancer had died and when this occurred.

Relative survival refers to the probability of being alive for a given amount of time after diagnosis compared with the general population. A 5-year relative survival figure of 100% means that the cancer has no impact on the person's chance of still being alive 5 years after diagnosis, whereas a figure of 50% means that the cancer has halved that chance.

Information on survival from cancer provides an indication of cancer prognosis and the effectiveness of treatments available. A range of factors influence survival from cancer, including the demographic characteristics of the patient (such as age, sex and genetics), the nature of the tumour (such as site, stage at diagnosis and histology type) and the health-care system (such as the availability of health-care services, screening, diagnostic and treatment facilities, and follow-up services) (Black et al. 1998; World Cancer Research Fund and American Institute for Cancer Research 2007).

Mortality

In this report, mortality refers to deaths from cancer for which the underlying cause was a primary cancer. The cancer that led to the death may have been diagnosed before or in the same year in which the person died or, in some cases, after death (for example, at autopsy). Information on the underlying cause of death is derived from the medical certificate of cause of death, which is issued by a certified medical practitioner.

Two data sources were used for this chapter: the National Mortality Database (NMD) and the Australian Cancer Database (ACD) 2018. The ACD data on mortality is only reliable from 2007–2017 and therefore is used for analysis of specific cancer groups (that is, blood cancer, bone cancer, and so on). The mortality data in the NMD are reliable from 1981–2020, however, they do not include histology data which means the data cannot be categorised into the same groups that are used in the incidence and survival chapters. For this reason, the NMD is only used for reporting all cancers combined as this allows trends over time to be charted. (See Appendix A for codes used for the different data sources). To avoid confusion that could ensue when reporting mortality for SEER- and ICD-coded cancer groups, mortality data for ICD-10-coded cancer groups allowing description of trends for specific cancers over time have not been described in the report, but instead have been included in the online tables.

This chapter presents mortality from cancer in people aged 15–24 in the period 2013–2017, including differences by sex and comparisons with other age groups. Trends in mortality rates from 1984–1988 to 2016–2020 are presented for all cancers combined.

2.2 All cancers combined

This chapter describes overall incidence, survival and mortality for people aged 15–24, then goes on to describe and discuss these for individual groups of cancers.

While the focus of this chapter is on people aged 15–24 (adolescents and young adults), this report also briefly discusses cancer in people aged 0–14 (children) and people aged 25–39 (older young adults).

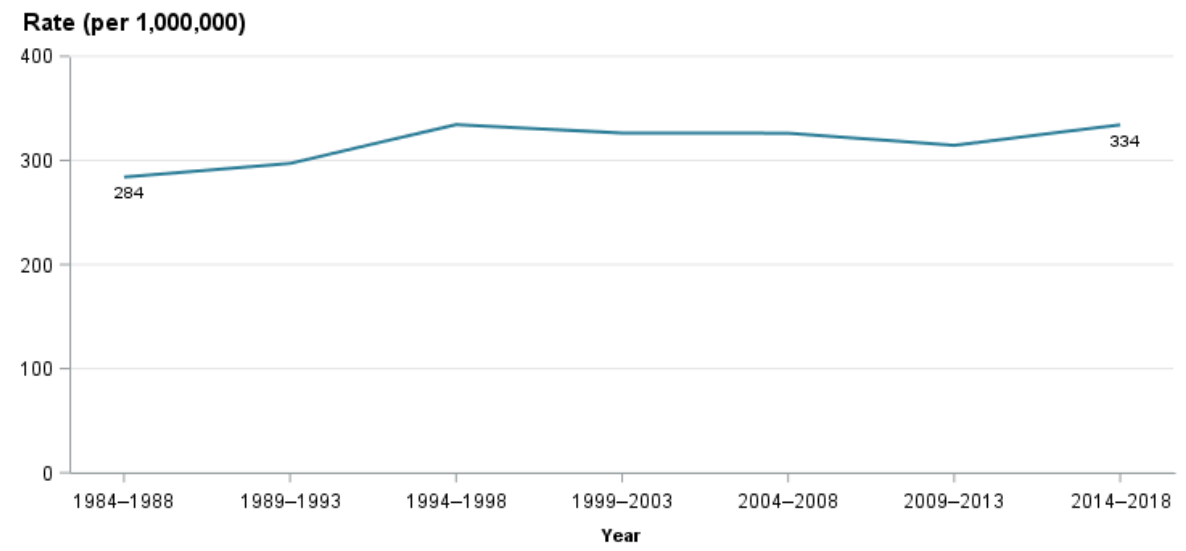
2.2.1 Incidence

In the 5-year period 2014–2018, 5,302 new cases of cancer were diagnosed in people aged 15-24, which is 0.8% of all cancers diagnosed in this period. This corresponds with an average of 2.9 cancer cases diagnosed each day and an incidence rate of 334 new cases per million population per year (hereafter expressed as cases per 1,000,000).

The number of new cases of cancer diagnosed in people aged 15–24 has increased over time, from 3,813 cases in 1984–1988 to 5,302 in 2014–2018, at least in part reflecting an increase in the size of the population aged 15–24 from 2.6 million in 1984 to 3.2 million in 2018.

However, it is less clear how the rate of cancer diagnosis in people aged 15–24 has changed since 1984–1988. The rate of cancer diagnosis was higher in 2014–2018 (334 per 1,000,000) than in 1984–1988 (284 per 1,000,000), however, since 1994–1998, when the rate was 334 cases per 1,000,000 persons (the same as in 2014–2018), rates have remained relatively unchanged (Figure 2.1).

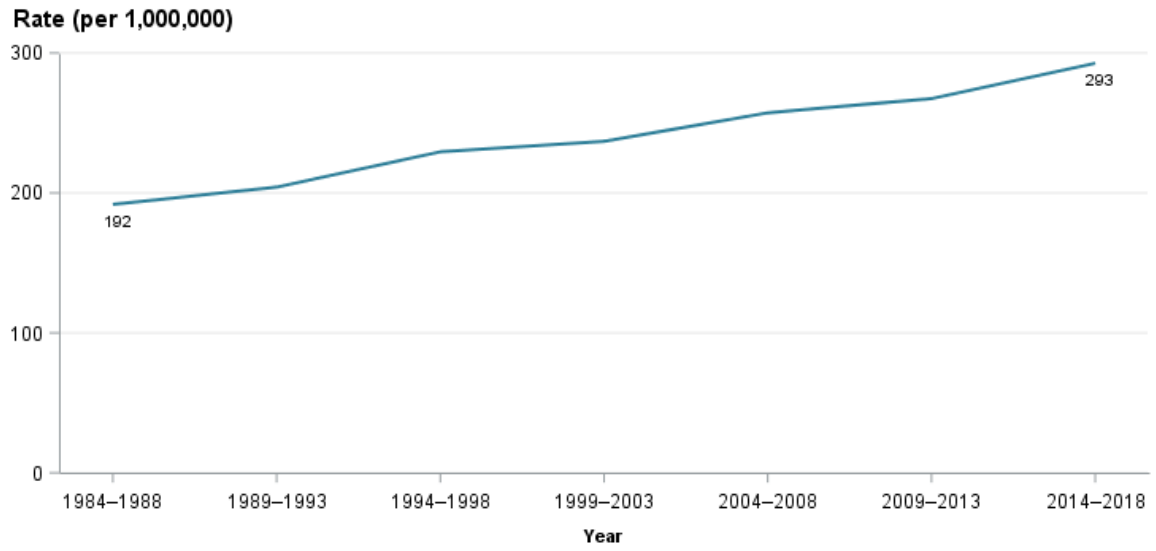
Figure 2.1: Trend in incidence rates for all cancers combined, 15–24 years



Source: AIHW ACD 2018.

In 1984–1988, melanoma was responsible for nearly a third of all cancer diagnoses in people aged 15–24. The incidence increased from 1984–1988 (94 cases per 1,000,000) to 1994–1998 (106 per 1,000,000) before decreasing to 42 cases per 1,000,000 persons in 2014–2018. If melanoma cases are removed from the analysis, rates of diagnosis for all cancers combined can be seen to have increased consistently from 1984–1988 to 2014–2018 (Figure 2.2).

Figure 2.2: Trend in incidence rates for all cancers combined (except melanoma of the skin), 15–24 years



Source: AIHW ACD 2018.

Incidence by sex

In the period 2014–2018, males and females aged 15–24 had similar rates of cancer, this contrasts with the general population where males had higher incidence rates than females (AIHW 2021a).

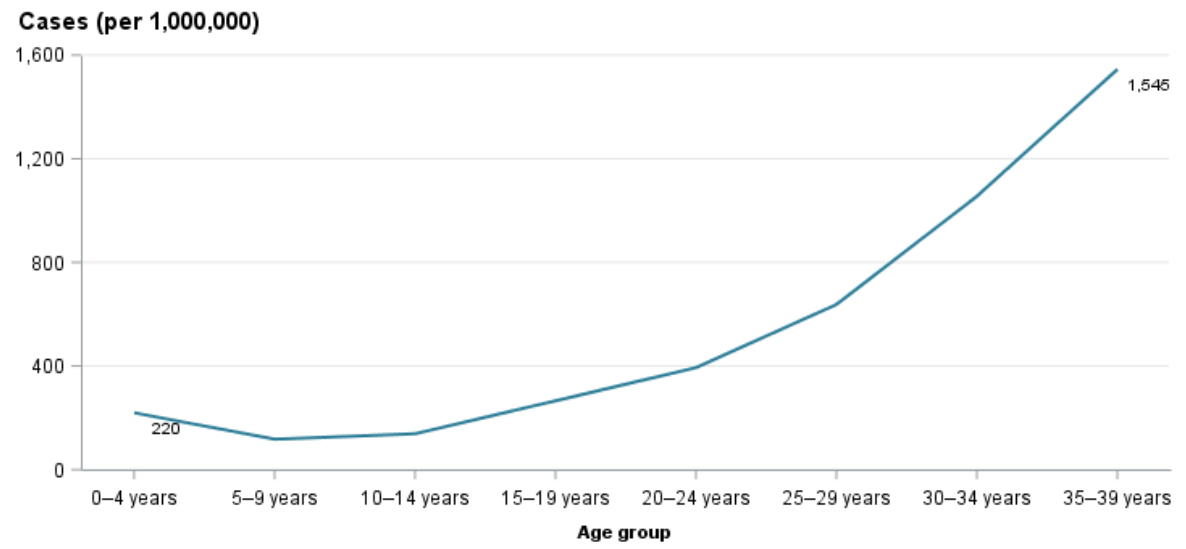
Incidence by age

In 2014–2018, people aged 15–19 had lower overall cancer incidence than people aged 20–24 (266 and 394 cases per 1,000,000, respectively).

In this same period, cancer incidence rates generally increased with age (Figure 2.3). Children (aged 0–14 years) had the lowest incidence rate (159 new cases per 1,000,000 persons), followed by people aged 15–24 (334 new cases per 1,000,000 persons) and older young adults (1,063 new cases per 1,000,000 persons).

More detail is available in the online tables.

Figure 2.3: Incidence rates for all cancers combined by age, 2014–2018



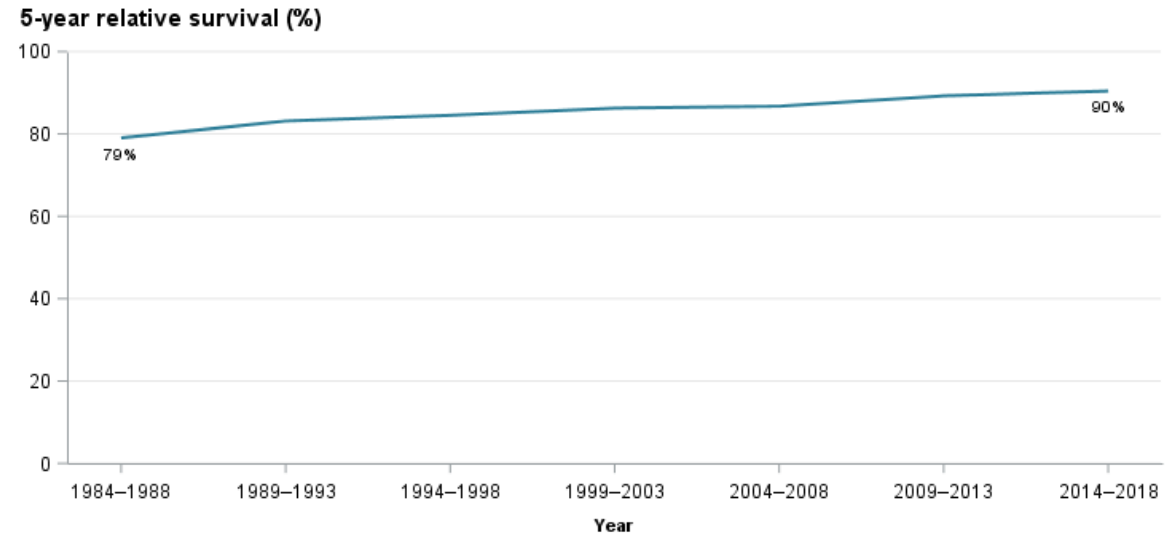
Note: Rates are age specific.

Source: AIHW ACD 2018.

2.2.2. Survival

Five-year relative survival for all cancers combined in people aged 15–24 gradually increased from 79% in 1984–1988 to 90% in 2014–2018 (Figure 2.4). The increase in survival for all cancers combined has been largely driven by improved relative survival for blood cancers.

Figure 2.4: Trend in 5-year relative survival for all cancers combined, 15–24 years



Source: AIHW ACD 2018.

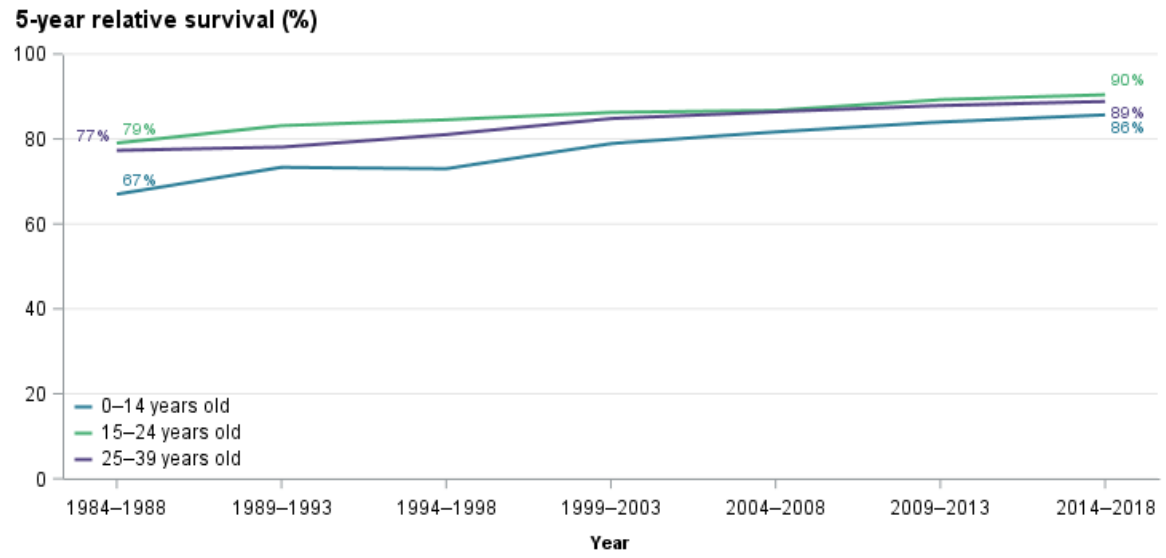
Survival by sex

In the period 2014–2018, 5-year relative survival was lower for males aged 15–24 (89%) than for females aged 15–24 (91%). Between 1984–1988 and 2014–2018, 5-year relative survival improved for males (74% to 89%) and females aged 15–24 (84% to 91%).

Survival by age

In the period 2014–2018, adolescents and young adults had a higher overall 5-year relative survival (90%) compared with children (86%) and older young adults (89%) (Figure 2.5).

Figure 2.5: Five-year relative survival for all cancers combined, by age group



Source: AIHW ACD 2018.

More detail is available in the online tables.

2.2.3 Mortality

The National Mortality Database (NMD) was used for this section since the Australian Cancer Database (ACD) data on mortality are currently only reliable from 2007–2017. At the time of writing, mortality data in the NMD is reliable from 1981–2020, however, it does not include histology data which means the data cannot be categorised into the same cancer groups that are used for the rest of this chapter. For this reason, the NMD is used for analysis of all cancers combined in this section while the ACD is used to describe mortality by cancer type in the rest of this chapter. (See Appendix A for codes used for the different data sources).

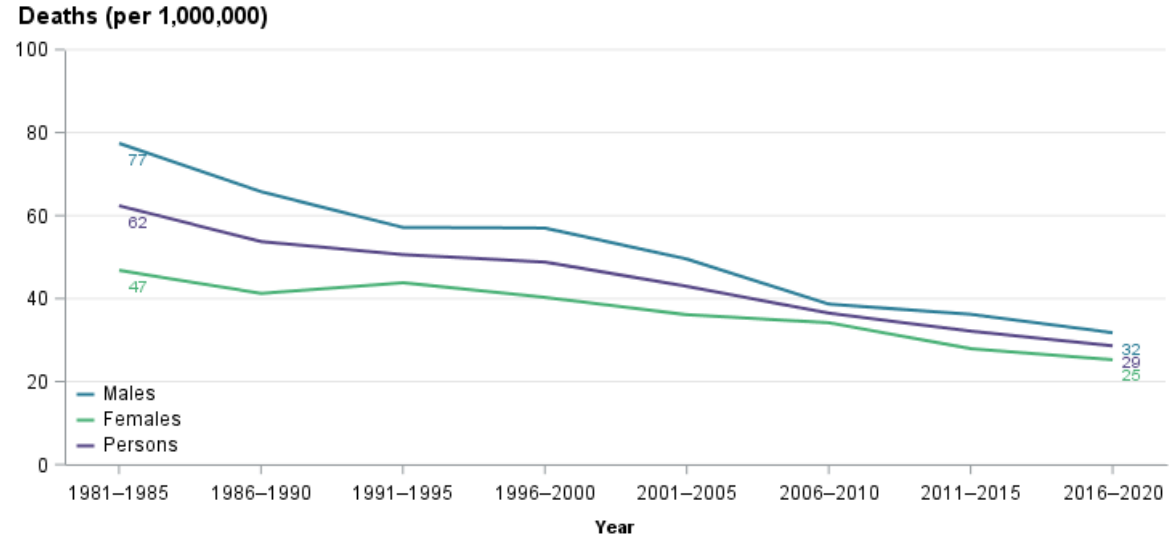
In the period 2016–2020, there were 458 people aged 15–24 who died as a result of cancer. This means that, on average, a person aged 15–24 died from cancer every 4 days in Australia. In 2021, cancer accounted for approximately 7.7% of deaths from all causes in people aged 15–24 compared to 30% in the general population (ABS 2021a). The mortality rate from all cancers combined in people aged 15–24 was 29 deaths per 1,000,000 persons in the period 2016–2020.

The number of people aged 15–24 who died from cancer decreased from 820 in 1981–1985 to 458 in 2016–2020. The mortality rate from all cancers combined in people aged 15–24

decreased from 62 deaths per 1,000,000 in 1981–1985 to 29 deaths per 1,000,000 in 2016–2020 (Figure 2.6).

Mortality rates have been consistently higher for males than females, however the gap between the sexes has decreased over time (Figure 2.6). While both sexes have experienced a decrease in mortality since 1981–1985, the decrease has been greater for males.

Figure 2.6: Trend in mortality rates for all cancers combined, 15–24 years, by sex



Notes

1. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.

2. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.

3. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

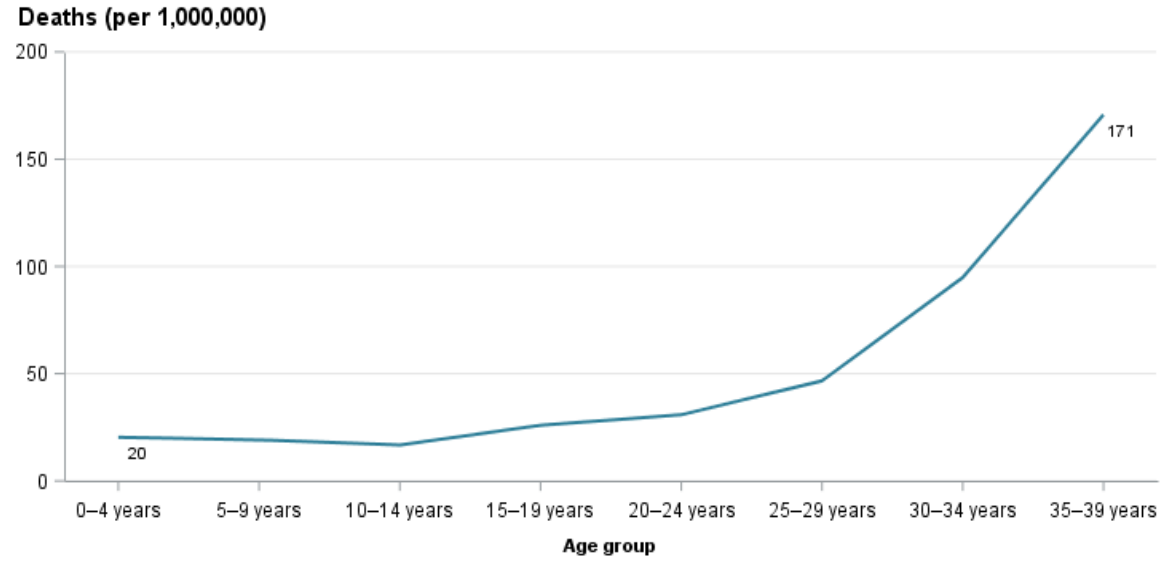
Source: NMD 2020.

There are likely to be several reasons for the clear decrease in mortality over this period. Primary prevention campaigns about sun safety behaviours (for example, SunSmart media campaign) may be partly responsible for improved mortality outcomes in Australians aged 15–24 (Haggar et al. 2012; Whiteman et al. 2008). Additionally, improvements in cancer detection, treatments and prevention may account for some of the decrease in mortality in people aged 15–24 since 1981–1985 (Sitas et al. 2013).

Mortality by age

In the period 2016–2020, cancer mortality rates generally increased with age (Figure 2.7). The mortality rates for all cancers combined increased with increasing age group, with this pattern apparent for most specific cancer groups, with exceptions (see Section 2.3.3).

Figure 2.7: Mortality rates from all cancers combined, by age group, 2016–2020



Notes

1. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.

2. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.

3. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

Source: NMD 2020.

More detail is available in the online tables.

2.3 Comparison of cancer groups

Specific cancer groups are discussed in detail in Section 2.4.

Table 2.1 summarises cancer incidence, relative survival and mortality for the 15 most common cancer diagnoses in people aged 15–24 years in the most recent time period for which data are available at the time of writing (2014–2018 for incidence and survival, and 2013–2017 for mortality when reporting by a SEER-based categorisation).

Table 2.1: Incidence, survival and mortality for the 15 most diagnosed cancers, people aged 15–24 years, 2014–2018 (2013–2017 for mortality)

	Incidence			Survival	Mortality	
Cancers	**Cases diagnosed**	**Per cent**	**Rate of diagnosis**	**5-year relative survival (%)**	**Deaths**	**Per cent**
Hodgkin lymphoma	674	12.7	42.5	98.0	16	3.2
Melanoma of skin	659	12.4	41.5	97.1	12	2.4
Testicular germ cell cancers	624	11.8	39.3	97.7	12	2.4
Carcinoma of thyroid	557	10.5	35.1	99.3	1	0.2
Carcinomas of colon and rectum	518	9.8	32.7	95.7	16	3.2
Mature non-Hodgkin lymphomas	283	5.3	17.8	90.4	17	3.4
Central nervous system cancers	280	5.3	17.6	74.8	83	16.6
Soft tissue sarcomas	247	4.7	15.6	71.4	73	14.6
Acute lymphoblastic leukaemia/lymphoma	217	4.1	13.7	80.8	46	9.2
Bone cancers	212	4.0	13.4	65.0	83	16.6
Acute myeloid leukaemia	145	2.7	9.1	71.7	37	7.4
Chronic myeloid cancer	143	2.7	9.0	92.4	7	1.4
Ovarian germ cell cancer	75	1.4	4.7	96.4	2	0.4
Carcinoma of major salivary glands	57	1.1	3.6	98.1	2	0.4
Carcinoma of breast	44	0.8	2.8	88.9	1	0.2
All other cancers	568	10.7	35.8	84.7	92	18.4
All cancers combined	**5,302**	**100.0**	**334.2**	**90.4**	**500**	**100.0**

Notes

1. Rates are crude and expressed per 1,000,000 persons.

2. Cancers are classified according to the modified SEER categorisation described in Appendix A1.

3. Data for all cancer groups are available in the online tables associated with this report.

Source: AIHW ACD 2018.

The 4 highest incidence cancers (Hodgkin lymphoma, melanoma, testicular germ cell cancer and thyroid carcinoma), were responsible for 47% of all cancer diagnoses in people aged 15–24, have high relative survival (at least 97% 5-year relative survival) and were responsible for only 8% of cancer-related deaths in this age group.

Colorectal cancer and mature non-Hodgkin lymphomas were together responsible for another 15% of all cancer diagnoses in this group, have relatively high survival (at least 90% 5-year relative survival) and were together responsible for 7% of all cancer related deaths in this age group.

Central nervous system cancers, soft tissue sarcomas, acute lymphoblastic leukaemia/lymphoma, bone cancer and acute myeloid leukaemia were the next most common cancers but have lower survival (65–81% 5-year relative survival) than the other top 15 cancers, and together were responsible for 64% of the deaths amongst people aged 15–24.

More detail is available in the online tables.

2.3.1 Comparison of cancer incidence by cancer type

Incidence by cancer type

In the period 2014–2018, the 15 most diagnosed cancers accounted for 89% of all cancers diagnosed in people aged 15–24 (Table 2.1).

Hodgkin lymphoma, melanoma of the skin and testicular germ cell cancer were the 3 highest incidence cancers for people aged 15–24 between 2014 and 2018 (674, 659 and 624 cases respectively).

Carcinoma of the thyroid and carcinoma of the colon and rectum were the next highest incidence cancers for people aged 15–24 in this period (557 and 518 cases, respectively).

Mature non-Hodgkin lymphoma, central nervous system cancers, soft tissue sarcomas, acute lymphoblastic leukaemia/lymphoma and bone cancers had the next highest incidence at between 200 and 300 cases each during this period.

See Table 2.1 for all 15 highest incidence cancers.

Between 1984–1988 and 2014–2018, incidence rates in people aged 15–24 increased by 3.7 times for carcinomas of colon and rectum (9 to 33 cases per 1,000,000), 2.7 times for carcinomas of thyroid (13 to 35 cases per 1,000,000), 2.6 times for chronic myeloid cancer (4 to 9 cases per 1,000,000), and 2.2 times for mature non-Hodgkin lymphoma (8 to 18 cases per 1,000,000).

Over the same period, incidence rates approximately halved for cervical carcinoma (6 to 3 cases per 1,000,000), carcinoma of sites in the head and neck (5 to 2 cases per 1,000,000) and melanoma of the skin (92 to 42 cases per 1,000,000).

These changes over time for specific cancer groups are described in some detail in Section 2.4.

Incidence by sex

For males, testicular germ cell cancer was the most diagnosed cancer followed by Hodgkin lymphoma, melanoma of the skin, carcinoma of colon and rectum and mature non-Hodgkin lymphoma. These 5 cancers accounted for 59% of all cancers diagnosed in males aged 15–24 (Table 2.2).

For females, thyroid carcinoma was the most diagnosed cancer, followed by melanoma of the skin, Hodgkin lymphoma, carcinoma of colon and rectum and central nervous system cancers. Together, these cancers accounted for 62% of all cancers diagnosed in females aged 15–24 (Table 2.2).

Table 2.2: The 10 most diagnosed cancers, 15–24 years, by sex, 2014–2018

Males				Females			
Cancer	**Cases**	**Per cent**	**Rate**	**Cancer**	**Cases**	**Per cent**	**Rate**
Testicular germ cell cancers	624	23.0	76.9	Carcinoma of thyroid	442	17.1	57.1
Hodgkin lymphoma	329	12.1	40.5	Melanoma of skin	384	14.8	49.6
Melanoma of skin	275	10.1	33.9	Hodgkin lymphoma	345	13.3	44.5
Carcinomas of colon and rectum	201	7.4	24.8	Carcinomas of colon and rectum	317	12.3	40.9
Mature non-Hodgkin lymphomas	170	6.3	20.9	Central nervous system cancers	125	4.8	16.1
Central nervous system cancers	155	5.7	19.0	Mature non-Hodgkin lymphomas	113	4.4	14.6
Acute lymphoblastic leukaemia/lymphoma	146	5.4	18.0	Soft tissue sarcomas	113	4.4	14.6
Bone cancers	141	5.2	17.4	Ovarian germ cell cancers	75	2.9	9.7
Soft tissue sarcomas	134	4.9	16.5	Chronic myeloid cancers	74	2.9	9.6
Carcinoma of thyroid	115	4.2	14.2	Acute myeloid leukaemia	71	2.7	9.2
				Bone cancers	71	2.7	9.2
				Acute lymphoblastic leukaemia/lymphoma	71	2.7	9.2
All other cancers	426	15.7	52.5	All other cancers	386	14.9	49.8
All cancers combined	**2716**	**100.0**	**334.5**	**All cancers combined**	**2587**	**100.0**	**334.0**

Notes

1. Rates are crude and expressed per 1,000,000 population.

2. Cases are rounded to the nearest number.

3. Twelve cancers are included for females, with acute myeloid leukaemia, bone cancers and acute lymphoblastic leukaemia/lymphoma each having an incidence of 71 cases.

Source: AIHW ACD 2018.

Incidence by age

The general tendency is for cancer incidence to increase with age (Figure 2.3).

In 2014–2018, people aged 15–19 years had lower overall incidence than those aged 20–24 years. However, people aged 15–19 years had higher incidence rates of bone cancers and acute lymphoblastic leukaemia/lymphoma than people aged 20–24 years.

Children (0–14) had higher incidence rates than adolescents and young adults (people aged 15–24) for acute lymphoblastic leukaemia/lymphoma (43 new cases per 1,000,000 children compared with 14 new cases per 1,000,000 persons aged 15–24) and central nervous system cancers (24 new cases per 1,000,000 children compared with 18 new cases per 1,000,000 persons aged 15–24).

Older young adults (people aged 25–39) had lower incidence rates than adolescents and young adults (people aged 15–24) for Hodgkin lymphoma, acute lymphoblastic leukaemia/lymphoma and bone cancers (36, 6 and 7 cases per 1,000,000 persons respectively compared with 43, 14 and 13 cases per 1,000,000 persons, respectively).

2.3.2 Survival

Survival by cancer type

For many of the cancers reviewed in this report, the number of cases and deaths were insufficient to allow a reliable estimate of survival.

Where possible, survival has been reported for each cancer in the online tables for each of the 5-year periods from 1984–1988, for males, females and persons.

Of the 30 Tier 2 cancers for which survival is reported for 2014–2018, for people aged 15–24:

- 2 have 5-year relative survival of less than 65%
- 5 have 5-year relative survival of between 65% and 74%
- 5 have 5-year relative survival of between 75% and 84%
- 8 have 5-year relative survival of between 85% and 94%
- 10 have 5-year relative of between 95% and 100%.

In the period 2014–2018, 9 of the 15 most diagnosed cancers among people aged 15–24 had 5-year relative survival of 90% or higher (Table 2.1).

Table 2.3: Five-year relative survival for the 5 highest survival cancers and 5 lowest survival cancers, 15–24 years, 2014–2018

Cancer type	5-year relative survival (%)
Highest survival	
Histiocytic and dendritic cell cancer	100.2
Carcinoma of kidney	100.2
Carcinoma of thyroid	99.3
Carcinoma of major salivary glands	98.1
Hodgkin lymphoma	98.0
Lowest survival	
Bone cancer	65.0
Soft tissue sarcoma	71.4
Acute myeloid leukaemia	71.7
Central nervous system cancer	74.8
Carcinoma of ovary	77.6
All other cancers	94.4
All cancers combined	**90.4**

Notes

1. Relative survival greater than 100% is possible. See Appendix E6.

2. Some forms of bone cancer, soft tissue sarcoma and central nervous system cancer have lower survival. See the online tables for survival estimates for all cancer types for which relative survival has been calculated.

Source: AIHW ACD 2018.

In 2014–2018, histiocytic and dendritic cell cancer and carcinoma of kidney had the highest 5-year relative survival (100%) followed by carcinoma of thyroid (99%). Bone cancer had the lowest 5-year relative survival (65%) followed by soft tissue sarcoma (71%) (Table 2.3). Of note, one form of bone cancer (Ewing family of bone sarcomas) had a 5-year relative survival of 45% for this age group, and one form of soft tissue sarcoma (rhabdomyosarcomas) had a 5-year relative survival of 52% for this age group.

Five-year relative survival increased by over 10 percentage points (from 79% to 90%) between 1984–1988 and 2014–2018. The improvement was greatest for blood cancers (27 percentage points – from 64% to 91%).

These changes over time for specific cancer groups are described in some detail in Section 2.4.

Survival by sex

Of the 10 most diagnosed cancers for males aged 15–24 in 2014–2018, 5 cancers had 5-year relative survival greater than 90% (Table 2.4).

Of the 12 most diagnosed cancers for females aged 15–24 in 2014–2018, 6 cancers had 5-year relative survival greater than 90% (Table 2.4).

Table 2.4: Five-year relative survival for the 10 most commonly diagnosed cancers, by sex, 15–24 years, 2014–2018

Males		Females	
Cancer type	**5-year relative survival (%)**	**Cancer type**	**5-year relative survival (%)**
Testicular germ cell cancers	97.7	Carcinoma of thyroid	99.6
Hodgkin lymphoma	98.8	Melanoma of skin	97.6
Melanoma of skin	96.5	Hodgkin lymphoma	97.3
Carcinomas of colon and rectum	94.0	Carcinomas of colon and rectum	96.7
Mature non-Hodgkin lymphomas	89.8	Central nervous system cancers	75.9
Central nervous system cancers	73.6	Mature non-Hodgkin lymphomas	91.1
Acute lymphoblastic leukaemia/lymphoma	83.7	Soft tissue sarcomas	76.3
Bone cancers	59.0	Ovarian germ cell cancers	96.4
Soft tissue sarcomas	67.4	Chronic myeloid cancers	88.3
Carcinoma of thyroid	98.4	Acute myeloid leukaemia	78.2
		Bone cancers	78.0
		Acute lymphoblastic leukaemia/lymphoma	74.6
All other cancers	84.5	All other cancers	83.5
All cancers combined	**89.4**	**All cancers combined**	**91.5**

Notes

1. Cancers are ranked in descending order of incidence.

2. Twelve cancers are listed for females (see Table 2.2).

Source: AIHW ACD 2018.

Survival by age

As a rule, cancer survival tends to decrease with age, but for the 10 highest incidence cancers amongst people aged 15–24, survival for children (0–14), adolescents and young adults (15–24) and older young adults (25–39) were broadly similar, with exceptions.

In 2014–2018, the exceptions were that, compared with adolescents and young adults:

- children had higher 5-year relative survival for acute lymphoblastic leukaemia/lymphoma (94% compared with 81%) and a tendency for higher survival for bone cancers (77% compared with 65%)
- children had lower 5-year relative survival for central nervous system cancers (62% versus 75%)
- older young adults had higher 5-year relative survival for bone cancers (81% versus 65%) and carcinoma of other and unspecified sites in head and neck (92% versus 78%)
- older young adults had lower survival for colorectal carcinomas (78% versus 96%) and carcinoma of lung, bronchus and trachea (53% versus 98%).

More detail is available in Section 2.4 and in the online tables.

2.3.3 Mortality

Reporting of mortality for specific cancers using the modified SEER categorisation (Appendix A1) is possible only for the period 2013–2017.

In the period 2013–2017, the 10 most common causes of cancer-related death accounted for 79% of all cancer deaths in people aged 15–24. These are described in Table 2.5.

Table 2.5: The 10 most common causes of cancer deaths, 15–24 years, 2013–2017

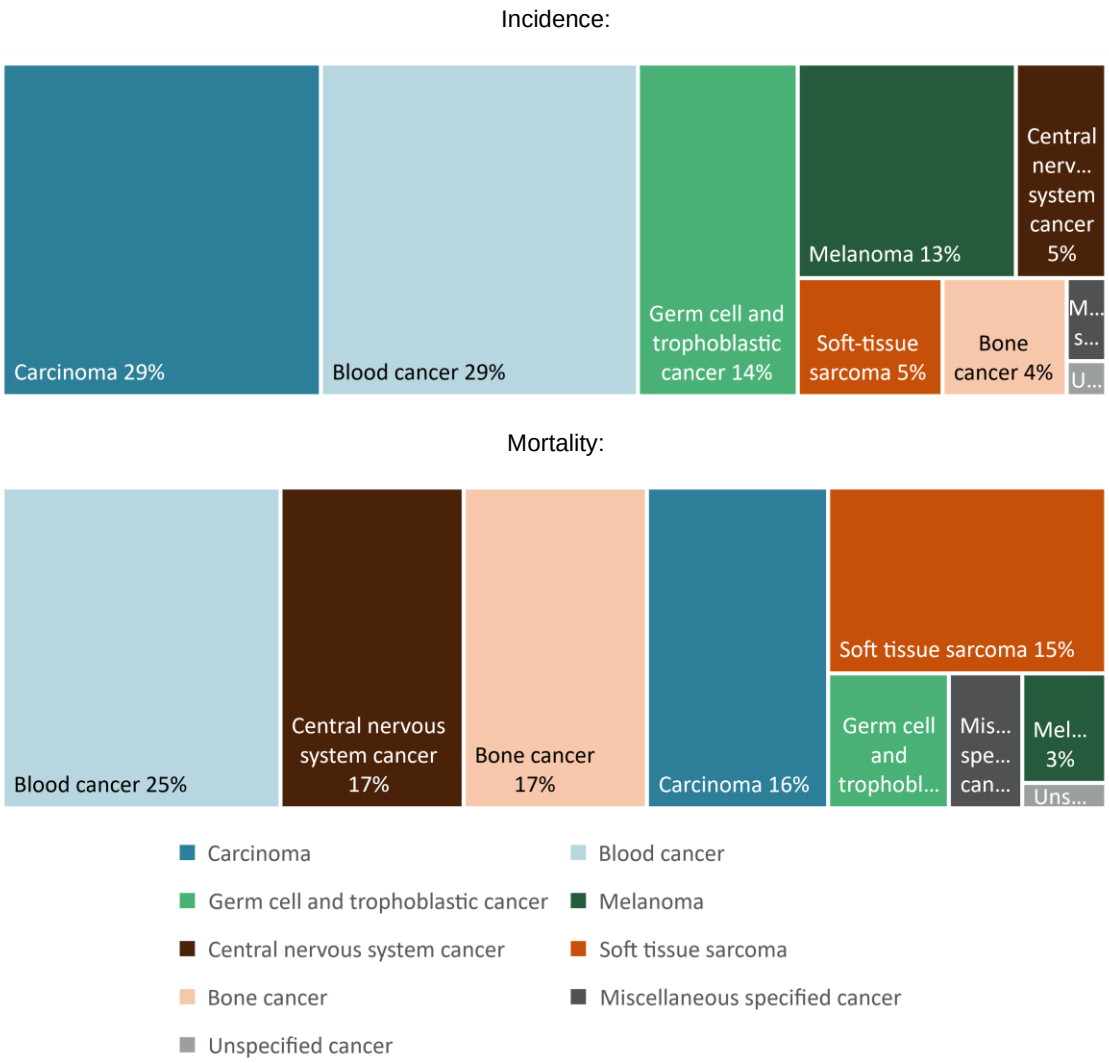
Cancer type	Deaths	Per cent of all deaths
Bone cancer	83	16.6
Central nervous system cancer	83	16.6
Soft tissue sarcoma	73	14.6
Acute lymphoblastic leukaemia/lymphoma	46	9.2
Acute myeloid leukaemia	37	7.4
Mature non-Hodgkin lymphoma and related cancer	17	3.4
Carcinoma of colon and rectum	16	3.2
Hodgkin lymphoma	16	3.2
Melanoma of skin	12	2.4
Testicular germ cell cancer	12	2.4
All other cancers	105	21.0
All cancers combined	**500**	**100.0**

Source: AIHW ACD 2018.

Three cancer groups were responsible for almost half of all cancer-related deaths in people aged 15–24. These were bone cancer, central nervous system cancers and soft tissue sarcomas (17%, 17% and 15% of deaths, respectively) (Figure 2.8).

Acute lymphoblastic leukaemia/lymphoma and acute myeloid leukaemia were together responsible for a further 17% of deaths.

Figure 2.8: Cancer incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years



Source: AIHW ACD 2018.

Mortality by sex

In the period 2013–2017, males accounted for more than half (56%) of all cancer deaths amongst people aged 15–24. This proportion of cancer deaths in people aged 15–24 is less evenly distributed than in the wider Australian population (49% males) (AIHW 2021a).

The 5 most common causes of cancer death were the same for both males and females, specifically bone cancer, central nervous system cancers, soft tissue sarcomas, acute lymphoblastic leukaemia and acute myeloid leukaemia (Figure 2.8).

These cancers accounted for 72% of all cancer deaths in males aged 15–24, and 55% of all cancer deaths in females aged 15–24 (Table 2.6).

Table 2.6: The 5 most common causes of cancer deaths, 15–24 years, by sex, 2013–2017

Males				Females			
Cancer	**Deaths**	**Per cent**	**Rate**		**Deaths**	**Per cent**	**Rate**
Bone cancer	59	21.2	7.3	Central nervous system cancer	34	15.3	4.4
Central nervous system cancer	49	17.6	6.1	Soft tissue sarcoma	26	11.7	3.4
Soft tissue sarcoma	47	16.9	5.8	Bone cancer	24	10.8	3.1
Acute lymphoblastic leukaemia/lymphoma	27	9.7	3.4	Acute myeloid leukaemia	19	8.6	2.5
Acute myeloid leukaemia	18	6.5	2.2	Acute lymphoblastic leukaemia/lymphoma	19	8.6	2.5
All other cancers	78	28.1	9.7	All other cancers	100	45.0	13.0
All cancers combined	**278**	**100.0**	**34.5**	**All cancers combined**	**222**	**100.0**	**28.8**

Notes

1. Rates are expressed per 1,000,000 population.
2. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

Source: NMD 2020.

Mortality by age

Cancer mortality rates tended to increase with age.

Counter to this tendency, in 2013–2017:

- children had a higher central nervous system cancer mortality rate than adolescents and young adults (8.7 compared with 5.2 deaths per 1,000,000)
- older young adults had lower bone cancer and acute lymphoblastic leukaemia mortality rates than adolescents and young adults (1.6 and 2.2 deaths per 1,000,000 for people aged 25–39 compared with 5.3 and 2.9 for people aged 15–24).

The pattern of cancer mortality also differed across age groups. Brain cancer was the most common cause of cancer death for those aged 0–14. Bone cancer was the most common cause of cancer death for those aged 15–24. Colorectal cancer was the most common cause of cancer death for those aged 25–39.

More detail is available in the online tables.

Box 2.2: Trends in mortality rates for adolescents and young adults

Time trend using SEER-based cancer groupings is not possible for data quality issues discussed previously. However, mortality data for cancer groupings based on the ICD-10 classification, are available for each of the 5-year periods from 1981–1985 to 2016–2020 in the online tables.

Cancer categorisations of specific cancer groups using ICD-10 and SEER-based recode are not identical. However, as it provides some insight into mortality changes over time, it may be informative to describe some of the more substantial changes over the past few decades.

From the online data tables, mortality rates for ICD-10 categorised cancers decreased, for people aged 15–24, between 1981–1985 and 2016–2020, for:

- acute lymphoblastic leukaemia, from 9.0 to 2.7 deaths per 1,000,000
- acute myeloid leukaemia, from 7.2 to 2.4 deaths per 1,000,000
- melanoma, from 4.6 to 0.7 deaths per 1,000,000
- non-Hodgkin lymphoma, from 4.7 to 1.4 deaths per 1,000,000
- Hodgkin lymphoma, from 2.7 to 0.4 deaths per 1,000,000.

There also appear to have been general, more modest decreases for many other cancers, for example for bone cancers and brain cancers.

Of note, more than half of the decrease in overall cancer mortality for people aged 15–24 can be explained by decreases in mortality due to blood cancers (that is, leukaemias and lymphomas).

Readers should be aware that these cancers, categorised using ICD-10, are similar to, but not identical to the SEER-based cancers described in the rest of this section and in the incidence and survival sections of this chapter. Caution is advised.

2.4 Specific cancer groups

This section discusses incidence, survival, and mortality for the main Tier 1 cancer groups (see Appendix A1).

2.4.1 Blood cancers

Blood cancers refer to a wide group of cancers that occur when blood cells develop abnormally (Cancer Council Victoria 2021a). The majority of blood cancers form in blood cells in the bone marrow (American Society of Hematology n.d.).

Blood cancers are a common cancer in Australia accounting for 11% of cancer cases in the entire population and 29% of cases in people aged 15–24.

Key findings:

- Rates of blood cancer increased from 1984–1988, but then have remained steady since 2004–2008.
- Males have had consistently higher rates of blood cancers than females.
- The blood cancers diagnosed most in people aged 15–24 in 2014–2018 were Hodgkin lymphoma, mature non-Hodgkin lymphoma and acute lymphoblastic leukaemia/lymphoma.
- The blood cancers with the lowest survival in people aged 15–24 in 2014–2018 and responsible for the most deaths in 2013–2017 were acute lymphoblastic leukaemia/lymphoma and acute myeloid leukaemia.

Blood cancers discussed in this report:

- acute lymphoblastic leukaemia/lymphoma
- acute myeloid leukaemia
- chronic myeloid cancers
- histiocytic and dendritic cell cancers
- Hodgkin lymphoma
- mature non-Hodgkin lymphoma and related cancers
- other and unspecified blood cancers.

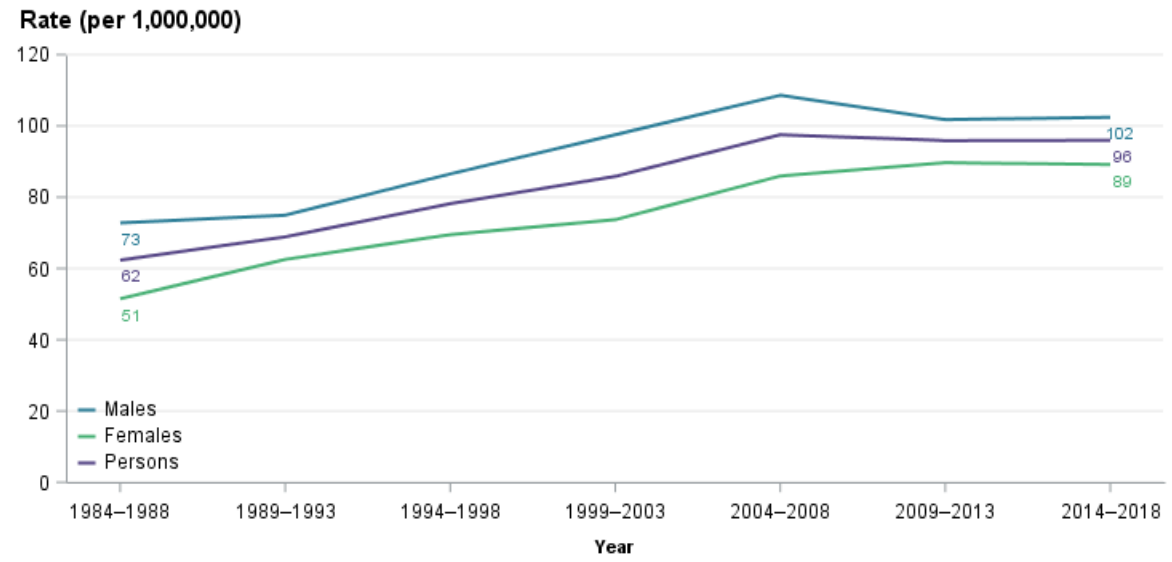
Detailed data is available in the online tables associated with this report.

Incidence

Rates of blood cancer have increased in people aged 15–24 from 1984–1988 to 2004–2008 and have remained steady since then (Figure 2.9). In 2014–2018, the most common type of blood cancer amongst people aged 15–24 was Hodgkin lymphoma (44%), followed by mature non-Hodgkin lymphomas (19%) and acute lymphoblastic leukaemia/lymphoma (14%). While rates of Hodgkin lymphomas and mature non-Hodgkin lymphomas have increased over time, the rate of acute lymphoblastic leukaemia/lymphoma has remained relatively stable.

In 2014–2018, males were responsible for more than half (55%) of blood cancer cases amongst people aged 15–24. Rates for males have been consistently higher than for females since 1984–1988 (Figure 2.9).

Figure 2.9: Incidence rate for blood cancers, 15–24 years, by sex



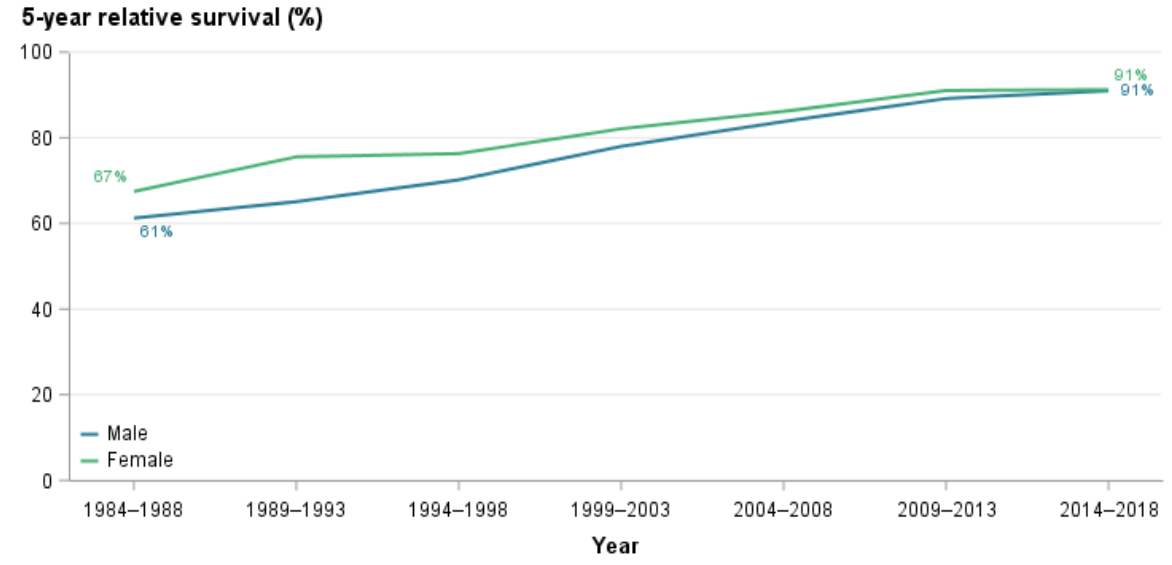
Source: AIHW ACD 2018.

Survival

Five-year relative survival for blood cancers has substantially increased for people aged 15–24 from 64% in 1984–1988 to 91% in 2014–2018. In 2014–2018, survival was similar for males and females aged 15–24 (Figure 2.10).

Of the blood cancers in 2014–2018, 5-year relative survival was lowest for acute myeloid leukaemia (72%), a little higher for acute lymphoblastic leukaemia (81%) and highest for Hodgkin lymphoma (98%) and histiocytic and dendritic cell cancers (100%).

Figure 2.10: Five-year relative survival for blood cancer, 15–24 years, by sex



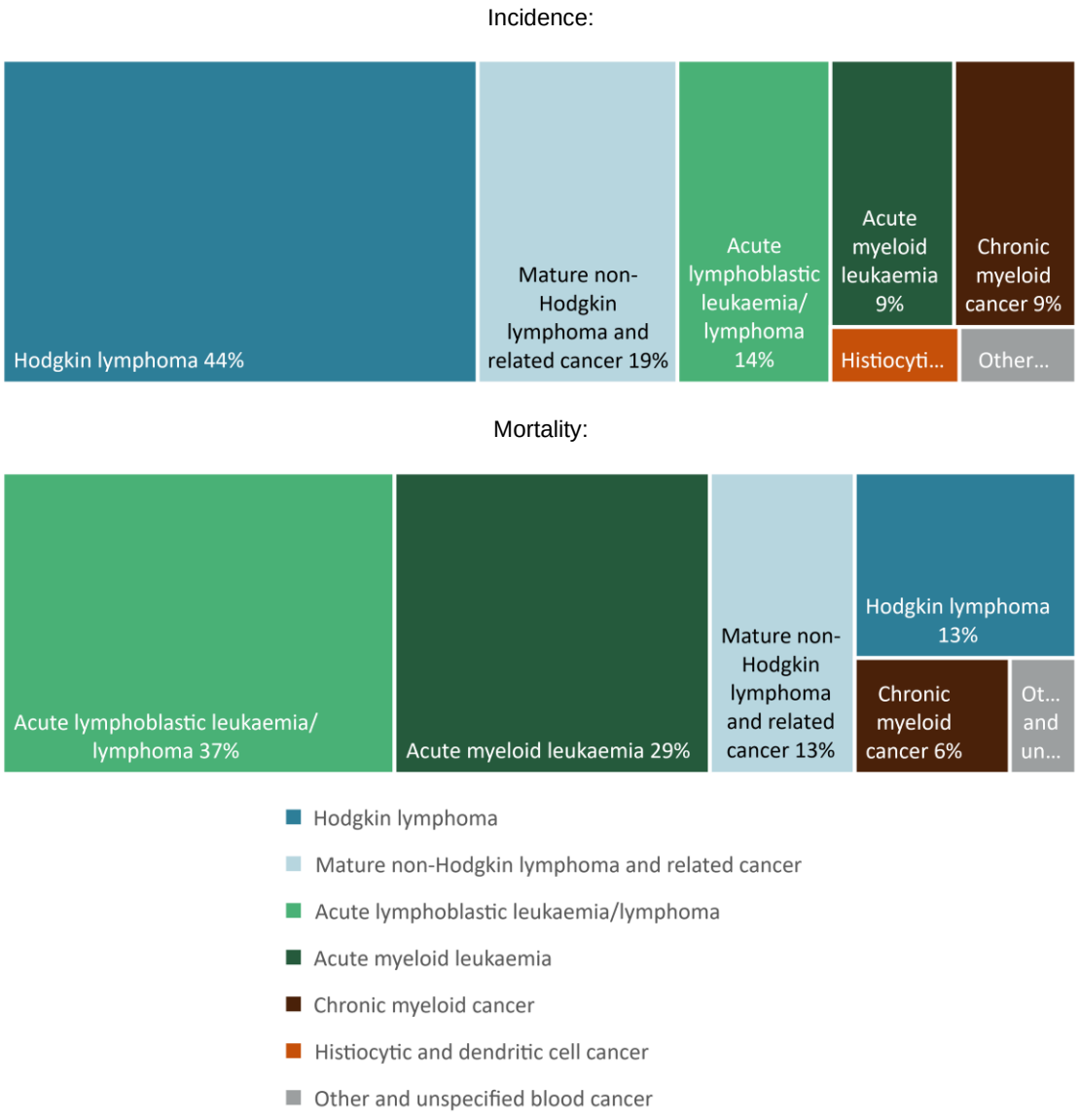
Source: AIHW ACD 2018.

Mortality

In 2013–2017, 126 people aged 15–24 died from blood cancer. Acute lymphoblastic leukaemia/lymphoma was responsible for most blood cancer deaths (37%) followed by acute myeloid leukaemia (29%). Histiocytic and dendritic cell cancers did not cause any deaths in this period (Figure 2.11).

In 2013–2017, deaths due to blood cancer were distributed evenly between males and females. However, acute lymphoblastic leukaemia/lymphoma was responsible for more blood cancer deaths in males than females.

Figure 2.11: Blood cancer incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years



Source: AIHW ACD 2018.

More detail is available in the online tables.

2.4.2 Central nervous system cancers

Central nervous system (CNS) cancers are cancers that originate in the brain or spinal cord. CNS cancers are not common cancers, comprising 1% and 5% of all cancers in the general population and adolescent and young adult population respectively.

Key findings:

- The majority of CNS cancers in people aged 15–24 in 2014–2018 were located in the brain (90%).
- Rates of CNS cancer have remained broadly similar since 1984–1988.
- CNS cancers are more common in males (55% of CNS cancers in 2014–2018).
- Most diagnosed CNS cancers in people aged 15–24 in 2014–2018 were other astroglial neoplasms and glioblastomas. These were the same CNS cancers responsible for the most deaths in people aged 15–24.

CNS cancers discussed in this report:

- ependymomas
- glioblastomas
- medulloblastoma and other embryonal CNS cancers
- oligodendrogliomas
- other astroglial neoplasms
- other specified CNS cancers
- unspecified CNS cancers.

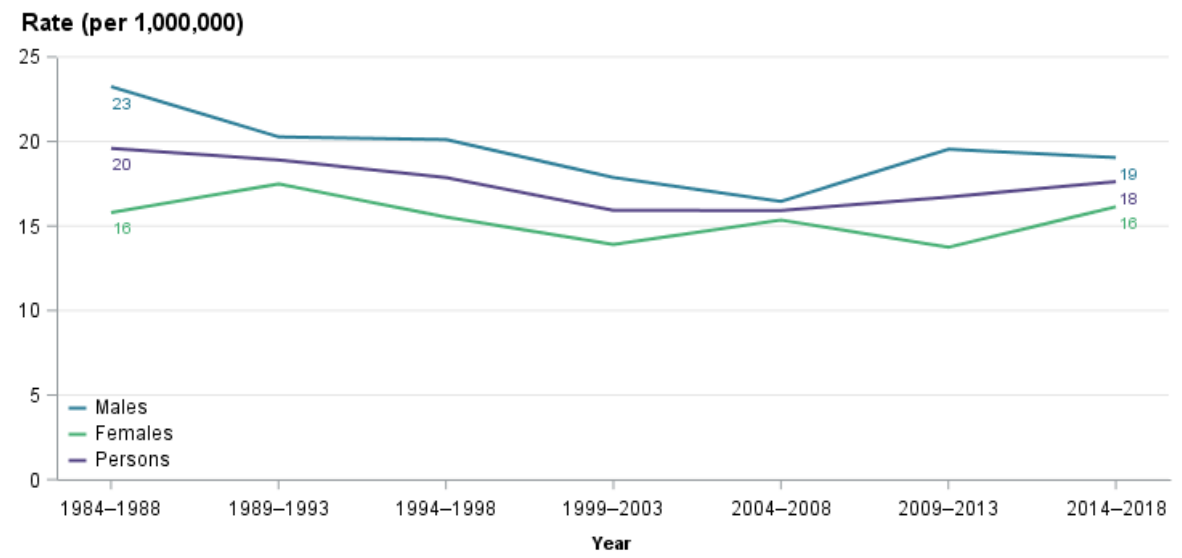
Detailed data is available in the online tables associated with this report.

Incidence

Rates of central nervous system cancers in people aged 15–24 have remained similar from 1984–1988 to 2014–2018 (Figure 2.12). However, while rates for males aged 15–24 have decreased slightly, rates for females aged 15–24 have remained similar. Males were responsible for over half (55%) of central nervous system cancer cases in 2014–2018.

Other astroglial neoplasms (43%) was the most common type of central nervous system cancer diagnosed in people aged 15–24 in 2014–2018, followed by glioblastomas (18%).

Figure 2.12: Incidence rate for central nervous system cancers, 15–24 years, by sex



Source: AIHW ACD 2018.

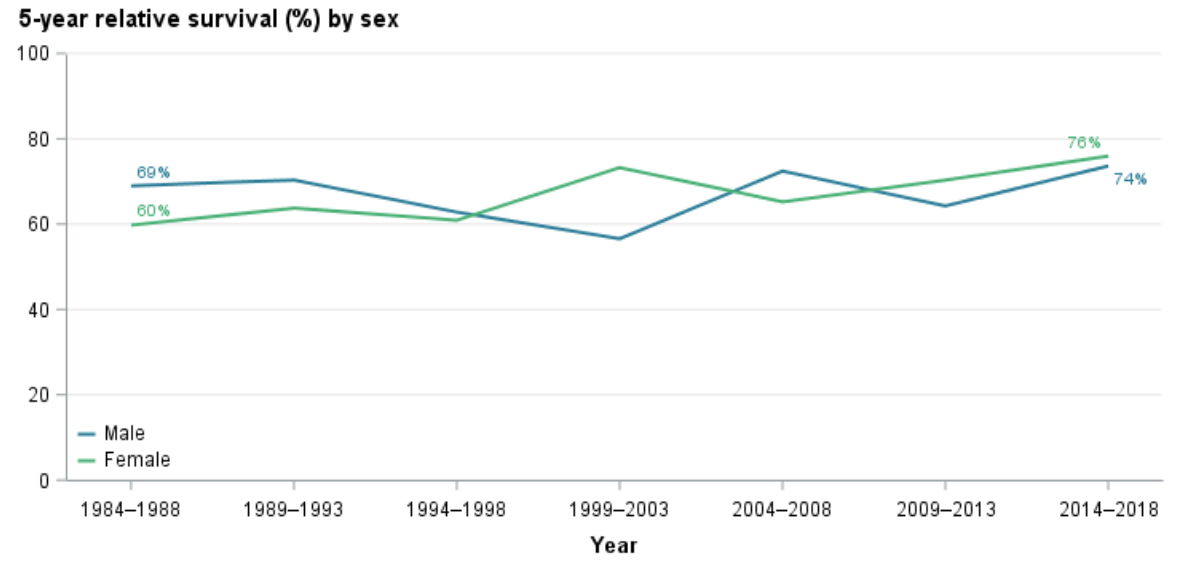
Survival

For people aged 15–24, 5-year relative survival for central nervous system cancers increased from 66% in 1984–1988 to 75% in 2014–2018.

Survival was not consistently higher in one sex than the other (Figure 2.13).

Five-year relative survival is reportable for 3 of the Tier 2 central nervous system cancers, being 68% for medulloblastomas and other embryonal central nervous system cancers, 81% for oligodendrogliomas, and 88% for other astroglial neoplasms in 2014–2018.

Figure 2.13: Five-year relative survival for central nervous system cancer, 15–24 years, by sex



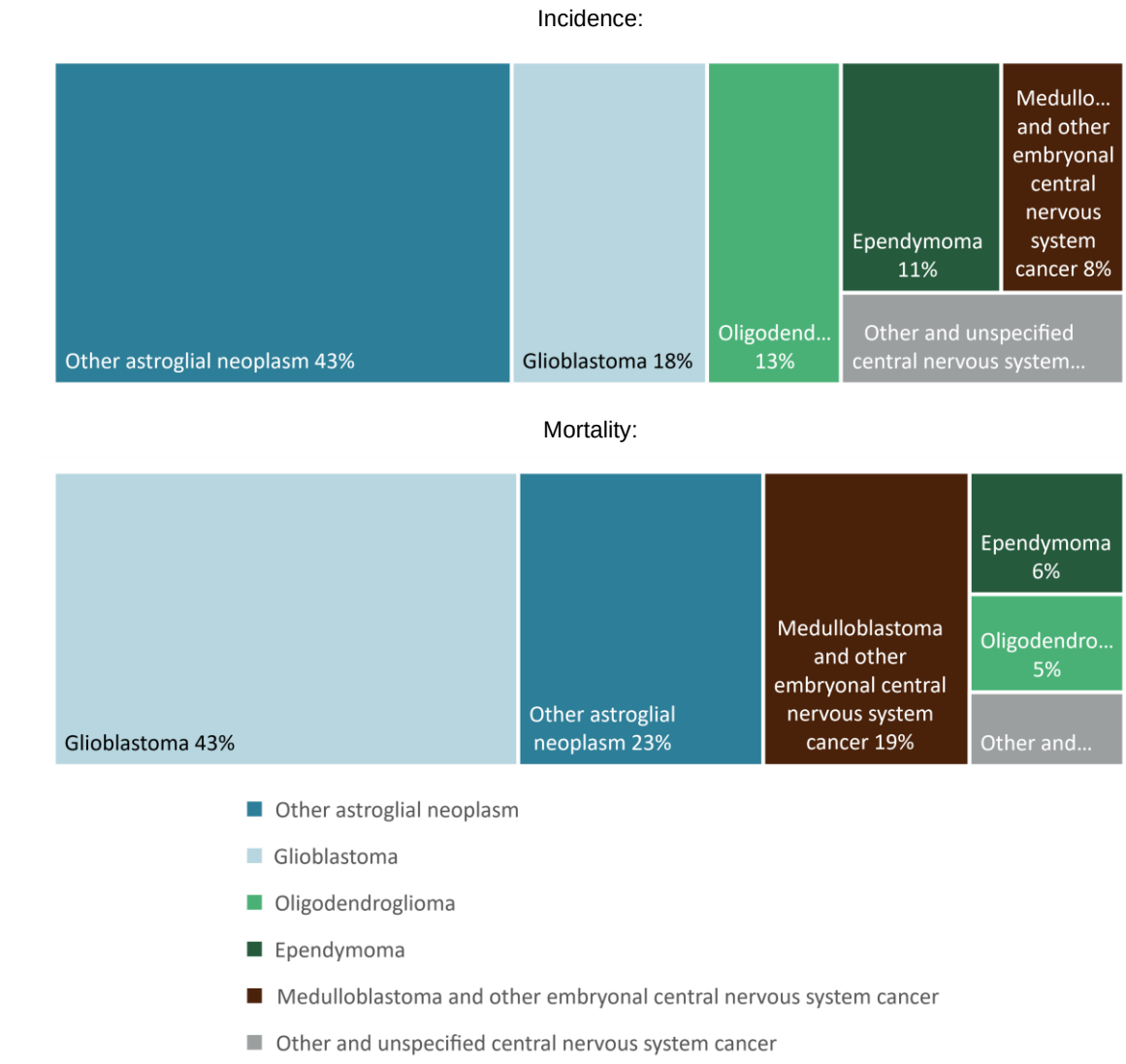
Source: AIHW ACD 2018.

Mortality

In 2013–2017, 83 people aged 15–24 died from central nervous system cancers. Nearly all of these deaths were from central nervous system cancers located in the brain (93%). Glioblastomas were responsible for most central nervous system cancer deaths (43%) followed by other astroglial neoplasms (23%) (Figure 2.14).

Males aged 15 to 24 years had a higher incidence rate of central nervous system cancers and accounted for 59% of central nervous system deaths.

Figure 2.14: Central nervous system cancer incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years



Source: AIHW ACD 2018.

More detail is available in the online tables.

2.4.3 Bone cancers

Bone cancers are a rare cancer that originate in the bone (Cancer Council Victoria 2021b). In 2014–2018 bone cancers comprised 0.2% and 4% of cancers diagnosed in the general population and in people aged 15–24, respectively.

Key findings:

- The incidence rate of bone cancers has been increasing in the general population but has remained stable in people aged 15–24.
- Bone cancers are more common in males than females across the general population and in people aged 15–24.
- Osteosarcoma was the most diagnosed cancer in 2014–2018 and responsible for half of the bone cancer deaths in people aged 15–24 in 2013–2017.
- Bone cancers are a low survival cancer with a 5-year relative survival rate of 65% for people aged 15–24 in 2014–2018.

Bone cancers discussed in this report:

- osteosarcomas
- chondrosarcomas
- Ewing family of bone sarcomas
- other specified bone cancers
- unspecified bone cancers.

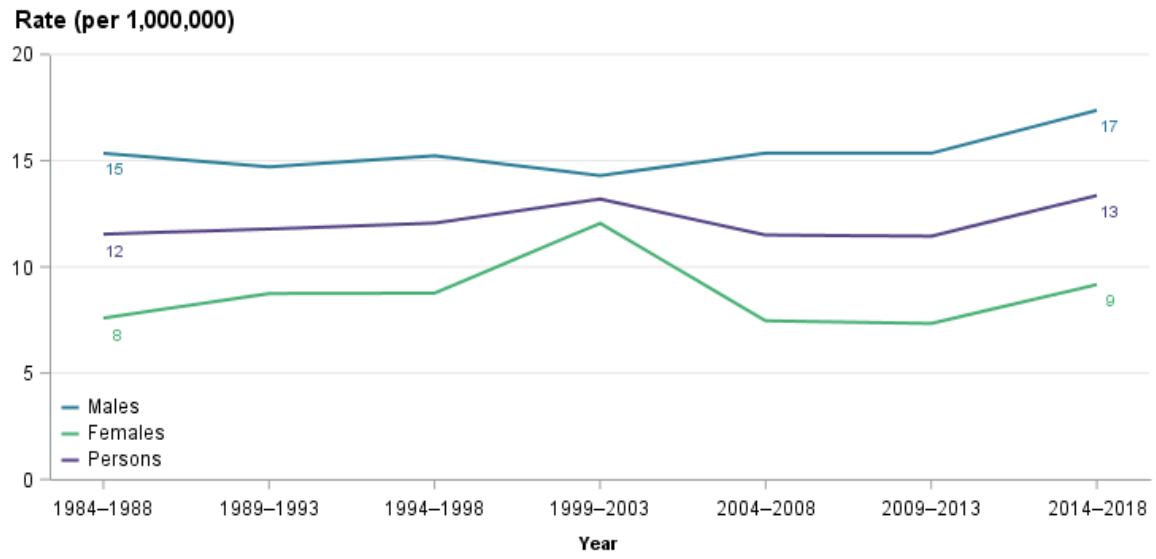
Detailed data is available in the online tables associated with this report.

Incidence

Incidence rates of bone cancer in people aged 15–24 from 1984–1988 to 2014–2018 have been fairly consistent (Figure 2.15). The most common types of bone cancer in this age group were osteosarcoma (51%) followed by Ewing tumour (27%) and chondrosarcoma (16%) in 2014–2018.

Males contributed around two-thirds of bone cancer cases (67%) in 2014–2018 and have had consistently higher rates than females (Figure 2.15).

Figure 2.15: Incidence rate for bone cancer,15–24 years, by sex



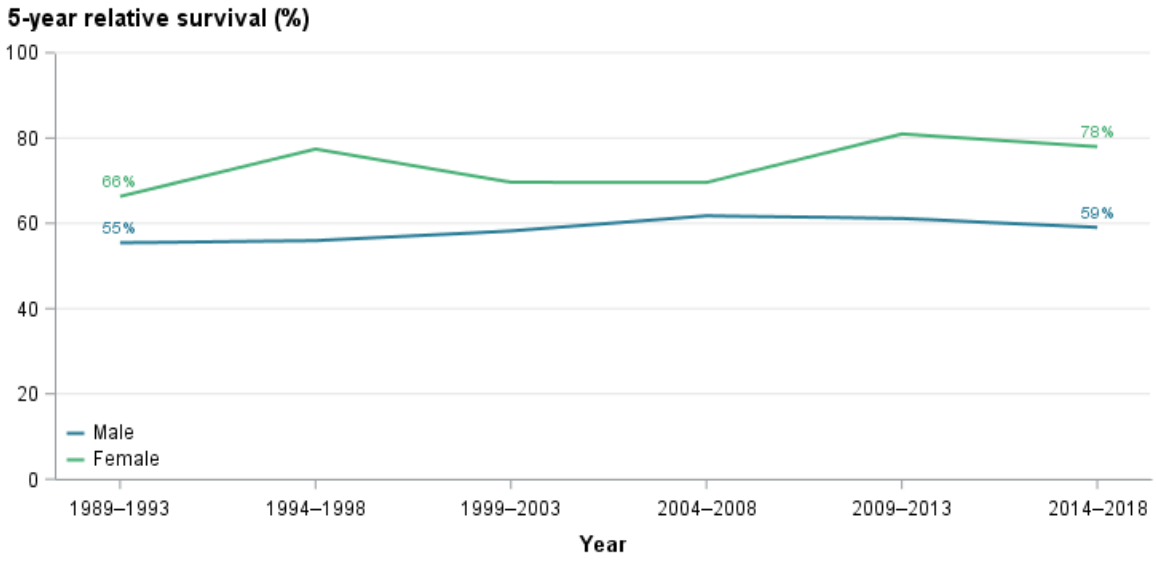
Source: AIHW ACD 2018.

Survival

Five-year relative survival for bone cancers has improved slightly from 57% in 1984–1988 to 65% in 2014–2018. Survival differs substantially for different types of bone cancers. Survival for the most common type of bone cancer, osteosarcoma, has improved over time (57% in 1984–1988 to 68% in 2014–2018).

Survival for females aged 15–24 has remained higher than survival for males aged 15–24 (Figure 2.16).

Figure 2.16: Five-year relative survival for bone cancer, 15–24 years, by sex

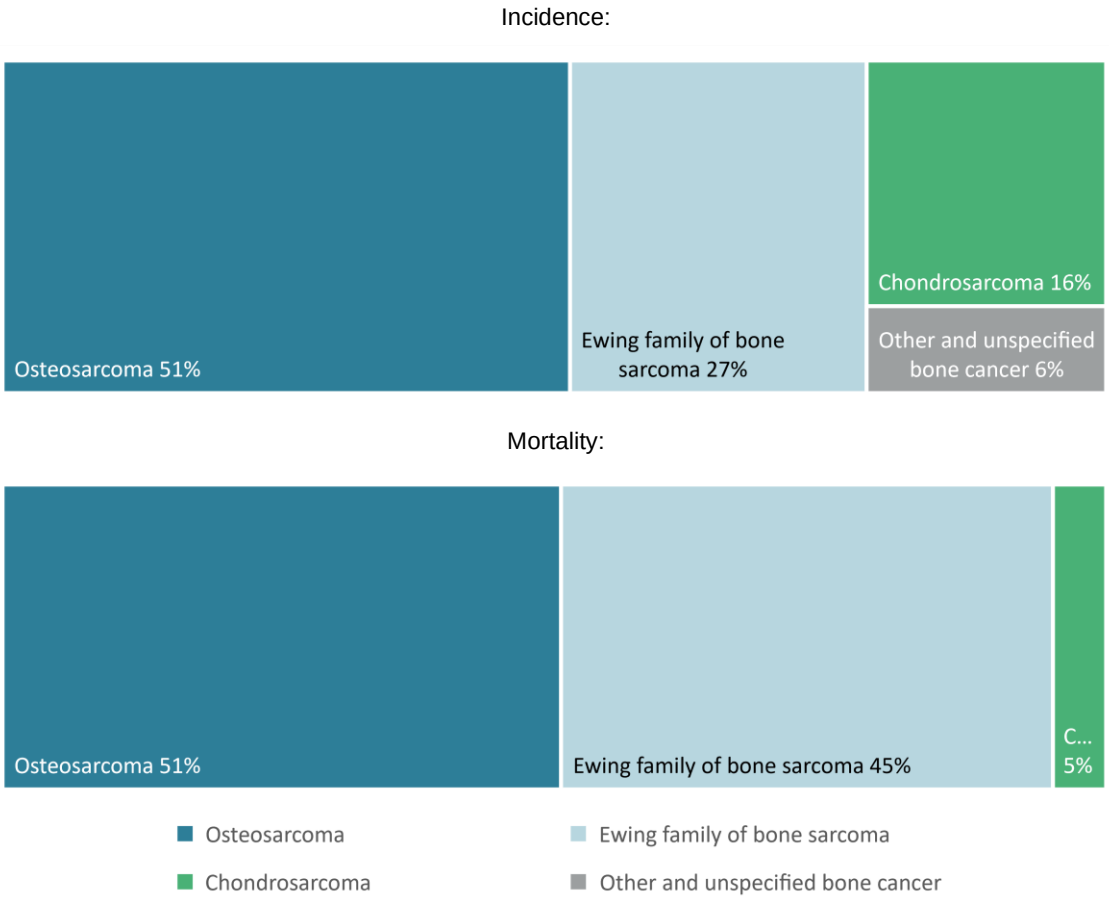


Source: AIHW ACD 2018.

Mortality

In 2013–2017, 83 people aged 15–24 died from bone cancer, with the majority (71%) of these being males. Of all deaths due to bone cancers, osteosarcomas resulted in the most deaths (51%), followed by Ewing family of bone sarcomas (45%) and chondrosarcomas (5%).

Figure 2.17: Bone cancer incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years



Source: AIHW ACD 2018.

More detail is available in the online tables.

2.5.4 Soft tissue sarcomas

Soft tissue sarcomas are rare cancers that develop in the soft tissue (Cancer Council Victoria 2021c). Soft tissue is the tissue that supports the body and organs. Muscles, tendons and fat are all examples of soft tissue. In 2014–2018 soft tissue sarcomas comprised 1% and 5% of cancers diagnosed in the general population and in people aged 15–24, respectively.

Key messages:

- Incidence of soft tissue sarcomas has remained fairly stable in people aged 15–24 since 1994–1998.
- Males have had higher incidence of soft tissue sarcomas than females since 1984–1988.
- Soft tissue sarcomas are a low survival cancer. Five-year relative survival in people aged 15–24 in 2014–2018 was 75%.
- Rhabdomyosarcomas were the most common type of soft tissue sarcoma in people aged 15–24 in 2014–2018, and were responsible for the most soft tissue sarcoma deaths in this age group in 2013–2017.

Soft tissue sarcomas discussed in this report:

- fibromatous sarcomas
- liposarcomas
- rhabdomyosarcomas
- synovial sarcomas
- Ewing family of soft tissue sarcomas
- nerve sheath tumours
- other specified soft tissue sarcomas
- unspecified soft tissue sarcomas.

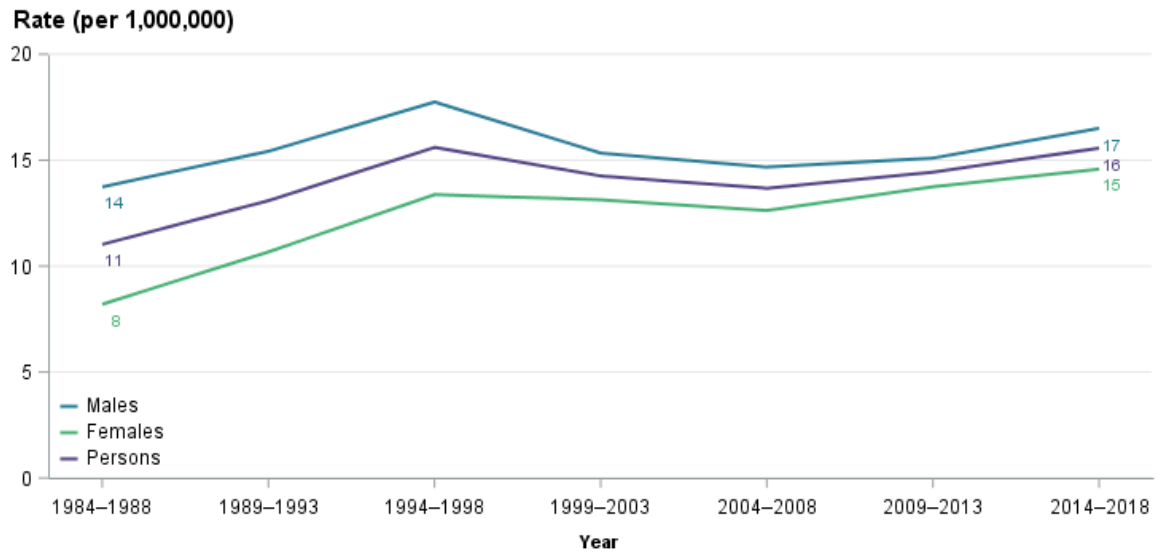
Detailed data is available in the online tables associated with this report.

Incidence

In 2014–2018, incidence rates of soft tissue sarcomas were higher than they were in 1984–1988, but have remained relatively stable since 1994–1998 (Figure 2.18). Rhabdomyosarcomas were the most common type of soft tissue sarcoma in people aged 15–24, accounting for 20% of soft tissue sarcomas in 2014–2018.

Males aged 15–24 have had higher incidence than females since 1984–1988, however, the difference in incidence rates between males and females has become smaller over time (Figure 2.18).

Figure 2.18: Incidence rate for soft tissue sarcoma, 15–24 years, by sex



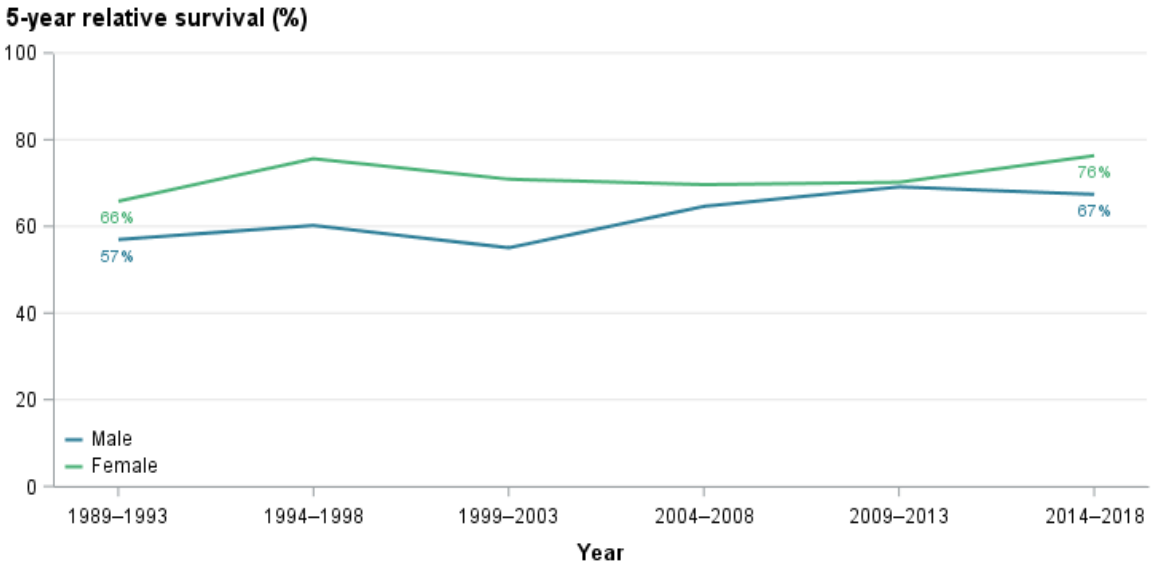
Source: AIHW ACD 2018.

Survival

Five-year relative survival for soft tissue sarcomas in people aged 15–24 has improved from 57% in 1984–1988 to 71% in 2014–2018. Five-year relative survival for rhabdomyosarcomas was 52% in 2014–2018.

Survival for both males and females aged 15–24 has increased from 1989–1993 to 2014–2018 (Figure 2.19).

Figure 2.19: Five-year relative survival for soft tissue sarcoma, 15–24 years, by sex



Source: AIHW ACD 2018.

Mortality

In 2013–2017 there were 73 deaths of people aged 15–24 from soft tissue sarcomas. Males accounted for 64% of these deaths. Rhabdomyosarcomas accounted for around one-quarter of soft tissue sarcoma deaths while synovial sarcomas accounted for 16% (Figure 2.20).

Figure 2.20: Soft tissue sarcoma incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years

Source: AIHW ACD 2018.

More detail is available in the online tables.

2.4.5 Germ cell and trophoblastic cancers

Germ cell cancers are cancers that develop in germ cells. Germ cells are the body's reproductive cells (sperm and eggs) (NCI n.d.). As such, germ cell cancers are most commonly located in testicles or ovaries since this is where most germ cells are located (Cancer Research UK 2022). However, germ cells can occur in other locations including the brain, the spine and the chest. Germ cell cancers usually occur during puberty and are most common in people aged 15–19 (Cleveland Clinic 2022).

Trophoblastic cancers are very rare and occur when tumours develop in the uterus during pregnancy (Cancer Research UK 2019). However, these cancers are distinct from uterine and endometrial cancers. Trophoblastic cancers have an extremely high survival rate.

In 2014–2018 germ cell and trophoblastic cancers comprised 0.7% and 14% of cancers diagnosed in the general population and in people aged 15–24, respectively.

Key findings:

- Since 1989–1993 the incidence rate of germ cell and trophoblastic cancers has increased in people aged 15–24.
- Incidence rates are significantly higher for males aged 15–24 than for females of the same age.
- Testicular germ cell cancers accounted for 81% of germ cell and trophoblastic cancer cases in people aged 15–24 in 2014–2018.
- Five-year relative survival for people aged 15–24 was 96% in 2014–2018.
- The majority of the 23 germ cell and trophoblastic cancer deaths in this age group in 2013–2017 were in males and about half the deaths were due to testicular germ cell cancer.

Germ cell and trophoblastic cancers discussed in this report:

- testicular germ cell cancer
- ovarian germ cell cancer
- central nervous system germ cell cancer
- mediastinal germ cell cancer
- germ cell cancer of other and unspecified sites.

Detailed data is available in the online tables associated with this report.

Box 2.3: Definitions

This chapter does not describe cancers by site (for example, testicular cancer and ovarian cancer). This chapter discusses cancers according to histology (the tumour's appearance) rather than location.

Testicular cancer

Testicular cancer can be a variety of cancer types. This includes germ cell cancers, carcinomas and soft tissue sarcomas. However, in people aged 15–24, nearly all testicular cancers are germ cell cancers (99% in 2014–2018).

Ovarian cancer

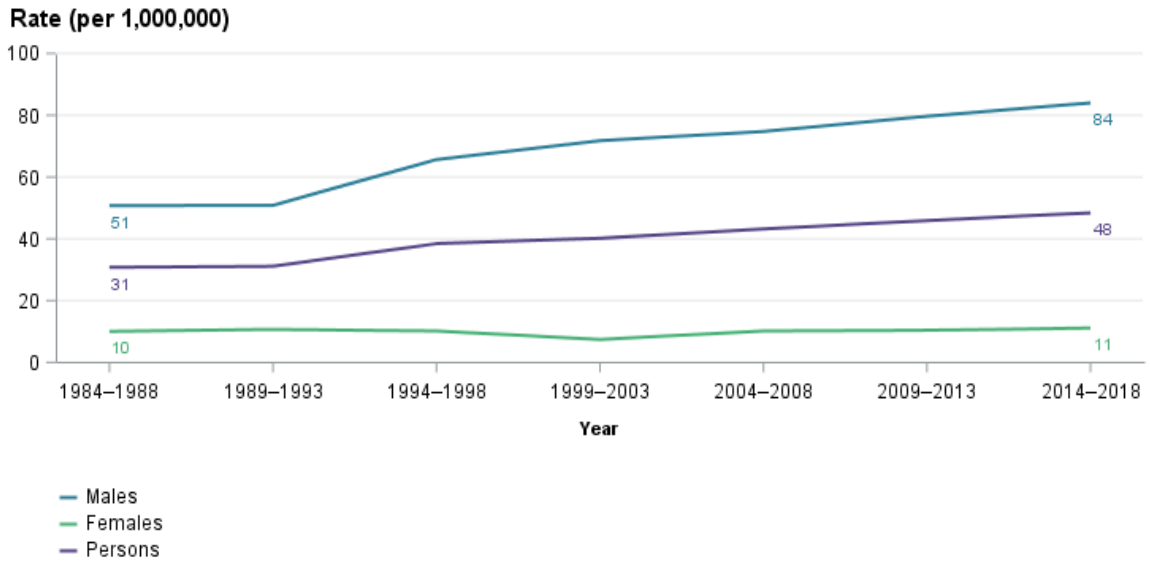
Ovarian cancer can be a variety of cancer types. This includes germ cell cancers, carcinomas and soft tissue sarcomas. In the people aged 15–24, the majority of ovarian cancers are germ cell cancers (57% in 2014–2018) or carcinomas (28% in 2014–2018).

Incidence

The incidence of germ cell and trophoblastic cancers has increased considerably in people aged 15–24 since 1989–1993 (Figure 2.21).

Testicular germ cell cancers were the third most common type of cancer in people aged 15–24 in 2014–2018 accounting for 12% of all cancers diagnosed in this age group. It was also the most common germ cell and trophoblastic cancer in people aged 15–24 across all time periods (81% in 2014–2018). As such, germ cell and trophoblastic cancers occurred mainly in males (89% in 2014–2018) with the incidence difference between males and females increasing over time (Figure 2.21).

Figure 2.21: Incidence rates for germ cell and trophoblastic cancer, 15–24 years, by sex

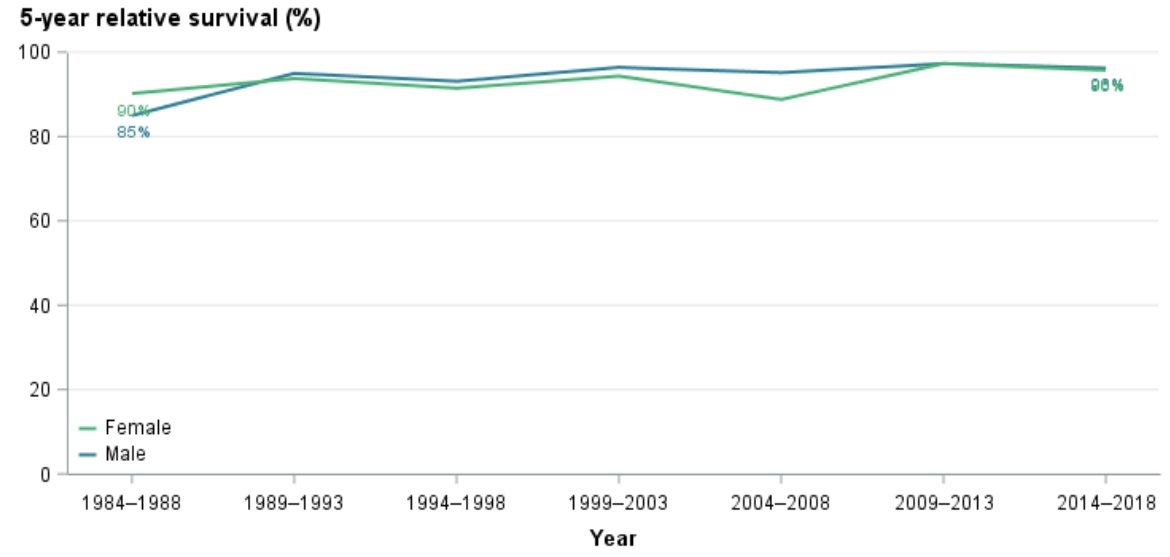


Source: AIHW ACD 2018.

Survival

Five-year relative survival in people aged 15–24 has increased from 86% in 1984–1988 to 96% in 2014–2018. Survival was similar for males and females in 2014–2018 (Figure 2.22). In 2014–2018, testicular germ cell cancer and ovarian germ cell cancer had high 5-year relative survival of 98% and 96%, respectively.

Figure 2.22: Five-year relative survival for germ cell and trophoblastic cancer, 15–24 years, by sex

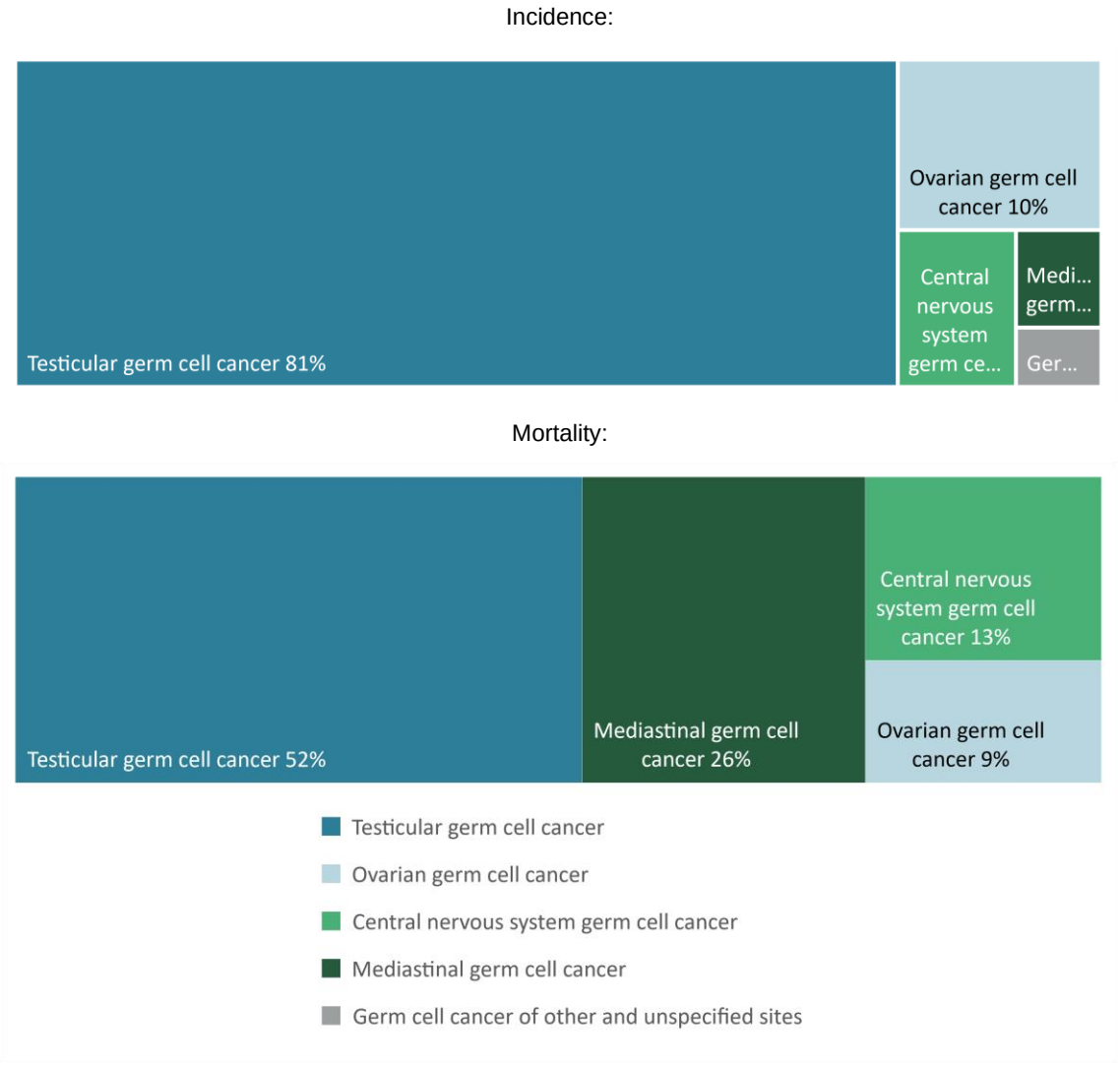


Source: AIHW ACD 2018.

Mortality

In 2013–2017, there were 23 deaths of people aged 15–24 from germ cell and trophoblastic cancers. Of these deaths, 52% were from testicular germ cell cancer followed by 26% from mediastinal germ cell cancer (Figure 2.23). Of the germ cell and trophoblastic cancer deaths in people aged 15–24, 91% were of males.

Figure 2.23: Germ cell and trophoblastic cancer incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years



Source: AIHW ACD 2018.

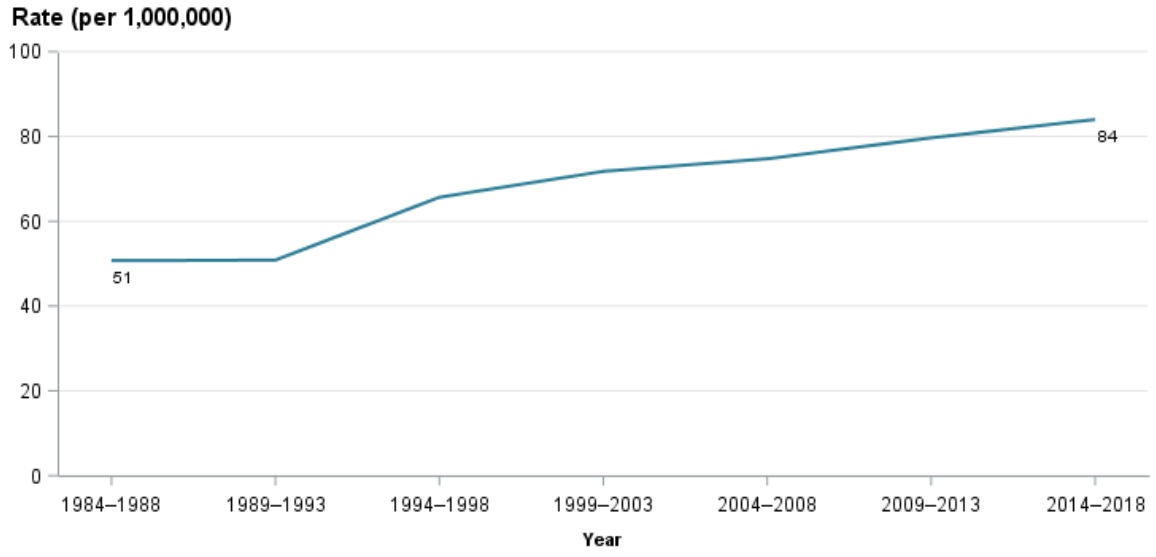
2.4.5.1 Germ cell and trophoblastic cancer in males

Incidence

Germ cell and trophoblastic cancer incidence in males aged 15–24 increased substantially between 1984–1988 and 2014–2018 (Figure 2.24). In 2014–2018, the majority of these cases were testicular germ cell cancers (92%), with testicular germ cell cancer being the most diagnosed cancer for males aged 15–24.

Increases in incidence rates for testicular germ cell cancers among males aged 15–24 have been observed internationally (Barr et al. 2016). While the reasons for increased testicular germ cell cancers in males aged 15–24 are not well understood, some of the known risk factors include family history and cryptorchidism (an undescended testicle). Some other possible risk factors are genetics, low birth-weight, early puberty (Baroni et al. 2019) and elevated androgens (including testosterone) at birth (Morimoto et al. 2018).

Figure 2.24: Incidence rates for germ cell and trophoblastic cancer, males 15–24 years

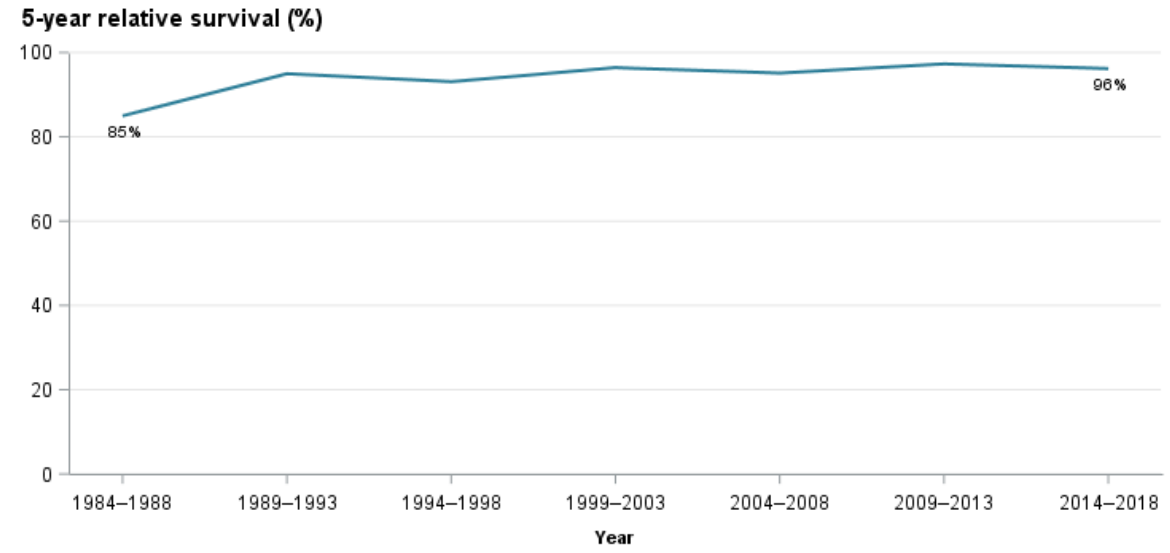


Source: AIHW ACD 2018.

Survival

Five-year relative survival for males aged 15–24 has increased from 85% in 1984–1988 to 96% in 2014–2018 (Figure 2.25).

Figure 2.25: Five-year relative survival for germ cell and trophoblastic cancer, males 15–24 years



Source: AIHW ACD 2018.

Mortality

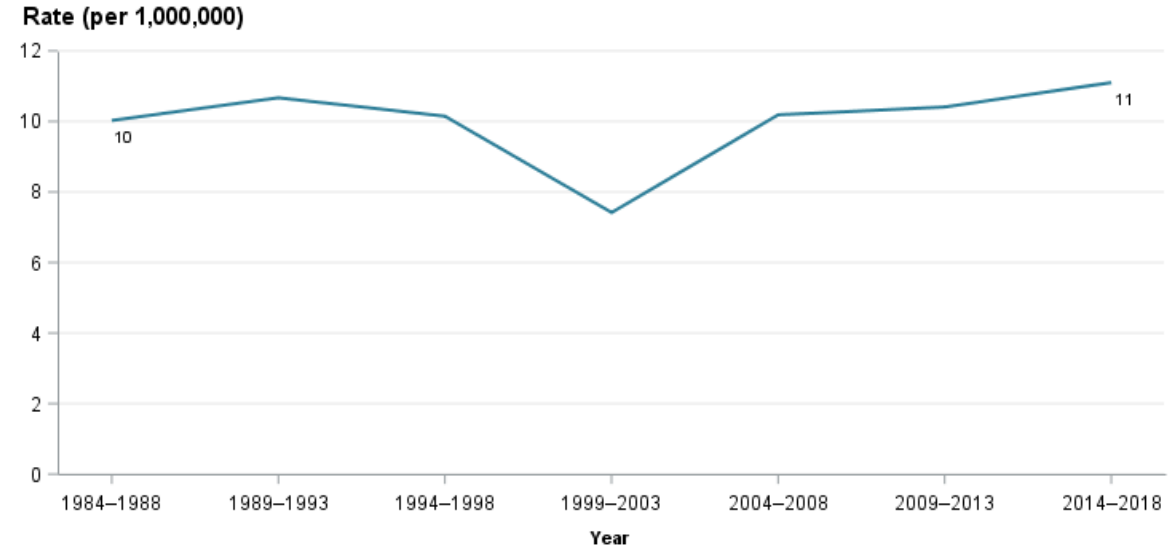
Germ cell and trophoblastic cancers caused around 20 deaths in males aged 15–24 in 2013–2017. While testicular germ cell cancer accounted for 92% of diagnosed germ cell and trophoblastic cancers, it was responsible for 57% of deaths caused by germ cell and trophoblastic cancers in males aged 15–24.

2.4.5.2 Germ cell and trophoblastic cancer in females

Incidence

Incidence of germ cell and trophoblastic cancers has remained consistent for females aged 15–24 from 1984–1988 to 2014–2018 after a dip in 1999–2003 (Figure 2.26). In 2014–2018, most of these cases were ovarian germ cell cancers (87%). Ovarian germ cell cancer was the seventh most diagnosed cancer for females aged 15–24 (75 cases) in this period.

Figure 2.26: Incidence rates for germ cell and trophoblastic cancer, females 15–24 years

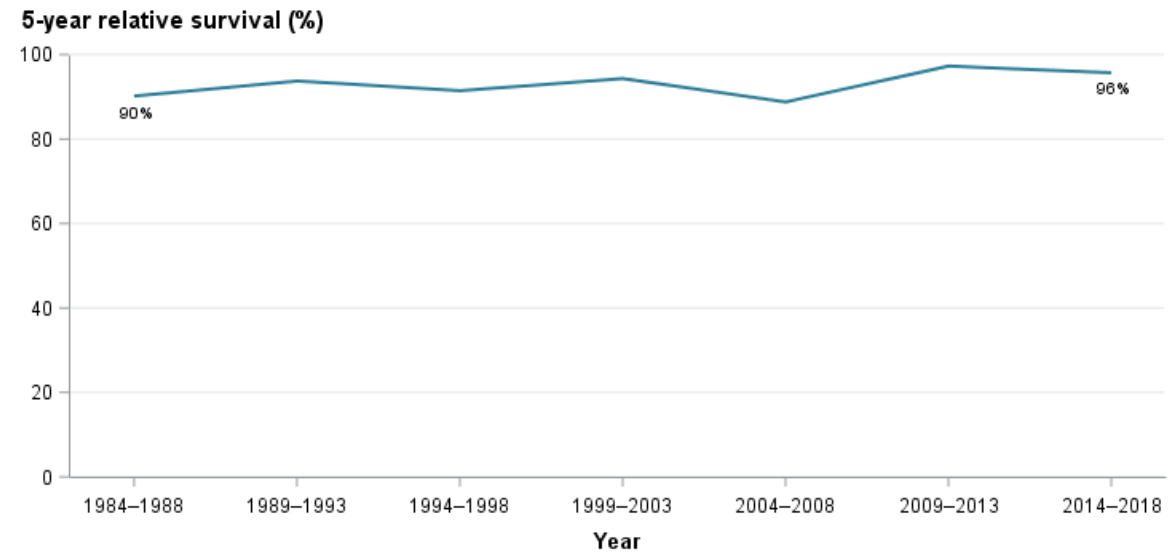


Source: AIHW ACD 2018.

Survival

Survival for females aged 15–24 has stayed consistent between 90% in 1984–1988 and 96% in 2014–2018 (Figure 2.27).

Figure 2.27: Five-year relative survival for germ cell and trophoblastic cancer, females 15–24 years



Source: AIHW ACD 2018.

Mortality

Germ cell and trophoblastic cancers caused few deaths in females aged 15–24, with 2 deaths in the period 2013–2017, both of which were ovarian germ cell cancer.

More detail is available in the online tables.

2.4.6 Melanomas

Melanoma is a type of cancer that forms in cells in the skin called melanocytes (Skin Cancer Foundation 2022). It is a common type of cancer that usually develops on the areas of the body exposed to sun (Cancer Council n.d.a). In 2014–2018 melanomas comprised 11% and 13% of cancers in the general population and in people aged 15–24, respectively.

Key findings:

- Since peaking in 1994–1998, melanoma incidence rates in people aged 15–24 have significantly decreased from 106 to 43 cases per 1,000,000 people in 2014–2018.
- In 2014–2018, 97% of melanomas in people aged 15–24 were melanomas of the skin.
- Melanomas of the skin were the second most common cancer diagnosed in people aged 15–24 in 2014–2018.
- Incidence rates of melanoma in this age group are consistently higher for females than males.
- Melanoma has a high survival rate. Five-year relative survival for people aged 15–24 in 2014–2018 was 97%.
- While the incidence rate of melanoma was higher in females, mortality was higher in males.

Melanomas discussed in this report:

- melanoma of skin
- melanoma of other and unspecified sites.

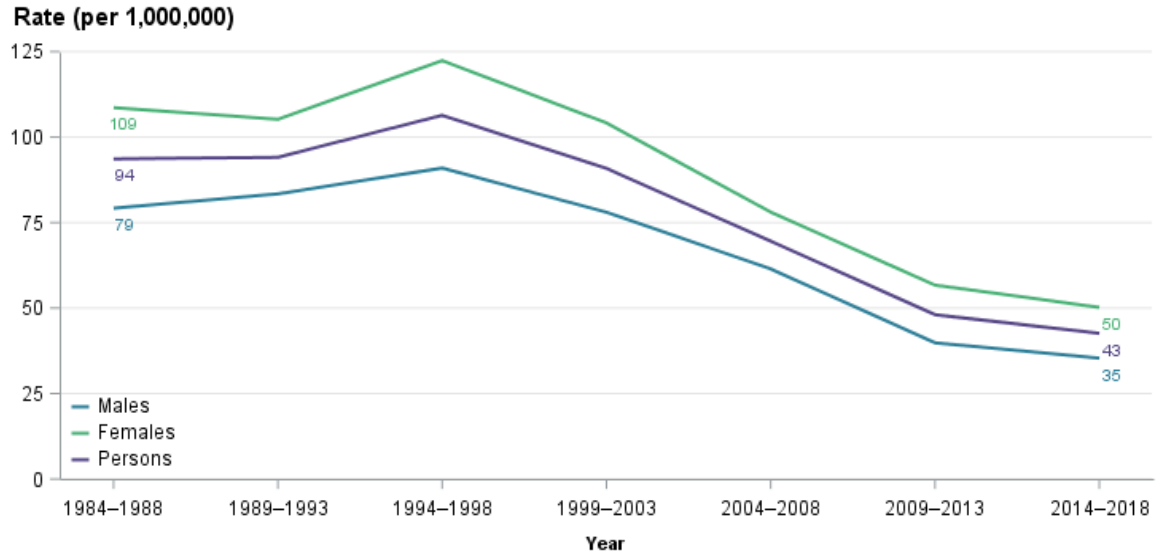
Detailed data is available in the online tables associated with this report.

Incidence

After a peak in 1994–1998, the incidence of melanoma in people aged 15–24 decreased strongly from 106 to 43 cases per 1,000,000 people in 1994–1998 and 2014–2018 respectively (Figure 2.28). Primary prevention campaigns about sun safety behaviours (for example, SunSmart media campaign) are likely responsible for the decrease in melanoma incidence rates in Australia since the mid-1990s (Iannacone et al. 2015). Despite this decrease, melanoma was still the second most common type of cancer diagnosed in people aged 15–24 in 2014–2018.

In 2014–2018 melanomas in this age group were predominantly melanomas of the skin (97%). Incidence rates of melanoma in this age group have been consistently higher for females than for males (Figure 2.28). In 2014–2018, females contributed over half (58%) of melanoma cases.

Figure 2.28: Incidence rates for melanoma, 15–24 years, by sex

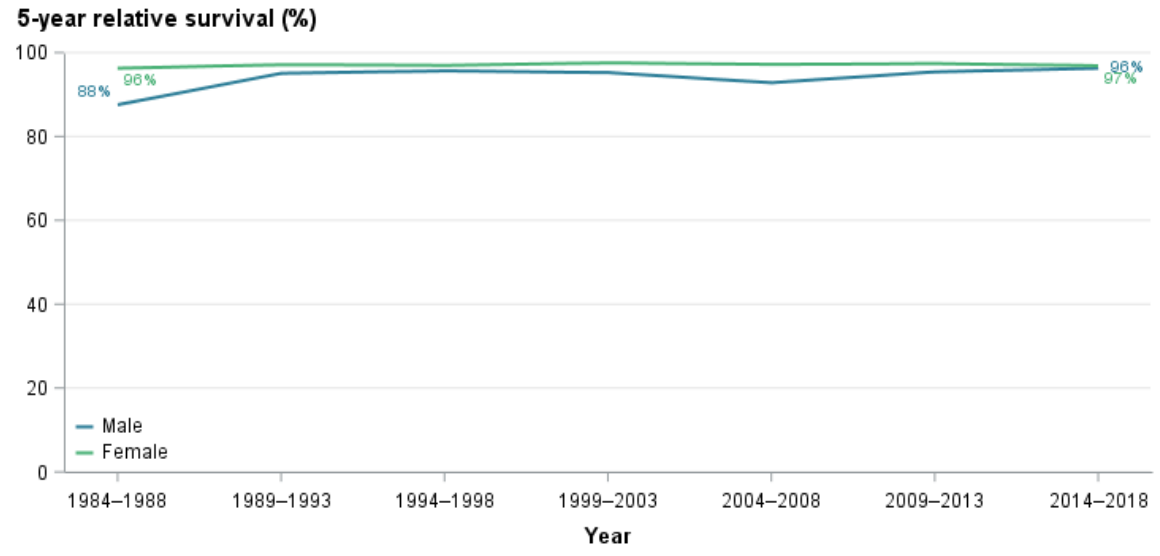


Source: AIHW ACD 2018.

Survival

Survival for melanoma is high. The 5-year relative survival for people aged 15–24 increased from 93% in 1984–1988 to 97% in 2014–2018. In this age group, females had higher survival than males in 1984–1988, but male survival has improved and is now similar to female survival (Figure 2.29).

Figure 2.29: Five-year relative survival for melanoma, 15–24 years, by sex



Source: AIHW ACD 2018.

Mortality

In the period 2013–2017, there were 13 deaths of people aged 15–24 due to melanomas. Nearly all deaths were due to melanoma of the skin and over 60% were of males.

2.4.7 Carcinomas

Carcinomas are a common type of cancer. These cancers form in cells in epithelial tissues. Epithelial tissue includes skin, the lining of the body's organs and cavities (Cancer Research UK 2020).

In 2014–2018, carcinomas comprised 70% and 30% of cancer cases in the general population and in people aged 15–24, respectively.

Key findings:

- Incidence rate for carcinomas in people aged 15–24 has almost doubled between 1984–1988 and 2014–2018.
- The most common types of carcinomas in people aged 15–24 in 2014–2018 were thyroid carcinoma and colorectal carcinoma.
- Females have had consistently higher incidence rates of carcinoma than males.
- In 2014–2018, 5-year relative survival for carcinomas in people aged 15–24 was 93%.
- In 2013–2017, females accounted for two-thirds of carcinoma deaths in this age group.

Carcinomas discussed in this report:

- carcinomas of tongue
- carcinomas of major salivary glands
- carcinomas of other and unspecified sites in head and neck
- carcinomas of stomach
- carcinomas of colon and rectum
- carcinomas of liver and intrahepatic bile ducts
- carcinomas of pancreas
- carcinomas of other and unspecified sites in gastrointestinal tract
- carcinomas of lung, bronchus and trachea
- carcinomas of breast
- carcinomas of cervix
- carcinomas of ovary
- carcinomas of kidney
- carcinomas of thyroid
- carcinomas of other and unspecified sites.

Carcinomas of colon and rectum as well as carcinomas of pancreas will be discussed in more detail in this section. Colorectal carcinomas are discussed in more depth to investigate the difference in trajectory depending on whether the tumours are neuroendocrine (see Box 2.4 for definition of neuroendocrine). Pancreatic carcinomas are discussed in more depth as the increase seen recently is concerning given the low survival this cancer has in the general population.

Detailed data is available in the online tables associated with this report.

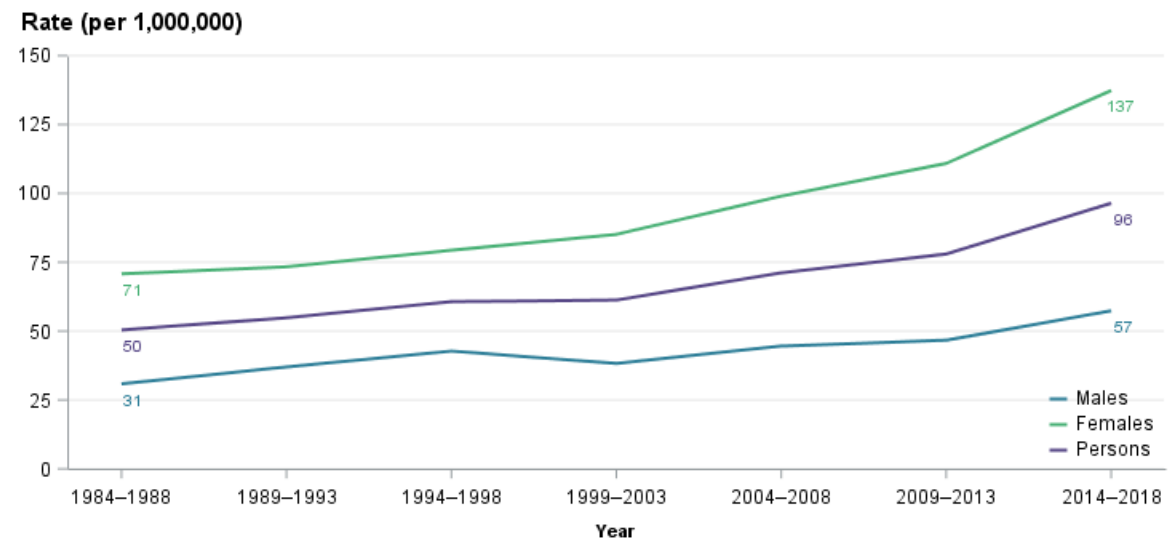
Box 2.4: Neuroendocrine neoplasms (NENs)

Neuroendocrine neoplasms develop in the neuroendocrine cells of the neuroendocrine system. The neuroendocrine system is comprised of nerves and glands which produce hormones. Neuroendocrine cells can be found in most organs but are primarily in the gastro-intestinal tract, pancreas and lungs (Cancer Council Victoria 2021d). NENs usually develop over a long time period. (Cancer Research UK 2021). NENs are rare in the general population, accounting for 3% of all cancers in 2014–2018. NENs are more common in people aged 15–24, comprising 10% of all cancers in 2014–2018. Furthermore, most NENs in people aged 15–24 and in the general population are carcinomas (97% and 99%, respectively).

Incidence

The incidence of carcinomas in people aged 15–24 has almost doubled between 1984–1988 and 2014–2018 (Figure 2.30).

Figure 2.30: Incidence rates for carcinomas, 15–24 years, by sex



Source: AIHW ACD 2018.

Thyroid carcinoma was the most common type of carcinoma diagnosed in people aged 15–24 accounting for 36% of carcinomas in 2014–2018. Thyroid carcinoma increased from 13 to 35 cases per 1,000,000 between 1984–1988 and 2014–2018. Increased incidence rates of thyroid carcinoma in people aged 15–24 may, in part, be explained by improved diagnostic tools (Barr et al. 2016; Vergamini et al. 2014).

Colorectal carcinomas were the second most common type of carcinoma diagnosed in people aged 15–24 in 2014–2018, accounting for 34% of carcinomas. Incidence rates in this age group increased from 9 to 33 cases per 1,000,000 between 1984–1988 and 2014–2018. Increases in incidence rates for colorectal carcinoma among people aged 15–24 have been observed internationally (Barr et al. 2016).

The incidence of carcinomas of other and unspecified sites in the head and neck decreased from 8 to 2 cases per 1,000,000 between 1994–1998 and 2014–2018.

Cervical carcinoma incidence rates for people aged 15–24 decreased from 6 to 3 cases per 1,000,000 between 1984–1988 and 2014–2018. This decrease is likely partly due to the HPV vaccine program that began in 2007 for children aged around 12–13 years old (HPV Vaccine n.d.a). The HPV vaccine has been proven to help prevent cervical cancer (Cancer Australia 2022). From 2007 to 2017 a 70% and 50% decrease of high-grade cervical abnormalities occurred in women younger than 20 and women aged 20–24, respectively (HPV Vaccine n.d.b).

This decrease may be partly due to early detection through the National Cancer Screening Program that commenced in 1991 (Brotherton et al. 2011). However, the effect is likely limited in people aged 15–24. The screening program was available to 18–70 year olds from the program's initiation until 2017 when the eligibility criteria changed to 25–74 year olds (Cancer Council n.d.b). While data is limited, there is reasonable evidence suggesting that Aboriginal and Torres Strait Islander women participate less in the National Cancer Screening Program. This likely is part of the cause for higher incidence rates of cervical cancer in Indigenous Australians (AIHW 2021b).

Carcinoma incidence in people aged 15–24 was higher for females than males (Figure 2.30), with females contributing more than two-thirds of cases (70%) in 2014–2018. In 2014–2018, thyroid carcinoma was the most common type of carcinoma in females (42% of all carcinoma cases) and colorectal carcinoma was the most common type of carcinoma in males (43% of all carcinoma cases).

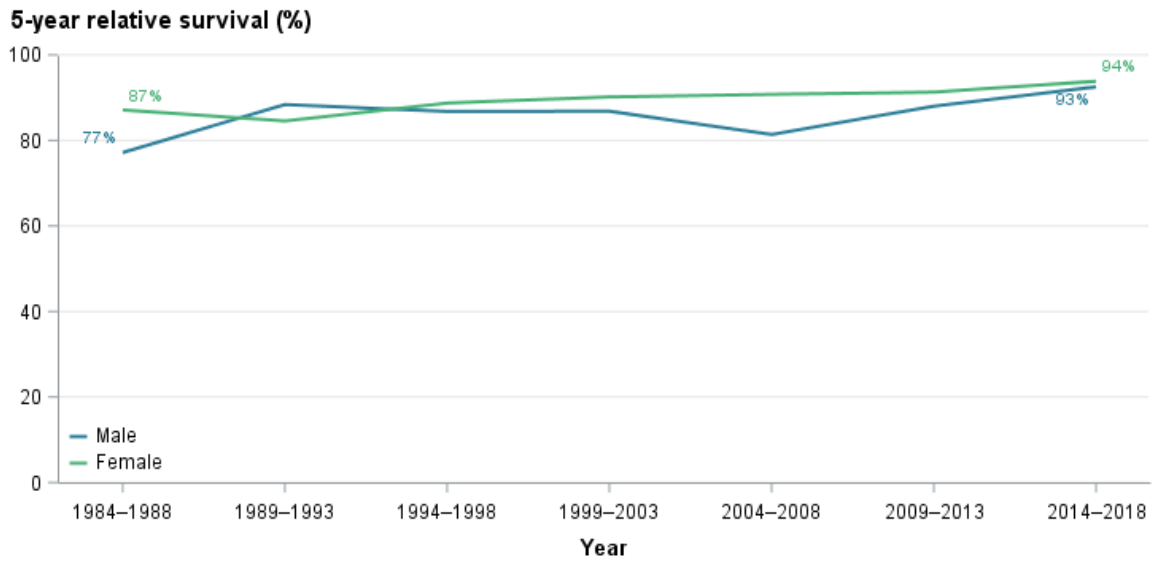
Survival

For people aged 15–24, 5-year relative survival for carcinoma increased from 84% in 1984–1988 to 93% in 2014–2018.

Survival rates for carcinoma were similar for males and females aged 15–24 except in 1984–1988 and 2004–2008 when survival was noticeably higher for females (Figure 2.31).

Of all the carcinomas described for people aged 15–24, carcinoma of the ovary had the lowest 5-year relative survival (78%) in 2014–2018. Survival for other and unspecified carcinomas was 80%, survival for carcinoma of the breast was 89%, with all other carcinomas having 5-year relative survival greater than 90% (including kidney carcinoma for which survival was 100%).

Figure 2.31: Five-year relative survival for carcinoma, 15–24 years, by sex



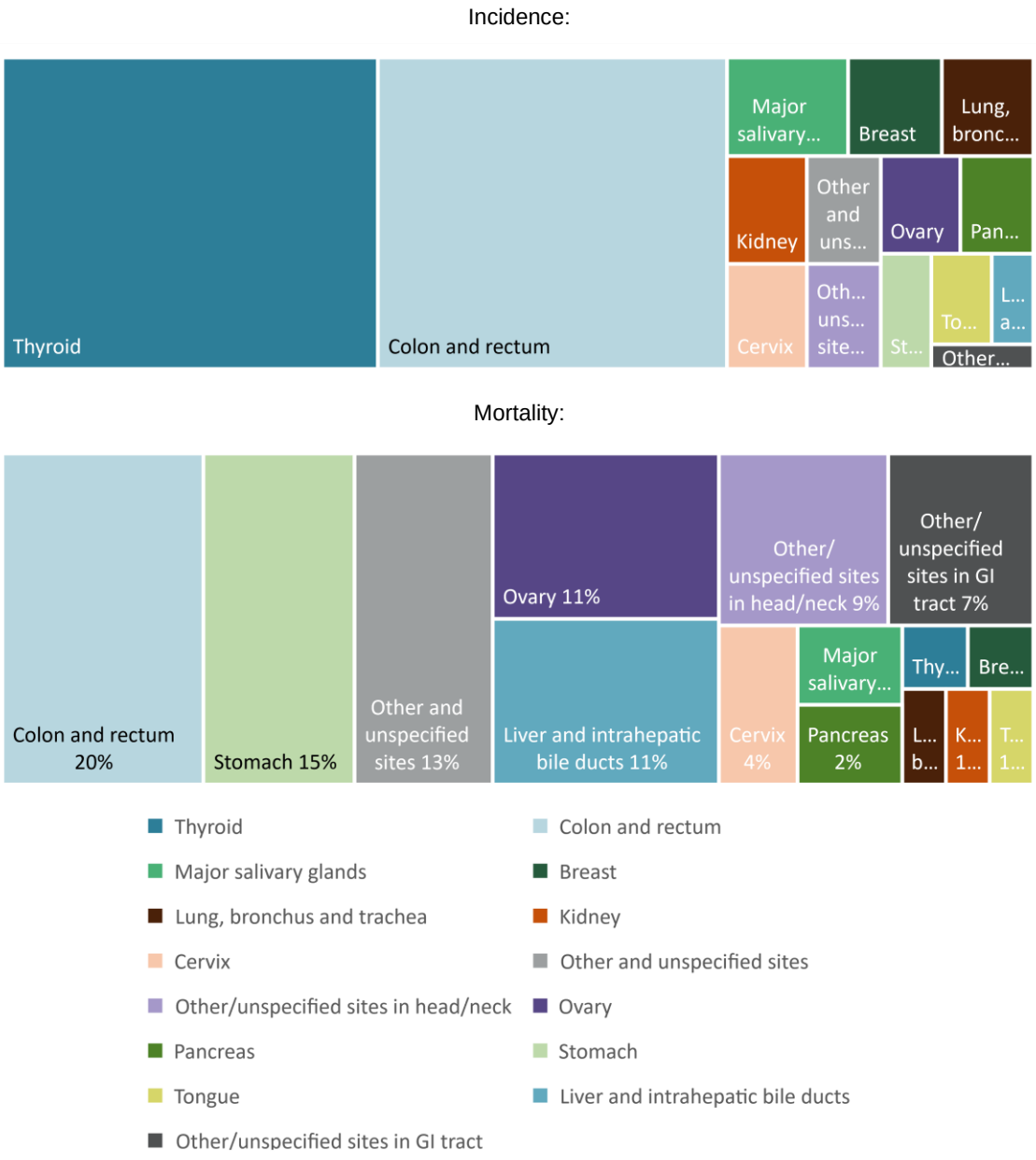
Source: AIHW ACD 2018.

Mortality

In the period 2013–2017, there were 82 deaths of people aged 15–24 due to carcinoma. Carcinomas of the colon and rectum were the most common type of carcinoma death (20%), followed by carcinoma of the stomach (15%) (Figure 2.32).

Females accounted for two-thirds of carcinoma deaths in people aged 15–24. Of all carcinoma-related deaths, ovarian carcinomas were the most common cause for females (16%), while carcinomas of the colon and rectum were the most common cause for males (33%).

Figure 2.32: Carcinoma incidence (2014–2018) and mortality (2013–2017) by type, 15–24 years



Source: AIHW ACD 2018.

Incidence, survival and mortality for specific carcinoma groups

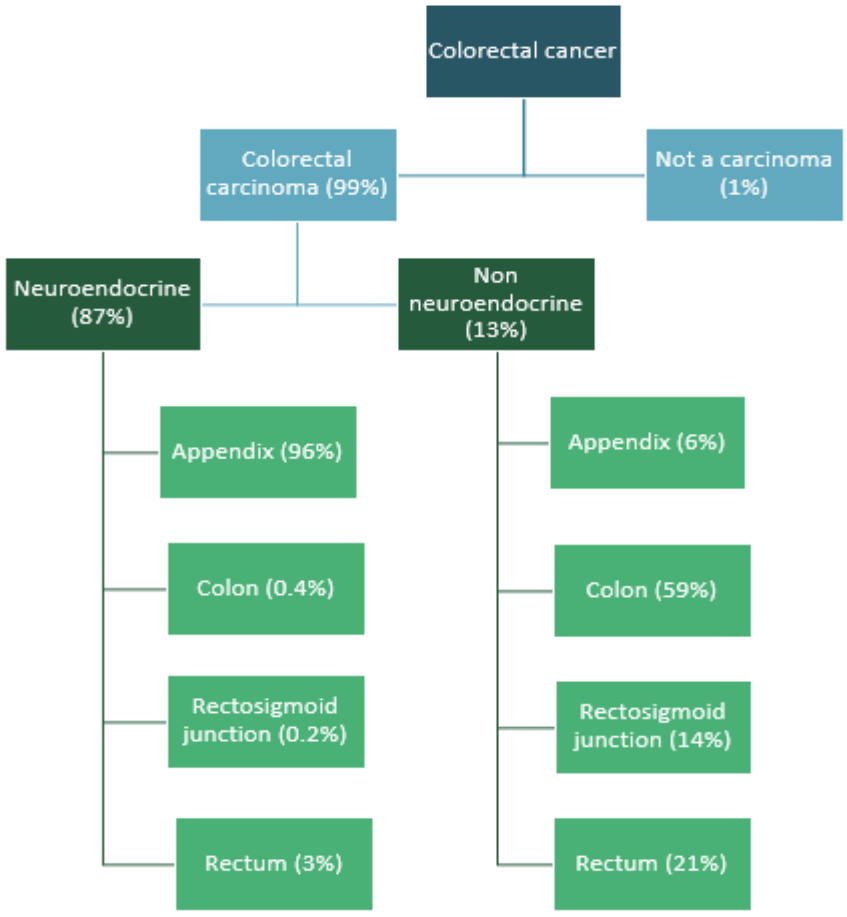
This section will discuss colorectal and pancreatic carcinomas in more detail. Colorectal carcinomas are discussed in more depth to investigate the difference in trajectory depending on whether the tumours are neuroendocrine (see Box 2.4 for definition of neuroendocrine). Pancreatic carcinomas are discussed in more depth as the increase seen recently is concerning given the low survival this cancer has in the general population.

Carcinomas of the colon and rectum

Key findings:

- Almost all colorectal cancers in the 15–24 age group are carcinomas (Figure 2.33).
- Carcinomas of the colon and rectum are becoming more common in young people, including in children, in adolescents and young adults, and in older young adults.
- Carcinomas of the colon and rectum in people aged 15–24 were more common in females than males
- Most colorectal carcinomas in people aged 15–24 were located in the appendix.
- Most colorectal carcinomas in people aged 15–24 were neuroendocrine (See Box 2.4 for definition of neuroendocrine).

Figure 2.33: Categorisation of colorectal cancer for 15–24 years, 2014–2018



Source: AIHW ACD 2018.

Incidence

Carcinomas of the colon and rectum are a type of colorectal cancer (colorectal cancer is more commonly referred to as bowel cancer). Age-standardised bowel cancer incidence rates for the Australian population have been decreasing overall (535 cases per 1,000,000 people in 2018 compared with 652 cases per 1,000,000 people in 2007). The decreasing incidence for the Australian population is strongly influenced by decreasing rates in the older population, however, for most younger populations the rate of colorectal cancer is increasing.

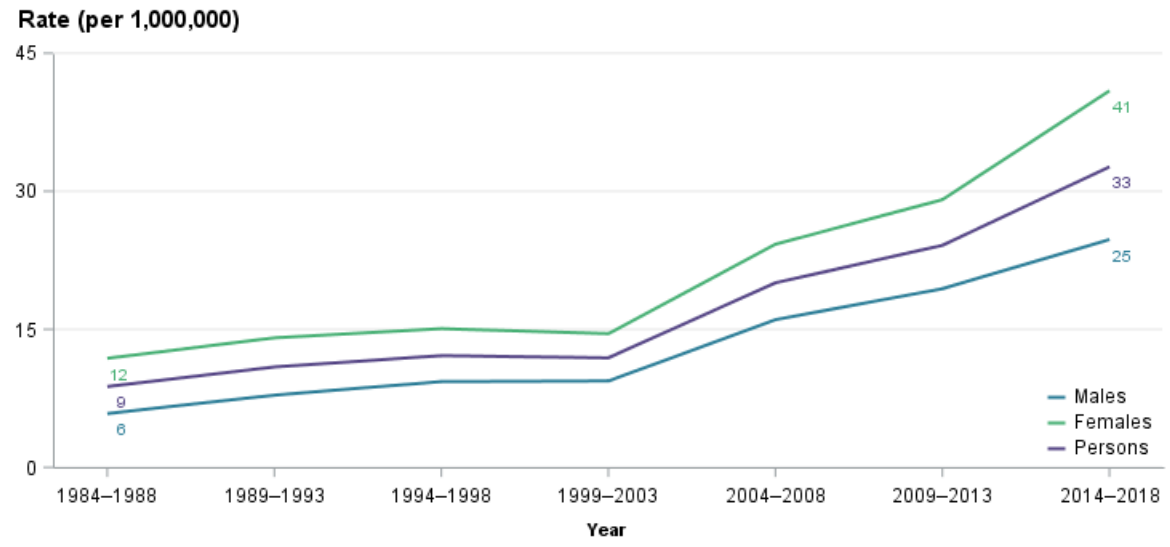
Between 1984–1988 and 2014–2018, at least 97.5% of the colorectal cancers diagnosed in people aged 15–24 were carcinomas of the colon and rectum.

For people aged 15–24, incidence has increased from an average of 24 cases of colorectal carcinoma per year in 1984–1988 to 104 cases per year in 2014–2018. The rate of colorectal carcinomas in people aged 15–24 increased from 9 to 33 cases per 1,000,000 between 1984–1988 and 2014–2018 (Figure 2.34). The factors driving the increasing incidence rates of colorectal cancer in the young remains an area of investigation that is at present not fully understood, but may be related to risk factors including genetic predisposition and heritable conditions such as inflammatory bowel disease (You et al. 2020). Environmental factors such as obesity, poor nutrition, smoking and alcohol consumption are known risk factors in the general population and likely play a role for young people (Haggar et al. 2012; Kim et al. 2019).

Colorectal carcinoma was the fifth most diagnosed cancer in people aged 15–24 in 2014–2018 with 518 cases but, in 1984–1988 it had been the ninth most common cancer in this age group.

Between 1984–1988 and 2014–2018, incidence rates for colorectal carcinomas were consistently higher for females aged 15–24 than for males of the same age (Figure 2.34). Females contributed 61% of cases in 2014–2018.

Figure 2.34: Incidence rates for colorectal carcinomas, 15–24 years, by sex

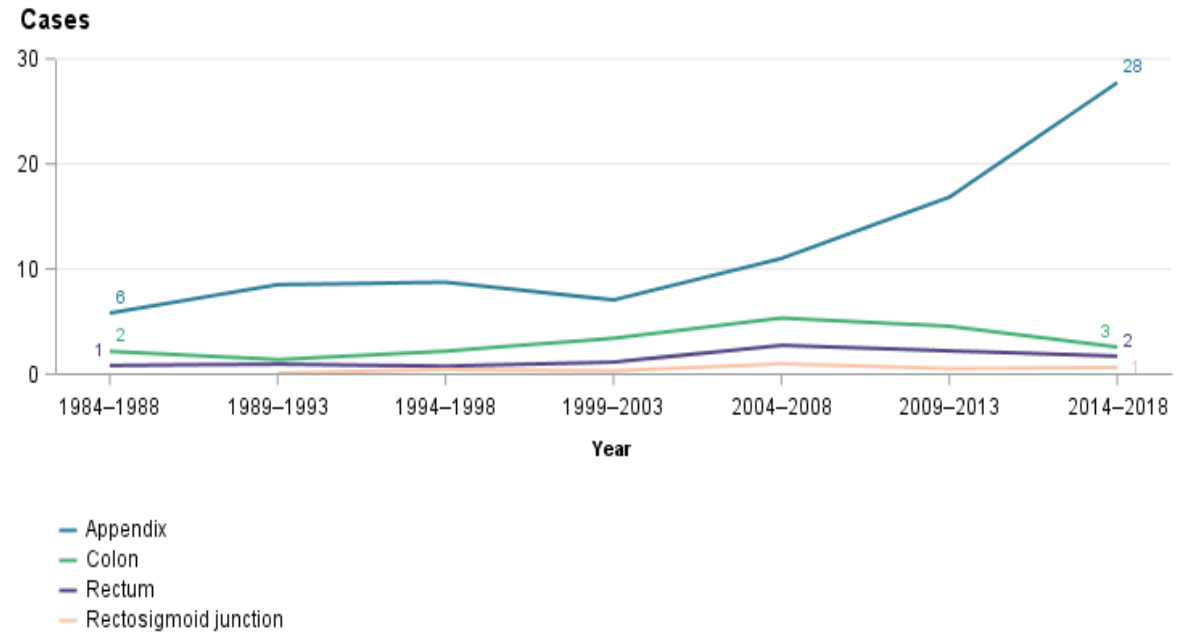


Source: AIHW ACD 2018.

Incidence by site

Colon and rectum carcinomas may originate in the broad areas of the colon, rectum or rectosigmoid junction (which is the limit separating the sigmoid colon and the rectum). The rate of colorectal carcinoma situated in the appendix in people aged 15–24 has substantially increased from 6 to 28 cases per 1,000,000 between 1984–1988 and 2014–2018 (Figure 2.35).

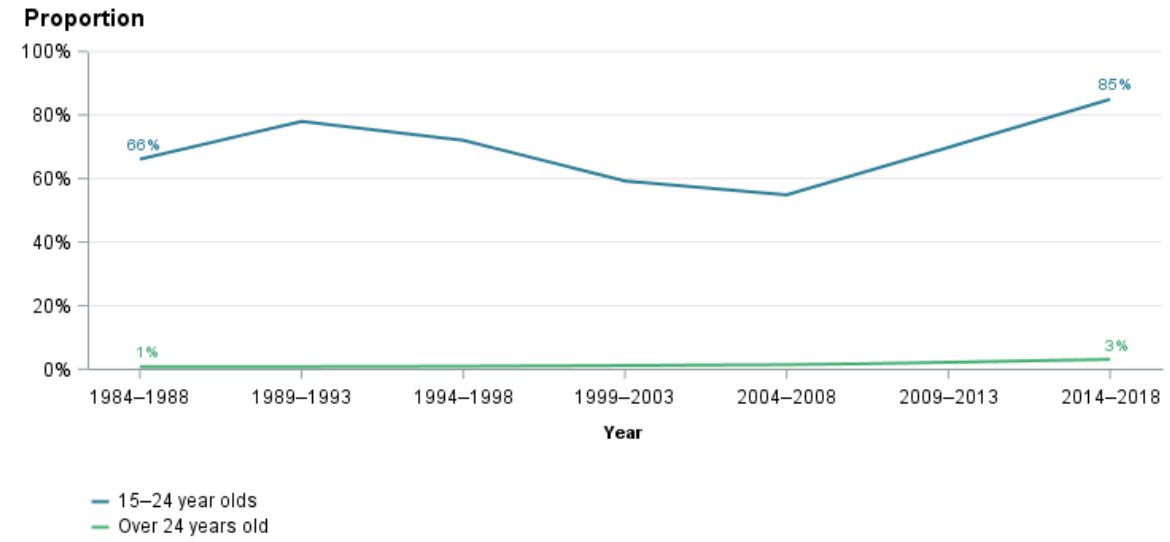
Figure 2.35: Incidence rates for colorectal carcinomas, 15–24 years, by site



Source: AIHW ACD 2018.

The proportion of colorectal carcinomas located in the appendix is much higher for people aged 15–24 (85% in 2014–2018) than for people older than this age group (3% in 2014–2018) (Figure 2.36).

Figure 2.36: Proportion of carcinomas of the colon located in the appendix, by age group



Source: AIHW ACD 2018.

Incidence of colorectal neuroendocrine carcinomas

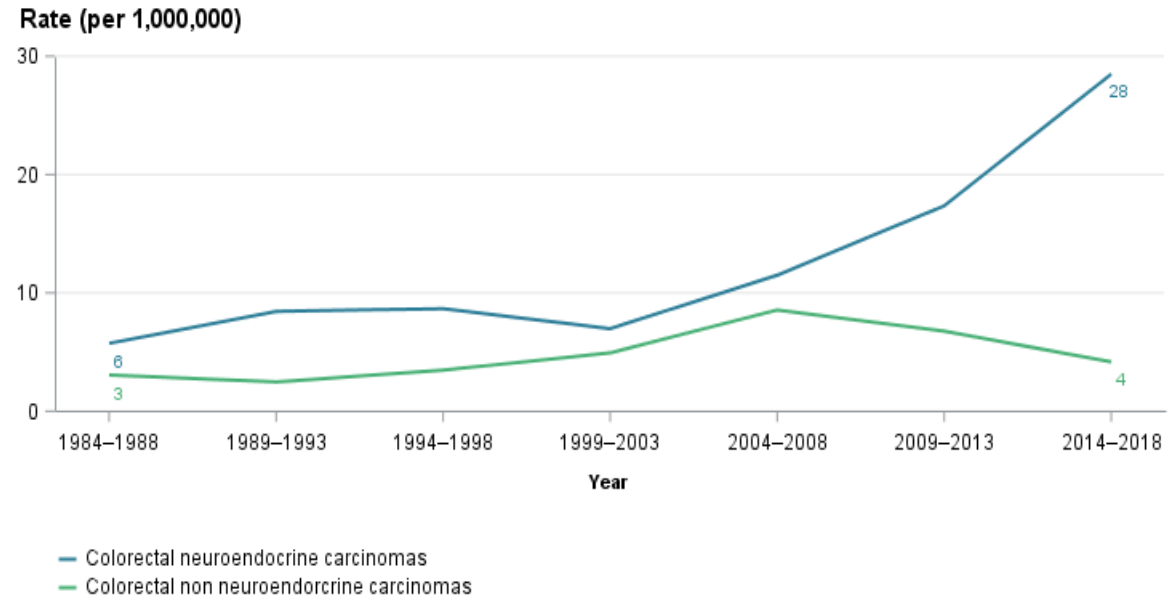
In this section carcinomas of the colon and rectum have been reported as either neuroendocrine tumours or not neuroendocrine tumours.

Colorectal neuroendocrine carcinomas are rare in the general population (5% of colorectal carcinomas in 2014–2018). However, in people aged 15–24, 87% of colorectal carcinomas were neuroendocrine in 2014–2018. (See Box 2.4 for an explanation of neuroendocrine cancers).

Colorectal neuroendocrine carcinomas are becoming increasingly common in 15–24-year-olds, increasing from 6 cases per 1,000,000 persons in 1984–1988 to 28 cases per 1,000,000 persons in 2014–2018 (Figure 2.37). Almost all colorectal neuroendocrine carcinomas are located in the appendix (96%).

However, some of the increase seen in colorectal neuroendocrine carcinomas may be due to a change in cancer classification. Around 2012 some NENs considered benign were redefined by the International Agency for Research on Cancer (IARC) to be malignant. This suddenly brought these NENs into the scope of the registries and the ACD. Therefore, we can expect to see an increase in NENs from around 2012. A sharp increase is unlikely given different registries implemented the change in classification at different times. However, collection has now stabilised so recent increases in rates are unlikely to be due to the change in classification.

Figure 2.37: Incidence rates for colorectal carcinomas, 15–24 years, with and without neuroendocrine tumours

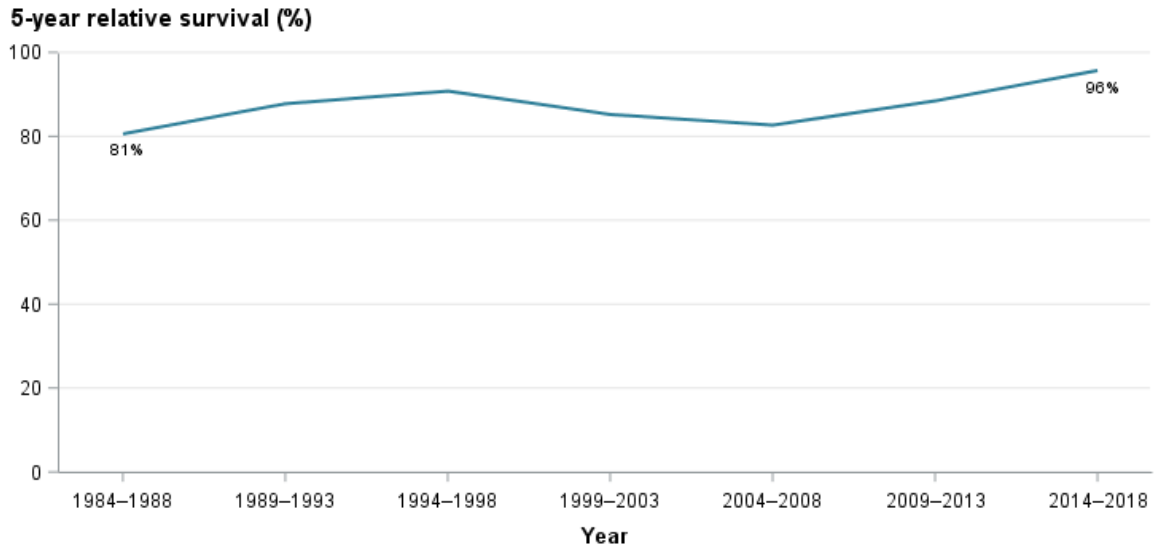


Source: AIHW ACD 2018.

Survival

Colorectal carcinomas have a high rate of survival. The 5-year relative survival for people aged 15–24 was 81% in 1984–1988 and 96% in 2014–2018 (Figure 2.38).

Figure 2.38: Five-year relative survival from colorectal carcinoma, 15–24 years



Source: AIHW ACD 2018.

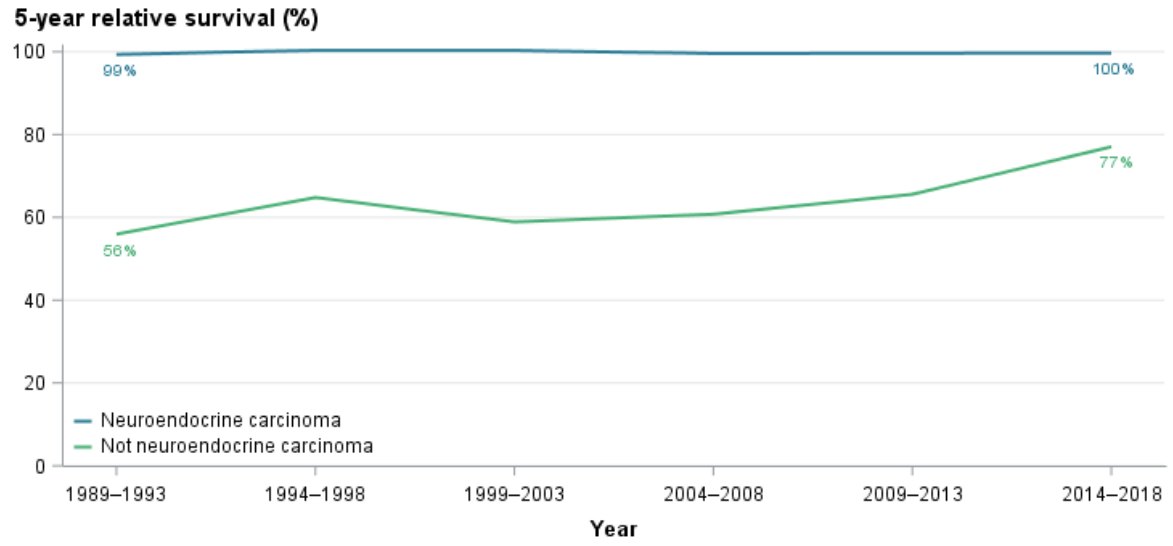
Survival of colorectal carcinomas with/without neuroendocrine tumours

The 5-year relative survival for colorectal carcinomas varies depending on whether it is a neuroendocrine cancer or not. In 2014–2018, 5-year relative survival was 99.7% for

colorectal neuroendocrine carcinomas compared with 77.0% for non-neuroendocrine colorectal carcinomas (Figure 2.39).

Neuroendocrine colorectal carcinomas survival has only improved nominally, as survival was already very high in 1989–1993 (99.3%). Five-year relative survival for non-neuroendocrine colorectal carcinomas increased substantially from 56% in 1989–1993 to 77% in 2014–2018. The increase in survival for non-neuroendocrine colorectal carcinomas has driven most of the increase in overall colorectal carcinoma survival.

Figure 2.39: Five-year relative survival from colorectal carcinoma for people aged 15–24 years with and without neuroendocrine tumours



Source: AIHW ACD 2018.

Mortality

In 2013–2017, there were 16 deaths of people aged 15–24 from colorectal carcinoma. Over half (9 deaths, 56%) of these deaths occurred in males. This was the most common type of carcinoma to result in death for people aged 15–24. The majority of these were neuroendocrine tumours (15 deaths, 94%) and those located in the colon (11 deaths, 69%).

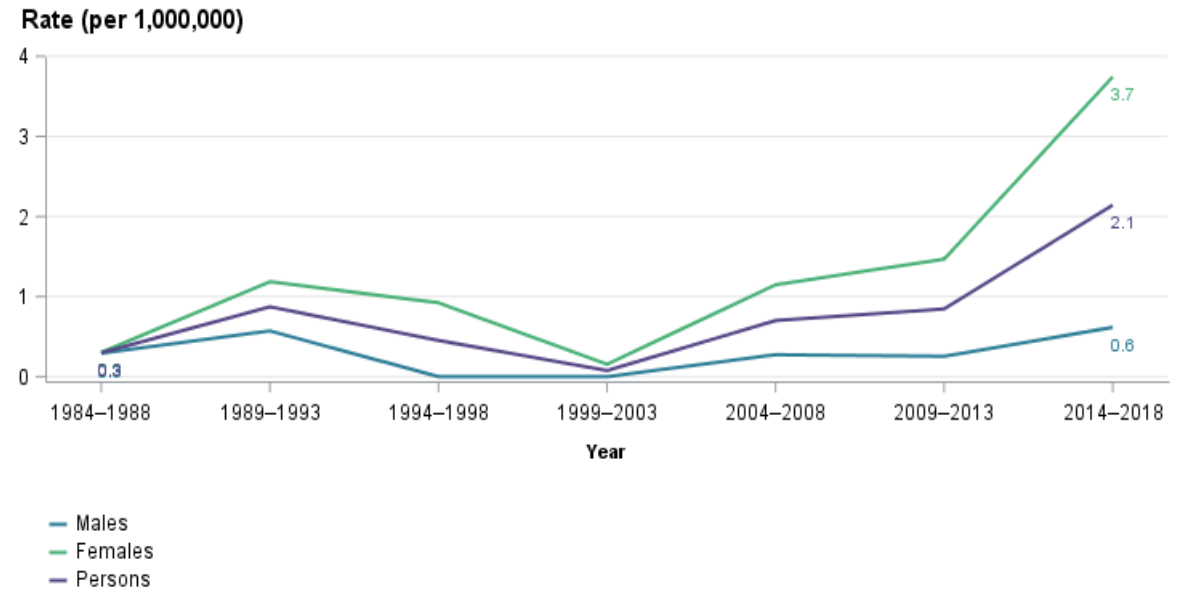
2.4.7.1.2. Carcinomas of the pancreas

Incidence

Pancreatic carcinomas are not common in the 15–24 age group, but the incidence is increasing.

Rates of pancreatic carcinomas in people aged 15–24 have increased from 0.3 cases per 1,000,000 (4 cases) in 1984–1988 to 2.1 cases per 1,000,000 (34 cases) in 2014–2018 (Figure 2.40). This increase was mainly driven by an increase in pancreatic carcinomas in females aged 15–24 (Figure 2.40). In 2014–2018, 85% of pancreatic carcinoma cases in this age group were female.

Figure 2.40: Incidence rate for carcinomas of the pancreas, 15–24 years, by sex



Source: AIHW ACD 2018.

In 2014–2018, pancreatic neuroendocrine carcinomas are more common in people aged 15–24 (32%) than in the general population (10%) (see Box 2.4 for an explanation of neuroendocrine cancers).

Survival

There is insufficient data to reliably describe survival for pancreatic carcinoma over time. However, there is sufficient data to describe 1-year relative survival in 2014–2018 (93%).

Mortality

Two deaths from pancreatic carcinoma occurred in people aged 15–24 between 2013 and 2017.

More detail is available in the online tables.

2.5 Survivorship population (prevalence)

Cancer survivors often face emotional, physical, and financial challenges as a result of the detection, diagnosis, and treatment of cancer. These factors—as well as the associated stressors, and reduced quality of life for cancer survivors and their family, friends, and caregivers—highlight the importance of follow-up health care, and of survivorship, as part of the cancer control continuum (NCI 2015).

The combined effect of several factors—increasing incidence, decreasing mortality, improving survival, and developments in treatment—is leading to an increase in the population who have ever been diagnosed with cancer.

Further, improvements in detection technology, improved surgical procedures, changes in pharmacology, and developments in treatment have an impact on the survivorship experience for people with cancer.

The survivorship population is measured using prevalence data. Prevalence refers to the number of people alive who have previously been diagnosed with cancer.

Data for this section are sourced from the 2018 ACD.

Data from the National Death Index on deaths (from any cause) that occurred up to 31 December 2018 were used to determine which people with cancer had died, and when this occurred. A person who was diagnosed with 2 separate cancers contributed separately to the prevalence of each cancer. However, this person would contribute only once towards prevalence counts.

Survivorship from all cancers combined by sex

At the end of 2018, 4,967 people were alive who had been diagnosed with cancer (excluding basal cell and squamous cell carcinoma of the skin) as an adolescent or young adult (15–24 years) in the previous 5 years.

Table 2.7: Limited-duration prevalence of all cancers combined, by sex, 15–24 years, as at end of 2018

	One-year prevalence	Five-year prevalence	Ten-year prevalence	Thirty seven-year prevalence
		Count		
Males	552	2,525	4,684	13,423
Females	546	2,450	4,486	13,198
Persons	1,097	4,974	9,169	26,620
		Per cent of total (all age) prevalence		
Males	50%	51%	51%	50%
Females	50%	49%	49%	50%
Persons	100%	100%	100%	100%

Notes

1. The number of prevalent cases is based on the number of individuals previously diagnosed with a cancer when they were in this age range, and who were alive at the end of 2018. It does not represent the total number of Australians with a cancer history, who were alive and in this age range at the end of 2018.

2. Cancers are coded based on the revised SEER adolescent and young adult site recode, adjusted to the Australian context. For the histology and topography codes associated with each site please see Appendix A1.

Source: AIHW ACD 2018.

Males made up 50% of 5-year prevalent cases. At the end of 2018, there were 9,169 people alive who had been diagnosed with cancer while aged 15–24 years in the previous 10 years (10-year prevalence). In total, at the end of 2018, there were 26,620 people alive, who had been diagnosed with cancer while aged 15–24 years in the previous 37 years (37-year prevalence) (Table 2.7). The 37-year prevalence has been used, because it is the maximum number of years for which prevalence can be calculated using the available data.

2.5.1 Survivorship by cancer type and sex

Among people aged 15–24, Hodgkin lymphoma had the highest 5-year prevalence (668 people), followed by melanoma of the skin (648 people), and testicular germ cell cancers (613 people) (Table 2.8).

Table 2.8: Five-year prevalence of the 10 most prevalent cancers, by sex, 15–24 years at time of diagnosis, as at end of 2018

Males		Females		Persons	
Cancer type	**Count**	**Cancer type**	**Count**	**Cancer type**	**Count**
Testicular germ cell cancers	613	Carcinomas of thyroid	441	Hodgkin lymphoma	668
Hodgkin lymphoma	327	Melanoma of skin	379	Melanoma of skin	648
Melanoma of skin	269	Hodgkin lymphoma	341	Testicular germ cell cancers	613
Carcinomas of colon and rectum	194	Carcinomas of colon and rectum	314	Carcinomas of thyroid	555
Mature non-Hodgkin lymphomas and related cancers	156	Central nervous system cancers	114	Carcinomas of colon and rectum	508
Central nervous system cancers	135	Mature non-Hodgkin lymphomas and related cancers	105	Mature non-Hodgkin lymphomas and related cancers	261
Acute lymphoblastic leukaemia/lymphoma	125	Soft tissue sarcomas	95	Central nervous system cancers	249
Carcinomas of thyroid	114	Ovarian germ cell cancers	75	Soft tissue sarcomas	201
Bone cancers	108	Chronic myeloid cancers	71	Acute lymphoblastic leukaemia/lymphoma	182
Soft tissue sarcomas	106	Bone cancers	63	Bone cancers	171
All other cancers	383	All other cancers	461	All other cancers	932
All cancers combined	**2,525**	**All cancers combined**	**2,450**	**All cancers combined**	**4,974**

Notes

1. The number of prevalent cases is based on the number of individuals previously diagnosed with a cancer when they were in this age range, and who were alive at the end of 2018. It does not represent the total number of Australians with a cancer history, who were alive and in this age range at the end of 2018.

2. Cancers are coded based on the revised SEER adolescent and young adult site recode, adjusted to the Australian context. For the histology and topography codes associated with each site please see Appendix A1.

3. Prevalence for individual cancers will not necessarily sum to total because a small number of individuals will have been diagnosed with more than one cancer.

Source: AIHW ACD 2018.

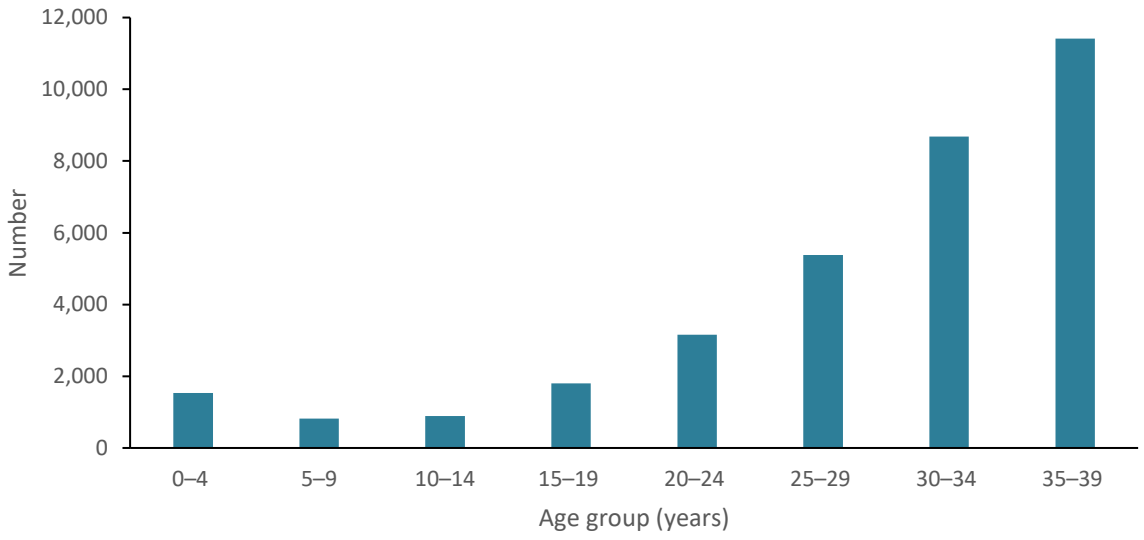
For males aged 15–24, testicular germ cell cancer had the highest 5-year prevalence (613 males), followed by Hodgkin lymphoma (327 males), and melanoma of the skin (269 males). For females aged 15–24, carcinoma of thyroid had the highest 5-year prevalence (441 females), followed by melanoma of the skin (379 females), and Hodgkin lymphoma (341 females).

2.5.2 Survivorship by age

Five-year prevalence for all cancers combined generally increased with age (Figure 2.41). In the prevalence statistics presented in this report, age refers to the age of a person at diagnosis who was still alive on the index date of 31 December 2018.

Five-year prevalence was greatest for people diagnosed with cancer as an older young adult (25–39 years) (25,527 people), followed by adolescents and young adults (15–24 years) (4,970 people), and children (0–14 years) (3,247 people).

Figure 2.41: Five-year prevalence of all cancers combined, by age at diagnosis, as at end of 2018



Notes

1. The number of prevalent cases is based on the number of individuals previously diagnosed with a cancer when they were in each of these age ranges, and who were alive at the end of 2018. It does not represent the total number of Australians with a cancer history, who were alive and in this age range at the end of 2018.

2. The 5-year age group to which a cancer patient is assigned is based on their latest diagnosis while in each of these age ranges.

3. Prevalence for adjacent age groups will not necessarily sum to the total (for the combined age range) because a small number of individuals will have been diagnosed with one cancer while in one age group, and then with another cancer when in the following age group.

Source: AIHW ACD 2018.

More detail is available in the online tables.

3 Treatment for cancer

Key findings

For people aged 15–24, in 2020–21 there were:

- 11,300 cancer-related hospitalisations
- 37,100 services provided in specified cancer-related hospital outpatient clinics
- 2,200 additional chemotherapy and 8,400 radiotherapy services provided in other settings
- An unknown number of other cancer-related services provided in other outpatient clinics, and by a range of medical and health professionals in other settings.

For people aged 15–24 in 2020–21:

- Two-thirds (69%) of cancer-related hospitalisations were same-day admissions.
- The average length of stay for overnight admissions was 7.2 days.
- Males accounted for 60% of all cancer-related admissions.
- The most common cancers associated with hospitalisation were acute lymphoblastic leukaemia (16% of admissions), Hodgkin lymphoma (14%) and bone cancer (11%).
- For males, testicular cancer, and for females acute myeloid leukaemia were also leading causes of cancer-related hospitalisation.
- There were an estimated 17,100 chemotherapy services provided (9,600 to admitted patients, 5,300 in outpatient clinics and 2,200 in other settings).
- The cancers most associated with chemotherapy in admitted hospital settings were acute lymphoblastic leukaemia (18% of chemotherapy procedures), Hodgkin lymphoma (18%), bone cancer (12%) and testicular cancer (12%). No detail is available for chemotherapy provided in other settings.
- There were an estimated 11,600 radiotherapy services provided (175 to admitted patients, 3,000 in outpatient clinics and 8,400 in other settings).
- There were few (175) radiotherapy procedures provided for admitted patients, but of these 50% were for thyroid cancer and 13% for cancer of unknown primary site. No detail is available for radiotherapy provided in other settings.
- In addition to services provided to non-admitted patients in chemotherapy and radiotherapy outpatient clinics, there were 28,800 services provided in one of 5 cancer-related outpatient clinics, with two-thirds (65%) provided in medical oncology consultation clinics.
- Other cancer-related services (for example, diagnostic services) will also have been provided, but data collections currently provide insufficient detail to identify these.

(continued)

Key findings (continued)

For people aged 15–24, there has been no clear trend in the rate of cancer-related hospital admissions over time.

For adjacent age groups:

- The rate of hospital admissions was lower for people aged 15–24 than for children (0–14) or older young adults (25–39) (respectively, 36, 48 and 88 admissions per 10,000 population).
- In 2020–21, there were 23,100 admissions of children and 49,200 admissions of older young adults to hospital due to cancer.
- For children, the leading causes of cancer-related hospitalisation were acute lymphoblastic leukaemia (40%) and brain cancer (11%).
- For older young adults, leading causes of cancer-related hospitalisation were breast cancer (26%), colorectal cancer (11%), testicular cancer (6%) and unknown primary site (6%). Breast cancer was responsible for 41% of cancer-related admissions of females aged 25–39.

For children, there were an estimated:

- 23,800 chemotherapy services provided (19,400 to admitted patients, 370 in outpatient clinics and an estimated 4,000 in other settings)
- 8,900 radiotherapy services provided (1,300 to admitted patients, 3,300 in outpatient clinics and an estimated 4,300 in other settings).

For older young adults, there were an estimated:

- 74,200 chemotherapy services provided (39,000 to admitted patients, 26,200 in outpatient clinics and an estimated 9,000 in other settings)
- 89,500 radiotherapy services provided (960 to admitted patients, 21,800 in outpatient clinics and an estimated 66,700 in other settings).

In 2020–21, in addition to services provided at outpatient chemotherapy and radiotherapy clinics, there were:

- 58,100 services provided to children in 5 outpatient cancer related clinics considered (with 80% of these provided in medical oncology consultation clinics)
- 96,200 services provided to older young adults in 5 outpatient cancer related clinics considered (with 52% of these provided in medical oncology consultation clinics).

Other cancer-related services (for example, diagnostic services) will also have been provided to both children and older young adults, but databases currently provide insufficient detail to identify and describe these.

Both the Cancer Council (https://www.cancer.org.au/) and Cancer Australia (https://www.canceraustralia.gov.au/) provide information about various cancer types and their treatment.

This chapter describes, for people aged 15–24:

- all cancer-related hospitalisations, including the type of cancers involved, using the National Hospital Morbidity Database
- hospital non-admitted patient activity for 7 cancer-related clinic types, using the non-admitted patient databases National Non-Admitted Patient (episode-level) Database (NNAP(el)D) and National Non-Admitted Patient Care (aggregate) Database (NNAP(agg)D)
- selected Medicare-funded services related to cancer, using the MBS database.

These 3 data sources have also been used in combination to describe the chemotherapy and radiotherapy services provided to people aged 15–24. Several important treatment areas are not able to be reported, including immunotherapy, because without access to appropriate linked data, it is not possible to be certain that such services have been used to treat cancer (as opposed to other diseases).

Although not the specific focus of this report, some data are also provided for adjoining age groups; children (people aged 0–14) and older young adults (people aged 25–39).

Detailed and complete cancer treatment statistics will only be possible with the use of a well-developed linked cancer and treatment data set (currently under development).

Cancer treatment takes a number of forms (including surgery, chemotherapy, radiotherapy, immunotherapy and other treatments), frequently in combination, and in a number of different settings (hospitals, outpatient clinics, specialist rooms and so on). In addition, different cancer types and the stage at which cancer is diagnosed will affect treatment decisions. Comprehensive statistical description of cancer treatment for Australia's adolescents and young adults is not yet technically possible (see above).

For more information about the data sources used, see Appendix C.

A range of statistical and background information on Australian hospitals and non-admitted patient activity can be found at https://www.aihw.gov.au/reports-data/myhospitals.

While there is sufficient diagnostic information to clearly identify cancer-related hospital admissions that relate to patients aged 15–24 as well as to describe the type of cancer treated, this is not possible for non-admitted patients and for those receiving Medicare-subsidised services. Non-admitted patient (outpatient clinic) data used in this report relate to services provided in 7 cancer-related clinic types while MBS data relate only to chemotherapy and radiotherapy services, the majority of which are assumed to relate to cancer.

In this report, cancer-related hospitalisations are defined as those where at least one of the following apply:

- the principal diagnosis (the diagnosis chiefly responsible for the episode of care) is cancer (ICD-10-AM codes C00–C97, D45, D46, D47.1, D47.3–D47.5)
- the additional diagnosis (a diagnosis that coexists with the principal diagnosis or arises during the episode of care and affects the care) is cancer (ICD-10-AM codes C00–C97, D45, D46, D47.1, D47.3–D47.5)
- the principal diagnosis is a cancer-related treatment (and cancer is not an additional diagnosis) (ICD-10-AM codes Z08, Z40.00, Z40.01, Z51.0, Z51.1, Z54.1, Z54.2).

A hospitalisation refers to an episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation care).

'Hospitalisation' also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital or changing type of care.

Box 3.1: Diagnosis

Several terms have been used in this chapter to describe the 'reason for hospitalisation'.

Reporting on the type of cancer responsible for the hospitalisation is complicated by the fact that there are frequently several diagnoses provided for each hospitalisation.

The principal diagnosis is 'the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital' (METEOR identifier: 269654 (AIHW 2016a)). This principal diagnosis can be a disease such as bowel cancer or, in the case of most cancer-related hospitalisations, a treatment such as chemotherapy.

'…additional diagnosis is a condition or complaint either coexisting with the principal diagnosis or arising during the episode of admitted patient care, episode of residential care or attendance at a health-care establishment' (AIHW NHMD user guide), but it can also be a cancer treatment (such as chemotherapy).

In this chapter, reference has been made to 'principal diagnosis', 'additional diagnoses' and also to a generic summary measure of 'the cancer considered the most responsible for the hospitalisation'.

In this chapter, where a hospitalisation has been ascribed to a specific cancer, this will be the cancer considered the most responsible for the admission. This cancer is formally described as 'the highest level cancer diagnosis', being the first mentioned cancer diagnosis of those recorded. In this report, up to 10 diagnoses have been considered for each hospitalisation: the principal diagnosis, as well as up to 9 additional diagnoses that have been provided for the admission.

For a hospital admission where the principal diagnosis was 'chemotherapy', the second diagnosis was 'colorectal cancer' and the third diagnosis was 'cancer of unknown primary site', the cancer considered the most responsible for the admission will be reported as colorectal cancer, because this is the first mentioned cancer in the hierarchy of diagnoses (the highest level cancer diagnosis).

3.1 Hospitalisations for all cancers combined

In 2020–21, there were 643,301 hospitalisations of people aged 15–24 in Australia (238,962 males, 403,936 females) (AIHW 2022b). About 1.8% (11,336) of these were cancer-related (Table 3.1).

Table 3.1: Cancer-related hospitalisations, 15–24 years, 2020–21

	Number	Per cent	Rate
Principal diagnosis of cancer	3,891	34.3	12.4
Additional diagnosis of cancer	7,000	61.8	22.3
Principal diagnosis of cancer-related service	445	3.9	1.4
All cancer-related hospitalisations	**11,336**	100.0	**36.3**

Notes

1. Hospitalisations for which the care type was reported as 'Newborn with no qualified days', and records for 'Hospital boarders' and 'Posthumous organ procurement' have been excluded from the analysis.
2. Rates are expressed per 10,000 population.

Source: AIHW National Hospital Morbidity Database 2020–21.

About a third (34%) of all cancer-related hospitalisations of people aged 15–24 had a principal diagnosis of cancer. The remainder had an additional diagnosis of cancer (62%), or a principal diagnosis related to the treatment of cancer (and cancer was not an additional diagnosis) (4%).

The bulk (80%) of hospitalisations with an additional diagnosis of cancer had chemotherapy as the primary diagnosis and were almost exclusively same-day hospital admissions. The balance of admissions with an additional diagnosis of cancer (just over 1,400 cancer-related admissions in 2020–21) had a principal diagnosis that was not cancer or a cancer-related treatment. The principal diagnosis for these hospitalisations covered a diverse range of conditions, notably:

- diseases of the blood and blood forming organs (441 admissions)
- symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified (240 admissions)
- diseases of the digestive system (121 admissions)
- factors affecting health status (106 admissions)
- infections and parasitic diseases (103 admissions).

While some of these diagnoses can be independent of the patient's cancer diagnosis, others will be associated with or be caused by the fact that the patient has cancer.

Almost all of these admissions where the principal diagnosis was not cancer or was not a cancer-related treatment had an additional diagnosis of cancer, notably acute lymphoblastic leukaemia (261 admissions), bone cancer (188 admissions), Hodgkin lymphoma (171 admissions), acute myeloid leukaemia (128 admissions), non-Hodgkin lymphoma (94 admissions) and brain cancer (86 admissions).

For hospitalisations with a principal diagnosis of cancer, 66% were overnight, with an average length of stay (ALOS) of 7.6 days (Table 3.2). In contrast, only 14% of hospitalisations with an additional diagnosis of cancer were overnight.

Table 3.2: Length of stay for cancer-related hospitalisations, 2020–21

	Same-day		Overnight		
	Number	Per cent	Number	Per cent	ALOS
Principal diagnosis of cancer	1,305	33.5	2,586	66.5	7.6
Additional diagnosis of cancer	6,033	86.2	967	13.8	6.4
Principal diagnosis of cancer-related service (and cancer is not an additional diagnosis)	431	96.9	14	3.1	2.8
All cancer-related hospitalisations	**7,769**	**68.5**	**3,567**	**31.5**	**7.2**

Notes

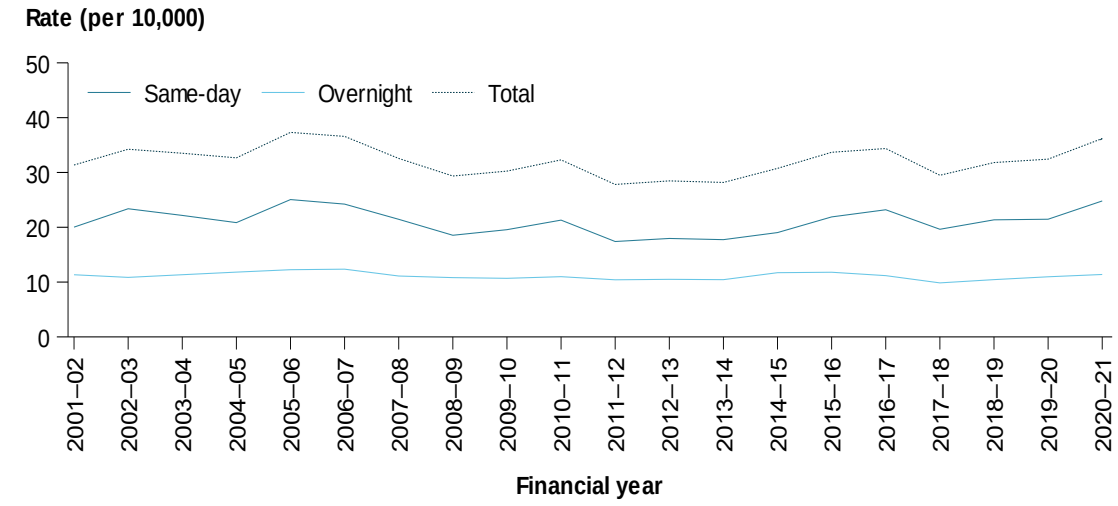
1. Hospitalisation for which the care type was reported as 'Newborn with no qualified days' and records for 'Hospital boarders' and 'Posthumous organ procurement' have been excluded from the analysis.
2. ALOS – average length of stay (days).

Source: AIHW National Hospital Morbidity Database 2020–21.

Figure 3.1 shows trends in hospitalisations for people aged 15–24 from 2001–02 to 2020–21. Note that changes in hospital admission policies and practices might affect comparisons over time.

Between 2001–02 and 2020–21, there was no clear trend in total cancer-related hospitalisations for people aged 15–24.

Figure 3.1: Trend in cancer-related hospitalisations for all cancers combined, by admission type, 15–24 years, 2001–02 to 2020–21



Notes

1. Hospitalisations for which the care type was reported as 'Newborn with no qualified days', and records for 'Hospital boarders' and 'Posthumous organ procurement' have been excluded from the analysis.
2. The rates are expressed per 10,000 population.

Source: AIHW National Hospital Morbidity Database 2020–21.

The crude cancer-related hospitalisation rate ranged from 27.8 per 10,000 people aged 15–24 in 2011–12 to 37.3 per 10,000 in 2005–06. The year-to-year fluctuation in the rate of cancer-related hospitalisations in people aged 15–24 was largely influenced by same-day hospitalisations, with the rate of overnight cancer-related hospitalisations relatively steady at between 10 and 12 admissions per 10,000 population over this period.

By sex

In 2020–21, males accounted for 60% (6,763) of all cancer-related hospitalisations of people aged 15–24, compared with only 37% of all hospitalisations for this age group. The cancer-related hospitalisation rate for males was higher than for females, at 42 admissions per 10,000 males compared with 30 admissions per 10,000 females.

For males, 29% of admissions were overnight, compared with 35% for females.

The average length of stay for overnight cancer-related hospitalisations for males aged 15–24 was 7.7 days, compared with 6.6 days for females aged 15–24 (Table 3.3).

For overnight hospitalisations where the principal diagnosis was cancer, males aged 15–24 had an ALOS of 8.3 days, compared with 6.6 days for females aged 15–24. For all other overnight hospitalisations, ALOS was slightly shorter for males (6.0 days), but similar for females (6.6 days).

More detail is provided in the online tables.

Table 3.3: Average length of stay for cancer-related hospitalisations, by sex, 15–24 years, 2020–21

	Males			Females		
	Same-day	Overnight		Same-day	Overnight	
	Number	Number	ALOS (days)	Number	Number	ALOS (days)
Principal diagnosis of cancer	733	1,477	8.3	572	1,109	6.6
Other cancer-related admissions	4,055	498	6.0	2409	483	6.6
All cancer-related hospitalisations	**4,788**	**1,975**	**7.7**	**2,981**	**1,592**	**6.6**

Notes

1. Hospitalisations for which the care type was reported as ‘Newborn with no qualified days’, and records for ‘Hospital boarders’ and ‘Posthumous organ procurement’ have been excluded from the analysis.
2. Number represents the frequency of episodes. ALOS – average length of stay (days).
3. In line with suppression rules, because of very small numbers of admissions in one category, ‘Additional diagnosis of cancer or principal diagnosis’ and ‘Principal diagnosis of cancer-related service (and cancer was not an additional diagnosis)’ have been combined in this table and reported as ‘Other cancer-related admissions’.

Source: AIHW National Hospital Morbidity Database 2020–21.

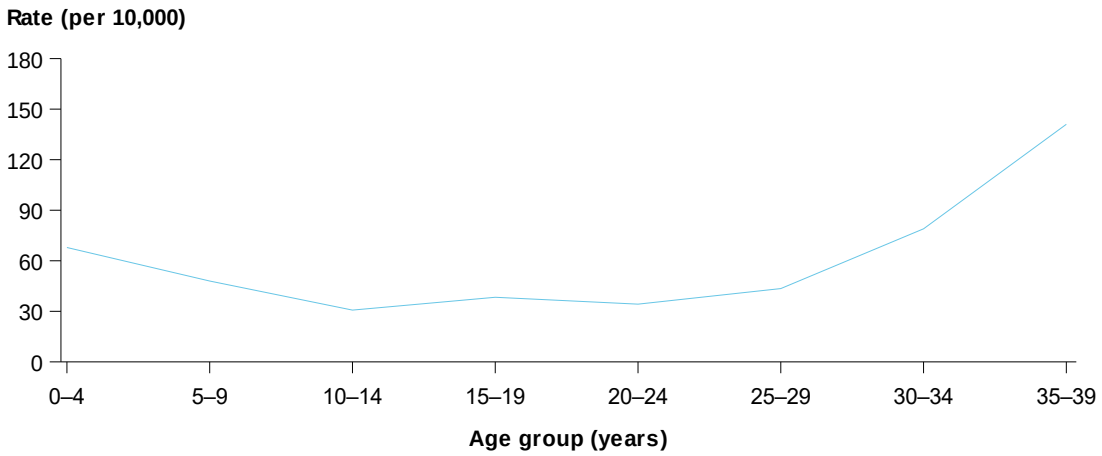
By age

In 2020–21, the age-specific cancer-related hospitalisation rate decreased with increasing age in the early years – from 68 hospitalisations per 10,000 persons aged 0–4, to 31 per 10,000 persons aged 10–14 (Figure 3.2).

The age-specific rate tended to be slightly higher (between 34 and 38 per 10,000 persons) for those aged between 15–19 and 20–24, then increased to 141 per 10,000 persons aged 35–39.

People aged 15–24 had an age-specific cancer-related hospitalisation rate of 36 hospitalisations per 10,000 people, compared with 48 hospitalisations per 10,000 people aged 0–14, and 88 hospitalisations per 10,000 people aged 25–39.

Figure 3.2: Age-specific cancer-related hospitalisations, 2020–21



Notes

1. Hospitalisations for which the care type was reported as 'Newborn with no qualified days', and records for 'Hospital boarders' and 'Posthumous organ procurement' have been excluded from the analysis.
2. The rates are age-specific and are expressed per 10,000 population.

Source: AIHW National Hospital Morbidity Database 2020–21.

3.2 Hospitalisations by cancer type

In 2020–21, the cancers most responsible for hospitalisation of people aged 15–24 were acute lymphoblastic leukaemia (1,825 admissions, 16% of admissions), Hodgkin lymphoma (1,638 admissions, 14%), bone cancer (1,293 admissions, 11%), testicular cancer (1,050 admissions, 9%) and acute myeloid leukaemia (859 admissions, 8%). Together these accounted for 59% of all cancer-related admissions. The 10 most common cancers in Table 3.4 accounted for 78% of all cancer-related hospitalisations of people aged 15–24.

More detail is provided in the online tables.

Table 3.4: Count of cancer-related hospitalisations, by diagnosis, people aged 15–24, 2020–21

	Principal diagnosis		Highest level additional diagnosis		Principal diagnosis is a cancer treatment	Total	
Cancer	**Count**	**%**	**Count**	**%**	**Count**	**Count**	**%**
Acute lymphoblastic leukaemia	646	17	1,179	17	0	1,825	16
Hodgkin lymphoma	276	7	1,362	19	0	1,638	14
Bone	565	15	728	10	0	1,293	11
Testis	195	5	855	12	0	1,050	9
Acute myeloid leukaemia	312	8	547	8	0	859	8
Non-Hodgkin lymphoma	298	8	401	6	0	699	6
Brain	248	6	260	4	0	508	4
Unknown primary site	210	5	189	3	0	399	4
Other soft tissue	150	4	231	3	0	381	3
Thyroid	223	6	17	0	0	240	2
Other cancers/cancer treatments	768	20	1,231	18	445	2,444	22
Total	**3,891**	**100**	**7,000**	**100**	**445**	**11,336**	**100**

Notes

1. Hospitalisations for which the care type was reported as ‘Newborn with no qualified days’, and records for ‘Hospital boarders’ and ‘Posthumous organ procurement’ have been excluded from the analysis.
2. Highest level additional diagnosis is the first mentioned cancer diagnosis in up to 9 additional diagnoses that have been provided for the admission, with the majority of these being the second diagnosis. The majority of these admissions also had a principal diagnosis of ‘pharmacotherapy session for neoplasm’.

Source: AIHW National Hospital Morbidity Database 2020–21.

By sex

Table 3.5 describes the 10 most common diagnoses for cancer-related hospitalisations of males and females.

Table 3.5: The 10 most common cancer diagnoses for hospitalisation of people aged 15–24, by sex, 2020–21

	Principal diagnosis		Highest level additional diagnosis		Principal diagnosis is a cancer treatment	Total	
Cancer	**Count**	**%**	**Count**	**%**	**Count**	**Count**	**%**
				Males			
Acute lymphoblastic leukaemia	426	19	837	19	0	1,263	19
Testis	195	9	854	19	0	1,049	16
Hodgkin lymphoma	144	7	683	16	0	827	12
Bone	360	16	428	10	0	788	12
Acute myeloid leukaemia	156	7	339	8	0	495	7
Non-Hodgkin lymphoma	200	9	261	6	0	461	7
Brain	122	6	166	4	0	288	4
Unknown primary site	117	5	122	3	0	239	4
Other soft tissue	90	4	139	3	0	229	3
Nasal cavity, middle ear and sinuses	7	0	126	3	0	133	2
Other cancers/cancer treatments	393	18	450	10	148	991	15
Total	2,210	100	4,405	100	148	6,763	100
				Females			
Hodgkin lymphoma	132	8	679	26	0	811	18
Acute lymphoblastic leukaemia	220	13	342	13	0	562	12
Bone	205	12	300	12	0	505	11
Acute myeloid leukaemia	156	9	208	8	0	364	8
Non-Hodgkin lymphoma	98	6	140	5	0	238	5
Brain	126	7	94	4	0	220	5
Ovary	49	3	145	6	0	194	4
Thyroid	165	10	13	1	0	178	4
Unknown primary site	93	6	67	3	0	160	3
Other soft tissue	60	4	92	4	0	152	3
Other cancers/cancer treatments	377	22	515	20	297	1,189	26
Total	**1,681**	**100**	**2,595**	**100**	**297**	**4,573**	**100**

Notes

1. Hospitalisations for which the care type was reported as ‘Newborn with no qualified days’, and records for ‘Hospital boarders’ and ‘Posthumous organ procurement’ have been excluded from the analysis.
2. Highest-level additional diagnosis is the first mentioned cancer diagnosis in up to 9 additional diagnoses that have been provided for the admission, with the majority of these being the second diagnosis. The majority of these admissions also had a principal diagnosis of ‘pharmacotherapy session for neoplasm’.

Source: AIHW National Hospital Morbidity Database 2020–21.

Acute lymphoblastic leukaemia (19%), testicular cancer (16%), Hodgkin lymphoma (12%) and bone cancer (12%) were the 4 cancers most responsible for hospitalisation of males aged 15–24 in 2020–21, together accounting for 58% of all cancer-related hospital admissions in this group.

Hodgkin lymphoma (18%), acute lymphoblastic leukaemia (12%), bone cancer (11%) and acute myeloid leukaemia (8%) were the 4 cancers most responsible for hospitalisation of females aged 15–24 in 2020–21, together responsible for 49% of all cancer-related hospital admissions in this group.

As an aid to interpreting the table, there were 426 admissions of males where the principal diagnosis was acute lymphoblastic leukaemia and a further 837 admissions of males where the highest level additional cancer diagnosis was acute lymphoblastic leukaemia, with a total number of 1,263 admissions of males where the highest-level cancer diagnosis was acute lymphoblastic leukaemia. As for many other cancer types, pharmacotherapy session for neoplasms was frequently the principal diagnosis where the highest level additional diagnosis (indicating which cancer was being treated) was acute lymphoblastic leukaemia.

More detail is available in the online tables.

By age

Table 3.6 below describes the 10 cancers most commonly responsible for hospitalisation of people aged 0–14, 15–24 and 25–39 in 2020–21.

For children, the cancers most responsible for hospitalisation were acute lymphoblastic leukaemia (just over 40% of all cancer-related admissions of children), followed by brain cancer (11%) and acute myeloid leukaemia (5%).

For people aged 15–24, the cancers most responsible for hospitalisation were acute lymphoblastic leukaemia (16% all cancer-related admissions of people aged 15–24), followed by Hodgkin lymphoma (14%), bone cancer (11%), testicular cancer (9%), acute myeloid leukaemia (8%), non-Hodgkin lymphoma (6%) and brain cancer (4%).

For older young adults, the cancers most responsible for hospitalisations were breast cancer (26% of cancer-related admissions of people aged 25–39 years (and 41% of cancer-related admissions of females)), followed by colorectal cancer (11%), testicular cancer (6%), cancer of unknown primary site (6%), acute myeloid leukaemia (5%), non-Hodgkin lymphoma (5%) and Hodgkin lymphoma (4%).

More detail is available in the online tables.

Table 3.6: Ten cancers most commonly responsible for hospitalisation of people aged 0–14, 15–24 and 25–39 in 2020–21

0–14 years			15–24 years			25–39 years		
	Admissions			Admissions			Admissions	
Cancer	Number	Rate	Cancer	Number	Rate	Cancer	Number	Rate
Acute lymphoblastic leukaemia	9,597	20.2	Acute lymphoblastic leukaemia	1,825	5.8	Breast	12,580	22.4
Brain	2,645	5.6	Hodgkin lymphoma	1,638	5.2	Colorectal	5,492	9.8
Acute myeloid leukaemia	1,251	2.6	Bone	1,293	4.1	Testis	2,741	4.9
Bone	1,012	2.1	Testis	1,050	3.4	Unknown primary site	2,731	4.9
Kidney	868	1.8	Acute myeloid leukaemia	859	2.7	Acute myeloid leukaemia	2,358	4.2
Other soft tissue	827	1.7	Non-Hodgkin lymphoma	699	2.2	Non-Hodgkin lymphoma	2,286	4.1
Non-Hodgkin lymphoma	759	1.6	Brain	508	1.6	Hodgkin lymphoma	2,196	3.9
Other central nervous system	733	1.5	Unknown primary site	399	1.3	Non-melanoma skin cancer	2,123	3.8
Other endocrine glands	625	1.3	Other soft tissue	381	1.2	Cervix	1,470	2.6
Eye	535	1.1	Thyroid	240	0.8	Melanoma of the skin	1,358	2.4
Other diagnoses	4,156	8.8	Other diagnoses	2,444	7.8	Other diagnoses	13,857	24.7
Total	**23,008**	**48.5**	**Total**	**11,336**	**36.2**	**Total**	**49,192**	**87.8**

Notes

1. Hospitalisations for which the care type was reported as ‘Newborn with no qualified days’, and records for ‘Hospital boarders’ and ‘Posthumous organ procurement’ have been excluded from the analysis.
2. Cancers here are those most responsible for the hospital admission (the highest level cancer diagnosis).
3. Rates are crude and per 10,000 population.

Source: AIHW National Hospital Morbidity Database 2020–21.

3.3 Treatment in hospital and other settings

As well as in admitted hospital patient settings, cancer treatment is also provided in non-admitted patient settings (outpatient clinics) and in other settings (for example, private clinics).

The following sections describe cancer services provided inside and outside of admitted patient settings, and includes reporting on:

- chemotherapy
- radiotherapy
- a selected range of other cancer-related services provided in non-admitted patient settings.

This list does not include all services, but simply those cancer-related services which are currently capable of being reported reliably.

Description of non-admitted patient (outpatient clinics) activity makes use of the national non-admitted patient data sets (the National Non-admitted Patient Care (aggregate) Database (NNAPC(agg)D) and the National Non-admitted Patient (episode-level) Database (NNAP(el)D)). Description of activity in other settings (for example, private clinics) makes use of MBS data.

Use of multiple data sets can create an opportunity for duplication (for example, an MBS-funded service provided during a hospital admission could be reported (and counted) twice – once in the NHMD and again in the MBS database). To reduce the risk of duplication, use has been made of several 'flags' within each data set. A patient's Medicare eligibility status and patient election status (that is, private or public patient) in the admitted patient data can approximate whether a service was Medicare-subsidised or not, and therefore whether that service is likely to be counted in the MBS data. Non-admitted patient data can differentiate between services that are Medicare-subsidised and those that are funded through other means. MBS data can differentiate between services that were provided in hospitals and those that were provided outside of an admitted patient setting.

While chemotherapy and radiotherapy (radiation therapy) are used to treat cancer, they can also be used to treat other conditions. The type of cancer being treated (and indeed, whether cancer is being treated at all), is available when reporting for admitted patients but is not available when reporting for patients in other settings.

3.4 Chemotherapy

Chemotherapy is mainly used to treat cancer but it also has other uses, for example to prepare for a bone marrow stem cell transplant or to treat an overactive immune system. While all chemotherapy procedures described for hospital inpatients earlier in this report will relate to cancer, some of the chemotherapy services provided in non-admitted hospital (for example, outpatient) or other settings (including those counted in MBS data) may not relate specifically to cancer.

In this report, chemotherapy is reported for admitted patients, non-admitted patients, and Medicare-subsidised services, with an estimate of the total number of services provided.

Chemotherapy procedures provided to admitted hospital patients

This section explores the number of chemotherapy procedures performed on admitted patients and the number of hospitalisations involving chemotherapy.

In the previous edition of this report (AIHW 2018), chemotherapy was defined as occurring when the diagnoses associated with a hospital admission was listed as 'pharmacotherapy session for neoplasm'.

In this edition, chemotherapy is defined as occurring when the hospital admission is categorised as cancer-related and one of the procedures is a pharmacotherapy intervention (see Appendix D). Reported admitted patient chemotherapy services may not include all those administered during the hospitalisation.

In public hospitals, admission practices for same-day chemotherapy vary across states and territories. For more information on variations in chemotherapy in hospitals, see *Variation in hospital admission policies and practices: Australian hospital statistics* (AIHW 2017).

In 2020–21, there were a total of 9,574 chemotherapy procedures administered during 7,579 individual cancer-related hospitalisations of people aged 15–24 (an average of 1.1 chemotherapy procedures per admission involving chemotherapy) (Table 3.7).

Of these 7,579 admissions, 4,777 were for males (63%) and 2,802 were for females (37%).

Table 3.7: Number of chemotherapy procedures for admitted hospital patients aged 15–24, by cancer diagnosis, 2020–21

	Chemotherapy procedures		Admissions involving chemotherapy	
	Count	Per cent	Count	Per cent
Acute lymphoblastic leukaemia	1,909	20	1,342	18
Hodgkin lymphoma	1,683	18	1,351	18
Bone	1,182	12	917	12
Testis	1,031	11	881	12
Non-Hodgkin lymphoma	711	7	503	7
Acute myeloid leukaemia	610	6	544	7
Other soft tissue	317	3	242	3
Brain	226	2	211	3
Unknown primary site	179	2	146	2
Colorectal	174	2	91	1
Other cancers/cancer treatments	1,552	16	1,351	18
Total	**9,574**	**100**	**7,579**	**100**

Notes

1. Hospitalisations for which the care type was reported as 'Newborn with no qualified days', and records for 'Hospital boarders' and 'Posthumous organ procurement' have been excluded from the analysis.

2. Cancer diagnosis is the highest level diagnosis, being the first mentioned cancer diagnosis in up to 10 diagnoses that have been provided for the admission.

3. The count of admitted chemotherapy procedures may be an underestimate.

4. Chemotherapy (pharmacotherapy) defined in Appendix D.

Source: AIHW National Hospital Morbidity Database 2020–21.

Of the admissions involving chemotherapy, 73% were for admissions where the most responsible cancer was in one of the following 6 specific cancer groups; Hodgkin lymphoma (18%, 1,351 admissions), acute lymphoblastic leukaemia (18%, 1,342 admissions), bone cancers (12%, 917 admissions), testicular cancer (12% 881 admissions), acute myeloid leukaemia (7%, 544 admissions) and non-Hodgkin lymphoma (7%, 503 admissions).

By sex

There were 4,777 cancer-related admissions of males aged 15–24 involving chemotherapy, compared with 2,802 admissions for females aged 15–24.

For males aged 15–24, the cancers most responsible for admissions involving chemotherapy were acute lymphoblastic leukaemia (955 admissions), testicular cancer (881 admissions), Hodgkin lymphoma (684 admissions), bone cancer (580 admissions), non-Hodgkin lymphoma (336 admissions) and acute myeloid leukaemia (325 admissions).

For females aged 15–24, the cancers most responsible for admissions involving chemotherapy were Hodgkin lymphoma (667 admissions), acute lymphoblastic leukaemia (387 admissions), bone cancer (337 admissions), acute myeloid leukaemia (219 admissions), non-Hodgkin lymphoma (167 admissions) and ovarian cancer (139 admissions).

More detail is available in the online tables.

By age

For the 3 age groups, 0–14, 15–24 and 25–39, there were, respectively, 14,806, 7,579 and 30,773 cancer-related hospital admissions involving chemotherapy providing, respectively, 19,430, 9,574 and 39,024 individual chemotherapy procedures.

- For people aged 0–14 years, 51% of cancer-related admissions involving chemotherapy related to acute lymphoblastic leukaemia, while 7% related to brain cancer and 6% to acute myeloid leukaemia.
- For people aged 15–24 years, 18% of cancer-related admissions involving chemotherapy related to Hodgkin lymphoma, 18% to acute lymphoblastic leukaemia, and 12% each to bone cancer and testicular cancer (Table 3.7).
- For people aged 25–39 years, 35% of cancer-related admissions involving chemotherapy related to breast cancer, 13% to colorectal cancer, 7% to testicular cancer, and 6% to Hodgkin lymphoma.

More detail is available in the online tables.

Chemotherapy services provided in non-admitted patient settings

Non-admitted patient data for 2020–21 are drawn from the National Non-admitted Patient (episode-level) Database (NNAP(el)D), and then adjusted for under-reporting using the National Non-admitted Patient Care (aggregate) Database (NNAPC(agg)D). No data for age-defined population groups are available for South Australia.

Excluding South Australia, an estimated 5,250 chemotherapy services were provided to people aged 15–24 in non-admitted (outpatient) clinic settings in 2020–21. It is not possible to describe which cancers these chemotherapy services addressed. Excluding South Australia, 1,122 of these chemotherapy services were Medicare-subsidised.

Excluding South Australia, there were an estimated 369 services delivered to children and 26,232 services delivered to older young adults in non-admitted chemotherapy treatment clinics in 2020–21.

More detail is available in the online tables.

MBS-subsidised chemotherapy services

In 2020–21, there were 6,198 MBS-subsidised chemotherapy services provided to people aged 15–24.

Of these, 2,838 were provided to admitted hospital patients. This is close to the 2,950 chemotherapy services that are estimated for those private patients who received chemotherapy procedures in public and private hospitals reported in Table 3.8. A further 3,360 were provided outside an admitted hospital setting.

In 2020–21, there were an estimated 11,542 MBS-subsidised chemotherapy services delivered to children (with 7,537 of these delivered to admitted patients), and 29,029 MBS-subsidised chemotherapy services delivered to older young adults (with 14,065 of these delivered to admitted patients).

All hospital and MBS-subsidised chemotherapy services combined

The need to avoid duplication and the challenges of combining data from different data sets has been discussed previously. Reported combined data described here should be considered indicative rather than exact.

As stated, in combining data from different sources, there is the opportunity for overlap and discrepancy. For instance, the number of in-hospital chemotherapy services funded by Medicare were 112 less, 1,146 more and 3,081 less (respectively) for people aged 15–24, children and older young adults, than the estimate based on NHMD data. Reported admitted patient chemotherapy services may not include all those administered during the hospitalisation.

For people aged 15–24, 9,574 chemotherapy services were provided during cancer-related hospital admissions, and 5,250 chemotherapy services were provided in hospital outpatient clinics (some of which may not have been cancer-related, and this excludes South Australia). The total number of chemotherapy services provided to people aged 15–24 in 2020–21 is estimated at between 16,950 and 17,062 (excluding services provided in non-admitted settings in South Australia) (Table 3.8).

Table 3.8: Count of all chemotherapy services, people aged 15–24, 2020–21

Setting	MBS-funded	Other-funded	Total
	Count of services		
In-hospital	2,950	6,624	9,574
Non-admitted (outpatients)	1,122	4,128	5,250
Other setting	2,238	0	2,238
Total (unadjusted)	6,310	10,752	17,062
In-hospital MBS 'discrepancy'	–112	0	–112
Total (adjusted)	**6,198**	**10,752**	**16,950**

Notes

1. Columns and rows will not add perfectly due to discrepancies between different data sources.

2. NHMD estimates 2,950 cancer-related private chemotherapy services, MBS describes 2,838 MBS-subsidised in-hospital chemotherapy services.

3. The count of admitted chemotherapy procedures may be an underestimate.

4. Non-admitted patient data excludes South Australia.

5. Non-admitted services are adjusted to account for under-reporting in the NNAP(EL)D relative to the NNAPC(AGG)D.

6. Some chemotherapy services may have been provided to treat diseases other than cancer.

Sources: MBS 2020–21; NHMD 2020–21; NNAP(EL)D 2020–21; NNAPC(AGG)D 2020–21.

For children (0–14 years), 19,430 chemotherapy services were provided to children during cancer-related hospital admissions, and 369 chemotherapy services were provided to children in hospital outpatient clinics (some of which may not have been cancer-related, and this excludes South Australia). The total number of chemotherapy services provided to children in 2020–21 is estimated at between 23,752 and 24,898 (excluding services provided in non-admitted settings in South Australia).

For older young adults (25–39 years), 39,025 chemotherapy services were provided during cancer-related hospital admissions, and 26,232 chemotherapy services were provided in hospital outpatient clinics (some of which may not have been cancer-related, and this excludes South Australia). The total number of chemotherapy services provided to people aged 25–39 in 2020–21 is estimated at between 71,138 and 74,219 (excluding services provided in non-admitted settings in South Australia).

More detail is available in the online tables.

3.5 Radiotherapy for cancer

Radiotherapy is an important part of cancer treatment. Australian research indicates that 48% of cancer patients should receive external beam radiotherapy at least once during their treatment (Barton et al. 2014).

Radiotherapy is provided in several settings, and so several data sources (the National Hospital Morbidity Database, the national non-admitted patient datasets (NNAP(EL)D and NNAPC(AGG)D) and the MBS data set, see Appendix C) have been used in this report to describe radiotherapy treatment for people aged 15–24.

While the National Radiotherapy Waiting Times Database was used previously, it has recently been found to contain some inconsistencies and has not been used in this report. Data in this report should not be compared with data presented in the previous report (AIHW 2018).

Radiotherapy procedures provided to admitted hospital patients

In 2020–21, there were a total of 156 cancer-related hospitalisations of people aged 15–24 that involved radiotherapy, comprising a total 175 radiotherapy procedures (an average of 1.1 radiotherapy procedures per admission). Thyroid cancer was responsible for half (50%) of these admissions, followed by cancer of unknown primary site (13%) and bone cancer (8%). Of these admissions, 64 were of males and 92 were of females. Under a third (59) of the 175 in-hospital radiotherapy services were provided to private patients in public and private hospitals and are assumed to be funded by Medicare. It should be noted that reported admitted patient radiotherapy services may not include all those administered during the hospitalisation.

In 2020–21, there were 1,187 cancer-related admissions of children (0–14 years) that involved radiotherapy, comprising a total of 1,332 radiotherapy procedures. The cancers most responsible for these admissions were brain cancer (668 admissions), kidney cancer (89 admissions), cancer of other endocrine glands (89 admissions), and bone cancer and cancer of the peritoneum (40 admissions each). Of admissions, 632 were of males while 555 were of females.

In 2020–21, there were 811 cancer-related admissions of older young adults (25–39) that involved radiotherapy, comprising a total of 957 radiotherapy procedures. The cancers most responsible for these admissions were thyroid cancer (304 admissions), cervical cancer (180 admissions) and cancer of unknown primary site (103 admissions). Of admissions, 249 were of males while 562 were of females.

Radiotherapy procedures provided to non-admitted patients

In 2020–21 (excluding South Australia, for which data was not available), there were an estimated 3,027 services delivered to people aged 15–24 in radiation therapy treatment clinics in non-admitted patient settings. There were also an estimated 331 radiation therapy (simulation and planning) sessions provided in these settings as well as an estimated 2,256 services in radiation oncology consultation clinics. Of services provided in these 3 clinics, 55% were provided to males.

It is not possible to describe for which cancer types these services were provided.

Regarding children (0–14 years), in 2020–21 there were 3,305 services delivered in non-admitted radiation therapy treatment clinics, along with 396 services in non-admitted radiation therapy simulation and planning clinics and 1,155 services in non-admitted radiation oncology consultation clinics. Of services provided in radiation therapy treatment and planning and simulation clinics, 52% were provided to males, while 59% of radiation oncology consultation clinics were provided to males.

Regarding older young adults (25–39), in 2020–21 there were 21,799 services delivered in non-admitted radiation therapy treatment clinics, along with 2,188 services in non-admitted radiation therapy simulation and planning clinics and 10,570 services in non-admitted radiation oncology consultation clinics. Approximately 30% of services provided in radiation therapy treatment clinics, radiation planning and simulation clinics, and in radiation oncology consultation clinics were provided to males (the balance to females).

MBS-subsidised radiation therapy services

In 2021–22, there were 9,903 MBS-subsidised radiation therapy services provided to people aged 15–24. Of these:

- almost all (9,824) were provided outside of an admitted hospital setting
- 79 were provided to admitted hospital patients. This is close to the 59 radiotherapy MBS services that were estimated for those private patients who received radiotherapy procedures in public and private hospitals reported in Table 3.9.

All hospital and MBS-subsidised radiation therapy services combined

The need to avoid duplication and the difficulties of combining data from different data sets has been discussed previously. Reported combined data described here should be considered indicative rather than exact.

When using data from different sources, there is the opportunity for overlap and discrepancy. For instance, the number of in-hospital radiotherapy services funded by Medicare were 20 more, 164 less and 554 more (respectively) for people aged 15–24, children (0–14) and older young adults (25–39), than the estimate based on NHMD data. Reported admitted patient radiotherapy services may not include all those administered during the hospitalisation.

Table 3.9: Count of all radiation therapy services, people aged 15–24, 2020–21

	MBS-funded	Other-funded	Total
Setting	**Count of services**		
In-hospital	59	116	175
Non-admitted (outpatients)	1,438	1,589	3,027
Other setting	8,386	0	8,386
Total (unadjusted)	9,883	1,705	11,588
In-hospital MBS 'discrepancy'	20	0	20
Total (adjusted)	9,903	1,705	11,608

Notes

1. Columns and rows will not add perfectly due to discrepancies between different data sources.

2. NHMD estimates 2,950 cancer-related private chemotherapy services, MBS describes 2,838 MBS-subsidised in-hospital chemotherapy services.

3. The count of admitted chemotherapy procedures may be an underestimate.

4. Non-admitted patient data excludes South Australia.

5. Non-admitted services are adjusted to account for under-reporting in the NNAP(EL)D relative to the NNAPC(AGG)D.

6. Some chemotherapy services may have been provided to treat diseases other than cancer.

Sources: MBS 2020–21; NHMD 2020–21; NNAP(EL)D 2020–21; NNAPC(AGG)D 2020–21.

For adolescents and young adults (people aged 15–24), 175 radiotherapy services were provided during cancer-related hospital admissions, and 3,027 radiotherapy services were provided in hospital outpatient clinics (some of which may not have been cancer related and this excludes South Australia). The majority (8,386) of radiotherapy services were provided in other settings. The total number of radiotherapy services provided to people aged 15–24 in 2020–21 is estimated at between 11,588 and 11,608 (excluding services provided in non-admitted settings in South Australia) (Table 3.9).

For children (people aged 0–14 years), 1,332 radiotherapy services were provided during cancer-related hospital admissions, and 3,305 radiotherapy services were provided in hospital outpatient clinics (some of which may not have been cancer related and this excludes South Australia). A large number (4,303) of radiotherapy services were provided in other settings. The total number of radiotherapy services provided to children in 2020–21 is estimated at between 8,776 and 8,940 (excluding services provided in non-admitted settings in South Australia).

For older young adults (people aged 25–39 years), 961 radiotherapy services were provided during cancer-related hospital admissions, and 21,799 radiotherapy services were provided in hospital outpatient clinics (some of which may not have been cancer related and this excludes South Australia). The majority (66,747) of radiotherapy services were provided in other settings. The total number of radiotherapy services provided to older young adults in 2020–21 is estimated at between 89,507 and 90,061 (excluding services provided in non-admitted settings in South Australia).

More detail is available in the online tables.

3.6 Other services provided in non-admitted patient clinics

A large range and number of services are provided in hospital outpatients departments. For many of these, it is not possible to clearly identify which relate specifically to cancer. In the case of chemotherapy and radiation treatment clinics reported in previous sections of this report, all of these are assumed to relate to cancer patients, although a small percentage may not.

There are several other clinics which are assumed to provide cancer-related services, these being radiation therapy (simulation and planning), gynaecological oncology, medical oncology consultation clinics, radiation oncology consultation clinics and allied health and/or clinical nurse specialist oncology classes.

In 2020–21, there were 37,084 cancer-related services provided to people aged 15–24 in these 7 clinics (of which 8,278 related to chemotherapy and radiation therapy, which were discussed in previous sections).

Half (18,627 services) of these services were provided at outpatient medical oncology consultation clinics, with a further 18% (6,761 services) at allied health and/or clinical nurse specialist oncology classes, 6% (2,256 services) were provided at radiation oncology consultation clinics, 1% (331 services) at radiation therapy (simulation and planning) clinics and 2% (832 services) at gynaecological oncology clinics.

Children and older young adults

Children (people aged 0–14) were the recipients of 61,773 cancer-related services in these 7 clinics (of which 3,675 related to chemotherapy and radiation therapy, which were discussed in previous sections).

Three-quarters (46,219 services) of these services were provided at outpatient medical oncology consultation clinics, with a further 17% (10,323 services) at allied health and/or clinical nurse specialist oncology classes, 2% (1,155 services) at radiation oncology consultation clinics, 1% (396 services) at radiation therapy (simulation and planning) clinics and 0% (7 services) at gynaecological oncology clinics.

Older young adults (people aged 25–39) were the recipients of 144,193 cancer-related services in these 7 clinics (of which 48,031 related to chemotherapy and radiation therapy, which were discussed in previous sections).

Just over a third (49,764 services) of these services were provided at outpatient medical oncology consultation clinics, with a further 17% (24,011 services) at allied health and/or clinical nurse specialist oncology classes, 7% (10,570 services) at radiation oncology consultation clinics, 2% (2,188 services) at radiation therapy (simulation and planning) clinics and 7% (9,628 services) at gynaecological oncology clinics.

4 Burden of cancer

Key findings

In 2022, for people aged 15–24:

- 6,848 disability-adjusted life years (DALY) were lost due to premature death from cancer or living with cancer and other neoplasms.
- Cancer was the second highest disease group for fatal burden, behind injuries.
- The total cancer burden was more pronounced in males (53% of total cancer burden) than in females (47%).
- Leukaemia was associated with the highest proportion of the cancer burden, followed by brain and central nervous system cancer, non-Hodgkin lymphoma, colorectal cancer, and Hodgkin lymphoma.
- Cancer burden decreased from 8,568 DALY in 2003 to 6,846 DALY in 2022.

Burden of disease (BOD) measures the combined impact of fatal and non-fatal burden. More than merely counting deaths or disease incidence and prevalence, it takes into account age at death, and severity of disease. Burden of disease analysis quantifies the gap between a population's actual health and an ideal level of health in a given year – that is, every individual living in full health based on the lowest observed death rate at each age group – for all diseases at the same time.

This chapter presents data on the burden of cancer in people aged 15–24, based on the Australian Burden of Disease Study 2022. The study provides Australia-specific burden of disease estimates best matched to the Australian context for the total 2022 population.

There have been 5 BOD studies between 2003 and 2022. Methodology has been improved incrementally, but data presented in this chapter for the 5 study years (2003, 2011, 2015, 2018 and 2022) are based on the most recent methodology, therefore allowing cautious comparison over time. The methodology is described in the *Australian Burden of Disease Study: methods and supplementary material 2018* (AIHW 2021c).

In the Australian Burden of Disease Study 2022, the cancer and other neoplasms disease group also includes the impact of benign, in situ, and uncertain neoplasms. Appendix A4 describes the complete listing of ICD-10 codes for each site. For more information, see the Australian Burden of Disease Study 2022 (AIHW 2022a).

Data are presented for the fatal burden, non-fatal burden, and the overall burden (fatal plus non-fatal burden) for adolescents and young adults. Fatal burden, which is expressed as years of life lost (YLL), measures the years lost between the age at which people die and the number of years they could have potentially gone on to live, based on the current best life expectancy across the world.

Non-fatal burden, which is expressed as years lived with disability (YLD), measures the years of healthy life lost due to living with a disease in a given year. Total YLD are influenced by the number of people with each disease, and the duration and severity of the effects of each disease.

The overall burden, which is expressed as disability-adjusted life years (DALY), is the sum of YLL and YLD. One DALY is one year of ‘healthy life’ lost due to premature death or living with the effects of an illness or injury. The more DALY associated with a disease, the greater the burden.

4.1 Burden of all cancers combined

In 2022, people aged 15-24 in Australia lost 6,848 DALY due to premature death from, or living with, cancer or other neoplasms. This burden was almost entirely due to dying prematurely (93%).

While cancer and other neoplasms was the 10th most burdensome disease group in people aged 15–24 overall, it was the second highest ‘disease group’ in terms of fatal burden, behind injuries (AIHW 2022a). Due to the recent COVID pandemic, total burden due to infectious diseases has recently overtaken the total burden due to cancer in this age group.

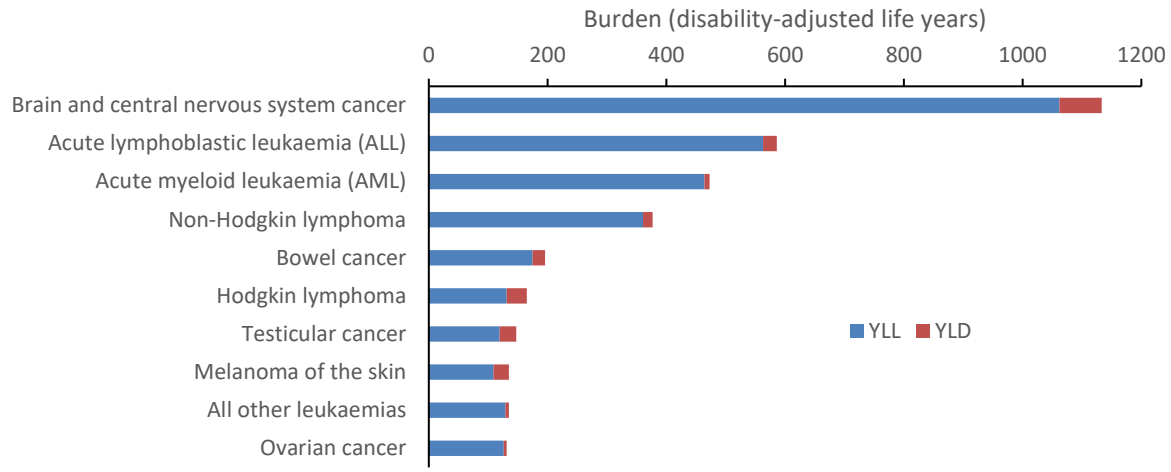
In the 5 BOD studies between 2003 and 2022, the number of DALYs from cancer has tended to decrease from 8,568 (3.2 per 1,000) to 6,848 (2.2 per 1,000), suggesting that the total burden of cancer in this age group has decreased over time. This decrease is entirely due to a decrease in fatal burden (the relatively small component of non-fatal burden has tended to increase over time from 5% of the cancer burden in 2003 to 7% of the cancer burden in 2022).

4.2 Burden by cancer type

In 2022, leukaemia as a group (1,194 DALY) and cancers of the brain and central nervous system (1,133 DALY) were the largest contributors to the cancer burden for people aged 15–24, followed by non-Hodgkin lymphoma (376 DALY), colorectal (bowel) cancer (195 DALY), and Hodgkin lymphoma (167 DALY) (Figure 4.1). The burden from these 5 cancer groups was predominantly due to dying early. Of the leukaemia's, acute lymphoblastic leukaemia (586 DALY) and acute myeloid leukaemia (473 DALY) were responsible for the largest burden.

Together, these 5 cancer groups accounted for 45% of the total cancer burden in people aged 15–24.

Figure 4.1: Disability-adjusted life years for the 10 leading causes of cancer burden, by fatal and non-fatal burden, 15–24 years, 2022



Note: Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A4).

Source: AIHW Australian Burden of Disease Database 2022.

4.3 Burden of cancer by sex

In 2022, the total cancer burden in people aged 15–24 was greater in males (53%) than females (47%) (Table 4.1).

In 2022, leukaemias (750 DALY, predominantly acute lymphoblastic leukaemia (379 DALY) and acute myeloid leukaemia (291 DALY)) contributed the greatest cancer burden in young males, followed by cancer of the brain and central nervous system (713 DALY), non-Hodgkin lymphoma (226 DALY), testicular cancer (146 DALY) and liver cancer (118 DALY). These 5 cancers represented 54% of the total cancer burden in males aged 15–24.

For young females, leukaemias (445 DALY, predominantly acute lymphoblastic leukaemia (207 DALY) and acute myeloid leukaemia (183 DALY)) contributed the greatest cancer burden, followed by cancer of the brain and central nervous system (421 DALY), non-Hodgkin lymphoma (151 DALY), Hodgkin lymphoma (149 DALY) and ovarian cancer (131 DALY). These 5 cancers represented 40% of the total cancer burden in females aged 15–24.

Table 4.1: Disability-adjusted life years for the 10 most common causes of burden due to cancer and other neoplasms, by sex, 15–24 years, 2022

Males		Females	
Cancer type	**DALY**	**Cancer type**	**DALY**
Brain and central nervous system cancer	713	Brain and central nervous system cancer	421
Acute lymphoblastic leukaemia (ALL)	379	Acute lymphoblastic leukaemia (ALL)	207
Acute myeloid leukaemia (AML)	291	Acute myeloid leukaemia (AML)	183
Non-Hodgkin lymphoma	226	Non-Hodgkin lymphoma	151
Testicular cancer	146	Hodgkin lymphoma	149
Liver cancer	118	Ovarian cancer	131
Bowel cancer	104	Bowel cancer	92
All other leukaemias	80	Melanoma of the skin	72
Benign and uncertain brain tumours	69	Stomach cancer	58
Melanoma of the skin	61	All other leukaemias	55
All other neoplasms	1,438	All other neoplasms	1,702
All neoplasms	3,625	All neoplasms	3,221

Note: Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A3).

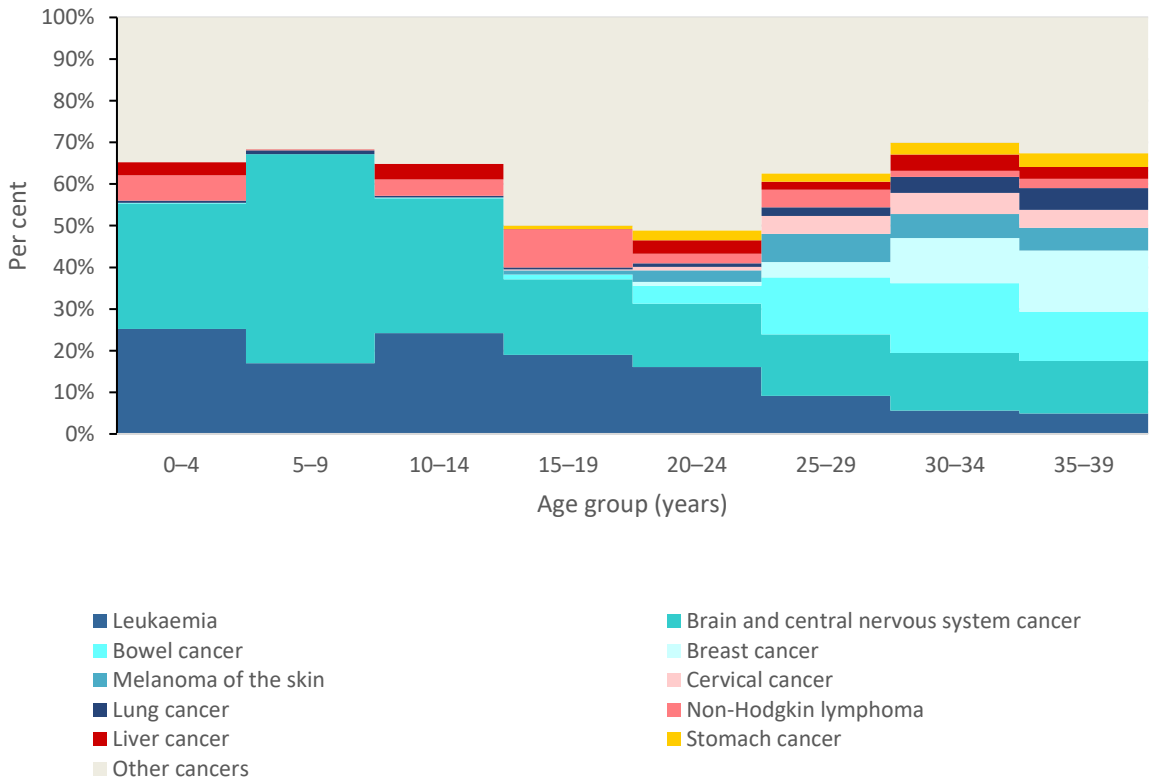
Source: AIHW Australian Burden of Disease Database 2022.

4.4 Burden of cancer by age

The pattern of cancer burden differed across the lifespan (Figure 4.2).

- For those aged 0–14, leukaemias and brain and central nervous system cancers were the most common causes of cancer burden, with non-Hodgkin lymphoma and liver cancer also contributing.
- For those aged 15–24, leukaemias, brain and central nervous system cancers and non-Hodgkin lymphoma were the most common causes of cancer burden, with a range of other cancers also contributing to the overall cancer burden.
- For those aged 25–39, brain and central nervous system cancers (and to a lesser extent leukaemias) contributed to total burden, with colorectal, breast and cervical cancer, melanoma and a range of other cancers (such as lung, liver and stomach cancer) starting to contribute.

Figure 4.2: Cancer burden (% DALY), by age group (years) and cancer type, 0–39 years, 2022



Note: Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A4).

Source: AIHW Australian Burden of Disease Database 2022.

More detailed data is available in the online tables.

4.5 Trend over time

For people aged 15–24, the total burden due to cancer has tended to decrease over time from 8,568 DALY in 2003 to 6,846 DALY in 2022. The DALY rate for people aged 15–24 has also tended to decrease during this period from 3.2 DALY per 1,000 population in 2003 to 2.2 DALY per 1,000 population in 2022.

Between 2003 and 2022, the total burden due to all causes experienced by people aged 15–24 changed very little (from 287,100 DALY to 308,400 DALY), and the percentage of the total burden due to cancer decreased from 3% in 2003 to 2% in 2022 in line with the decrease in cancer burden described above.

The percentage of the cancer burden in people aged 15–24 that was non-fatal increased from 5% to 7% over this period.

For children (0–14) and older young adults (25–39), burden also tended to decrease over time, from 9,399 to 7,680 DALY and from 35,039 to 33,128 DALY, respectively, between 2003 and 2022. The DALY rate also decreased over time, from 2.4 to 1.6 DALY per 1,000 population for children and from 8.1 to 5.9 DALY per 1,000 population for older young adults between 2003 and 2022. For children and older young adults, the percentage of the cancer burden that was non-fatal increased from 4% to 5% and from 6% to 8%, respectively, over this period.

Table 4.2 describes the cancer burden for people aged 15–24 from burden of disease studies since 2003. While there appears to have been a general decrease in burden over time, this is not always clear for each cancer type.

Estimates of burden for most cancer types exhibit volatility (Table 4.2). The data appear to show decreases in disease burden for brain and central nervous system cancers, acute lymphoblastic leukaemia, Hodgkin lymphoma, melanoma, and ovarian cancer, and a possible increase in burden for testicular cancer.

More detail is available in the online tables.

Table 4.2: Burden of disease for the 10 leading cancers, for each BOD study, 15–24 years, 2003–2022

	2003	2011	2015	2018	2022
Cancer	Total burden (DALY)				
Brain and central nervous system cancer	1,483	1,017	1,033	952	1,133
Acute lymphoblastic leukaemia (ALL)	882	906	656	358	586
Acute myeloid leukaemia (AML)	480	335	632	419	473
Non-Hodgkin lymphoma	506	251	554	428	376
Bowel cancer	152	358	234	99	195
Hodgkin lymphoma	367	297	102	100	167
Testicular cancer	85	94	90	350	146
Melanoma of the skin	369	213	217	87	134
All other leukaemias	202	5	142	334	135
Ovarian cancer	280	199	140	79	131
All other neoplasms	3,762	3,171	3,893	2,804	3,370
All neoplasms	8,568	6,846	7,693	6,010	6,846

Note: DALYs are disability-adjusted life years and are a measure of total burden due to a disease.

Source: AIHW Australian Burden of Disease Database 2022.

5 Focus on key population groups

Key findings

Indigenous Australians

In the 9-year period 2010–2018, a total of 266 Indigenous people aged 15–24 (an average of 30 per year) were diagnosed with cancer in the 5 states/territories (New South Wales, Victoria, Queensland, Western Australia and the Northern Territory) for which Indigenous identification is considered adequate. However, this is likely to be an undercount.

In this period, the incidence rate for Indigenous people aged 15–24 (221 cases per 1,000,000 persons) was significantly lower than for non-Indigenous people aged 15–24 (308 cases per 1,000,000 persons).

Although counts vary from year to year, the trend is for cancer incidence for Indigenous people aged 15–24 to increase by around one case each year since 2008.

In the 10-year period 2011–2020, 45 Indigenous people aged 15–24 in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory died because of cancer, corresponding to a death rate (34 deaths per 1,000,000 population) that was similar to that for non-Indigenous people aged 15–24 (31 deaths per 1,000,000 population). While death rates decreased for non-Indigenous people aged 15–24 between 2001–2010 and 2011–2020 (from 41 to 31 per 1,000,000 population), a decrease was not clearly apparent for Indigenous people aged 15–24.

For the period 2009–2018, adjusted 5-year relative survival (adjusted to the national cancer distribution) for Indigenous people aged 15–24 was 82%, compared with 89% for non-Indigenous people aged 15–24.

State and territory

In 2010–2018, cancer incidence rates for people aged 15–24 were similar across jurisdictions (but lower in the Northern Territory) after melanoma is excluded from the comparison.

Incidence rates for all cancers combined for people aged 15–24 did not change significantly between 2001–2009 and 2010–2018, except in Queensland where rates decreased from 368 to 324 cases per 1,000,000 population. This reflects substantial decreases in melanoma incidence rates across the country during this period, especially in Queensland where rates for people aged 15–24 fell by over 50 cases per 1,000,000 population.

There are some differences in death rates between states and territories, with rates in Tasmania tending to be slightly higher and rates in Victoria and the Australian Capital Territory tending to be slightly lower.

Between 2001–2009 and 2010–2018, cancer death rates declined clearly in Victoria and Queensland, tended to be lower in New South Wales, Western Australia, South Australia and the Northern Territory, and showed no change in Tasmania and the Australian Capital Territory.

(continued)

Key findings (continued)

In 2010–2018, cancer survival was similar across jurisdictions. Cancer survival for people aged 15–24 in New South Wales and South Australia was clearly higher in 2010–2018 than in 2001–2009. Cancer survival in all the other jurisdictions have tended to increase also.

Regional and remote populations

In the period 2010–2018, cancer incidence for people aged 15–24 was higher in *Inner regional* areas, similar in *Outer regional* areas, and slightly lower in *Remote and very remote* areas, compared with *Major cities*. A major contributing factor to this pattern is the higher rates of melanoma in regional areas (over 40% higher than in *Major cities*).

The cancer incidence rate did not change significantly between 2001–2009 and 2010–2018 in any of the remoteness areas. Melanoma incidence rates have decreased in *Major cities* and regional areas, in line with a decrease in Australia generally.

In 2011–2020, cancer death rates for people aged 15–24 were higher in regional areas than in *Major cities*. For this age group, cancer death rates in remote areas were similar to those in *Major cities*.

Death rates in *Major cities* and *Inner regional* areas have clearly decreased between 2001–2010 and 2011–2020, with rates in *Outer regional* areas tending to be lower, and no clear difference for *Remote and very remote* areas.

In 2010–2018, adjusted 5-year relative survival for people aged 15–24 was similar in *Major cities* and *Inner regional* areas, but lower in *Outer regional* and *Remote and very remote* areas when compared with *Major cities*.

Between 2001–2009 and 2010–2018, cancer survival for people aged 15–24 increased in *Major cities* and *Inner regional* areas but remained similar in *Outer regional* and *Remote and very remote* areas.

While there is insufficient data to draw conclusions for most cancer types, survival for blood cancers has increased in both *Major cities* and regional/remote areas; and while survival for blood cancers outside *Major cities* was significantly lower in 2004–2008 than it was inside *Major cities*, by 2014–2018 there was little difference between these 2 areas.

Socio-economic group

In 2010–2018, cancer incidence rates for people aged 15–24 were similar for the 5 socio-economic indexes for areas (SEIFA) quintiles.

There was little change in cancer incidence for people aged 15–24 in any of the SEIFA quintiles between 2001-2009 and 2010–2018.

In 2011–2020, for people aged 15–24, there was a clear and consistent decrease in cancer death rates as socioeconomic disadvantage decreased. This pattern is also apparent in data for the previous (2001–2010) period.

Cancer death rates for people aged 15–24 have tended to decrease between 2001–2010 and 2011–2020 in all SEIFA quintiles.

In 2010–2018, survival was lower in the most disadvantaged SEIFA quintile (87%) than in the others (90%–92%).

Between 2001–2009 and 2010–2018, survival tended to become higher in all quintiles.

Data for this chapter are sourced from the ACD 2018 and the AIHW NMD.

Because the annual numbers of cases or deaths in many populations are quite small, incidence, mortality and survival have been reported for a longer period than in the rest of this report. The periods chosen typically approximate the most recent decade for which data are available, and where possible, the preceding decade. Various data constraints mean that a range of periods have been used – 2010–2018 (and 2001–2009) for incidence and survival, 2011–2020 (and 2001–2010) for mortality, and 2009–2018 for Indigenous survival.

The aim is to provide data for as contemporary a period as possible, while avoiding volatility as much as possible, and providing recent historical data that would provide a sense of consistency or some information about trend where possible.

Data in this section are only provided for people aged 15-24. Extensive use of confidence limits are made. Where clear differences between populations exist, these are referred to as significant differences or statistically significant differences. When differences fail to reach statistical significance, but other factors suggest a real difference is likely, then these have been referred to as tendencies.

Statistics have been reported for persons (and not for males and females) due to relatively small counts.

Statistics for cancer groups have been provided in the online tables, but have not been described extensively in the text.

Box 5.1: Confidence intervals, and their place in this chapter

Describing cancer statistics for small populations is challenging, and many of the populations in this chapter are small, with relatively small numbers of cases and deaths upon which to report.

Year-to-year volatility, especially the case in small populations, can result in wild fluctuations in calculated rates (as demonstrated when comparing rates for the relatively large non-Indigenous population and the relatively small Indigeous population in Figure 5.2).

Aggregating years of data and reporting for persons only (that is, not for males or for females), as well as aggregating cancer types helps to boost the numbers upon which reliable rates rely.

However, residual volatility can still be substantial.

So as to provide the reader with a sense of the reliability of a rate, confidence intervals accompany rates in the figures for this chapter and in the online tables.

The method for calculating confidence intervals used in this chapter is described in Appendix E1.

When a cancer is diagnosed depends on when individuals are tested. It is possible that a cancer diagnosed in October 2018, may otherwise have been diagnosed in January 2019, and if so, would not have been counted in this report. Chance can result in several cancers being diagnosed in one year, and few in the next. While chance variation from year to year is not so much of a problem when reporting for large populations, it can substantially affect statistics for small populations, and therefore comparison between these populations (see Figure 5.2).

The following example is offered to assist the reader interpret results.

A rate of 9 new cases of cancer per 1,000,000 population, with a 95% confidence interval of 8 to 10 can be interpreted as meaning that the best estimate for the rate is 9, but there is a 5% chance that it could either be less that 8 or higher than 10. By convention, this rate can be considered (statistically significantly) different from a rate for another population that has a confidence interval of between 11 and 14 (the confidence intervals don't overlap), but not different from one which has a confidence interval of between 9 and 17 (the confidence intervals overlap).

However, confidence intervals are a guide. If rates for one group are consistently higher than for another, but each rate fails to be statistically significantly higher at the 95% level of confidence, it may nonetheless be reasonable to assume that a real difference is likely to exist. This approach has been taken in this chapter.

5.1 Aboriginal and Torres Strait Islander People

Early access to cancer diagnosis and treatment services is key to improving outcomes. Indigenous Australians are more likely than non-Indigenous Australians to live in remote areas, where access to appropriate services can be more difficult. Late diagnosis of cancer can contribute to lower survival rates for some cancers, leading to higher mortality.

Based on 2016 Census, the Australian Bureau of Statistics (ABS) projects there to be approximately 879,000 Indigenous Australians living in Australia in 2021, and of these around 167,000 (19%) are aged 15–24 (ABS 2021b). Of all Indigenous Australians, 38% live in *Major cities*, 44% live in *Inner regional* or *Outer regional* areas and 18% live in *Remote or Very remote* areas (AIHW 2021d).

New cases

Reliable national data on the diagnosis of cancer for Indigenous Australians are not available. For the most recent reporting period, Indigenous status is considered to be of sufficient quality for reporting cancer incidence for 5 jurisdictions: New South Wales, Victoria, Queensland, Western Australia, and the Northern Territory. About 90% of all Indigenous Australians live in those jurisdictions (ABS 2022b).

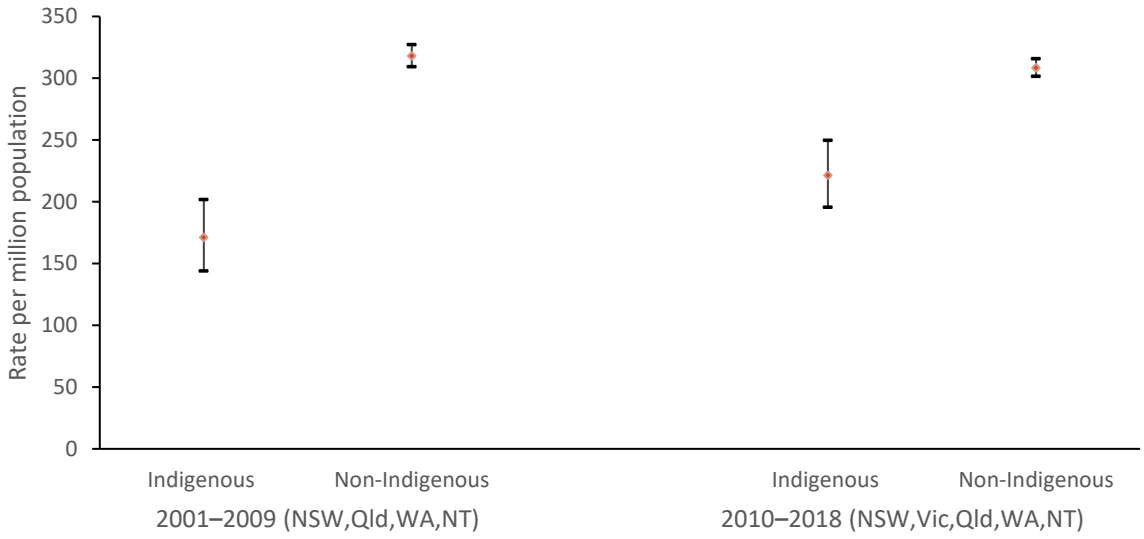
For the 5 jurisdictions in 2010–2018, 7% of people aged 15–24 diagnosed with cancer (561 cases) did not have Indigenous status information provided. Also, of those for whom Indigenous status information was provided, it is not known how many Indigenous people aged 15–24 are misclassified as 'non-Indigenous' or classified as 'unknown' Indigenous status. However, as some Indigenous Australians are likely to be misclassified as 'non-Indigenous Australians' or classified as 'unknown' Indigenous status, the statistics presented in this report are very likely to be underestimates.

In the 9 years 2010 to 2018, there were 266 Indigenous people aged 15–24 diagnosed with cancer from the 5 jurisdictions (New South Wales, Victoria, Queensland, Western Australia and the Northern Territory), an average of 30 per year. Since 2008, the number of new cases varied considerably from year to year between 19 (in 2013) and 37 (in 2018) (see online tables for Figure 5.2). The general trend is for the number of diagnoses to increase by around one per year, on average.

In the same period (2010–2018), there were 7,377 non-Indigenous people aged 15–24 in these 5 jurisdictions diagnosed with cancer (an average of 820 per year). Since 2008, the number of new cases varied from year to year between 705 (in 2010) and 890 (in 2016). The general trend is for the number of diagnoses to increase by around 12 per year, on average (see online tables for Figure 5.2).

In the period 2010–2018, there was an average of 221 new cases of cancer diagnosed per 1,000,000 Indigenous people aged 15–24, compared with 308 new cases per 1,000,000 non-Indigenous people aged 15–24 (Figure 5.1). It is unclear to what extent the estimate for Indigenous people is an undercount.

Figure 5.1: Incidence of all cancers combined, 2001–2009 and 2010–2018, by Indigenous status, 15–24 years



Notes

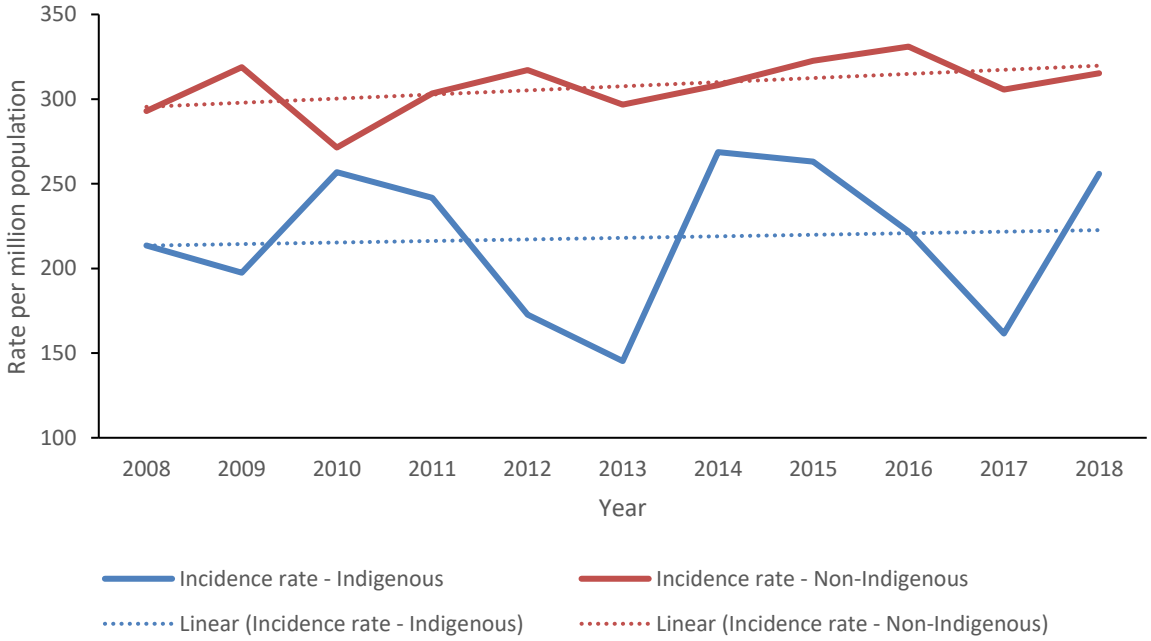
1. Rates for the 2 time periods are not strictly comparable, as rates in the first period do not include diagnoses of people resident in Victoria, while those in the second period do.
2. Comparison of rates in 2001–2009 and 2010–2018 may be affected by changes to Indigenous status over time.
3. Rates, particularly for Indigenous people, could be higher depending on the actual indigenous status of 561 diagnoses for which Indigenous status has not been stated, and also the number of Indigenous cases categorised as non-Indigenous cases. It should be noted that the Indigenous rates in 2010–2018 are based on a total of 266 diagnoses of Indigenous people aged 15–24. Consequently, the opportunity for upward revision of Indigenous rates is substantial (and unknown).

Source: AIHW ACD 2018.

With exceptions, cancers diagnosed in Indigenous people aged 15–24 were proportionally similar to those diagnosed in non-Indigenous people aged 15–24, with the exception of melanoma. For Indigenous and non-Indigenous people aged 15–24, respectively, in 2010–2018:

- 32% and 30% of diagnoses were blood cancers
- 27% and 28% were carcinomas
- 15% and 15% were germ cell cancers (predominantly testicular cancer)
- 6% and 5% were soft tissue sarcomas
- 5% and 6% were central nervous system cancers
- 7% and 4% were bone cancers
- 6% and 12% were melanomas.

Figure 5.2: Incidence of all cancers combined, for people aged 15–24 years, by Indigenous status, 2008–2018



Note: New cases from New South Wales, Victoria, Queensland, Western Australia, and the Northern Territory.

Source: AIHW ACD 2018.

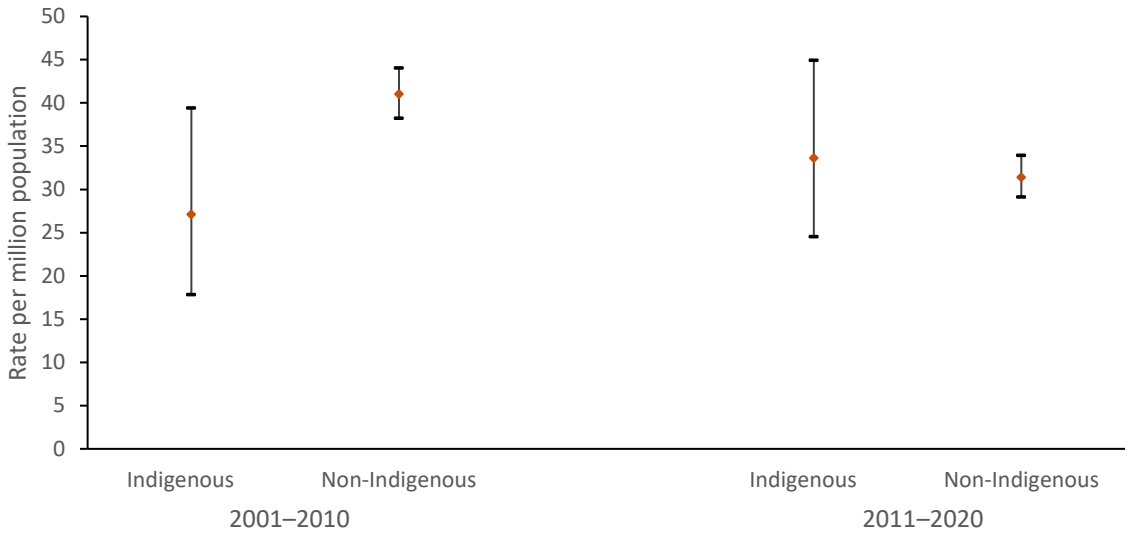
Deaths

Information in the NMD on Indigenous status in 2001–2010 and 2011–2020 is considered to be of sufficient quality for reporting deaths data for 5 jurisdictions: New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory. In 2022, just under 90% of all Indigenous Australians lived in these jurisdictions (ABS 2022b). For these 5 jurisdictions, 8 people aged 15–24 (1%) recorded in the NMD who died from cancer had an unknown/unstated Indigenous status in 2011–2020, compared with 11 people aged 15–24 (1%) in 2001–2010.

In 2011–2020, 45 Indigenous people aged 15–24 and 656 non-Indigenous people aged 15–24 died of cancer. In the preceding period (2001–2010), 27 Indigenous people aged 15–24 and 785 non-Indigenous people aged 15–24 died of cancer. Due to limitations regarding the available Indigenous status information, including some Indigenous deaths potentially being recorded as non-Indigenous, death rates for Indigenous people aged 15–24 are very likely to be underestimates for both periods.

In 2011–2020, the cancer-related death rate for Indigenous people aged 15–24 was 33.6 deaths per 1,000,000 population compared with 31.4 deaths per 1,000,000 population for non-Indigenous people of the same age. These rates were not statistically significantly different from one another (Figure 5.3). Figure 5.3 also shows that while mortality rates had decreased significantly for non-Indigenous people aged 15–24 between 2001–2010 and 2011–2020, there didn't appear to be any significant change for Indigenous people of the same age.

Figure 5.3: Mortality rate due to all cancers combined, 2001–2010 and 2011–2020, by Indigenous status, 15–24 years



Notes

1. Mortality data are for New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory.
2. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.
3. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.
4. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

Source: AIHW NMD.

Reporting of mortality for cancers using the SEER-based categorisation is currently possible only for 2013–2017. In this period there were 29 deaths of Indigenous people aged 15–24 and 419 deaths of non-Indigenous people aged 15–24.

The relatively small numbers restrict meaningful comparison between the 2 populations. However, for Indigenous people aged 15–24, blood cancers, carcinomas, bone cancers and soft tissue sarcomas were responsible for 90% of deaths due to cancer, while for non-Indigenous people aged 15–24 these cancer groups plus central nervous system cancers were responsible for a similar proportion (88%) of deaths due to cancer.

Survival

To improve statistical power, 5-year survival estimates have been calculated for a 12-year period, 2009–2020.

Box 5.2: Adjusted survival – why, and what is it?

To improve valid comparison between the populations, survival in this chapter has been 'adjusted to the national incidence distribution by site'.

The incidence of some higher survival cancers (such as melanoma) is lower in the Indigenous population, and so lower survival in this group could be due to the greater proportion of cancers which are harder to survive. 'Adjusted survival' 'tweaks' calculated survival so that it reflects what the survival would have been if the mix of cancers in the 2 populations had been the same as in the national population (that is, differences between the populations will reflect any real difference in survival rather than reflect the difference in the mix of cancers in the Indigenous and non-Indigenous populations) (see Appendix E2).

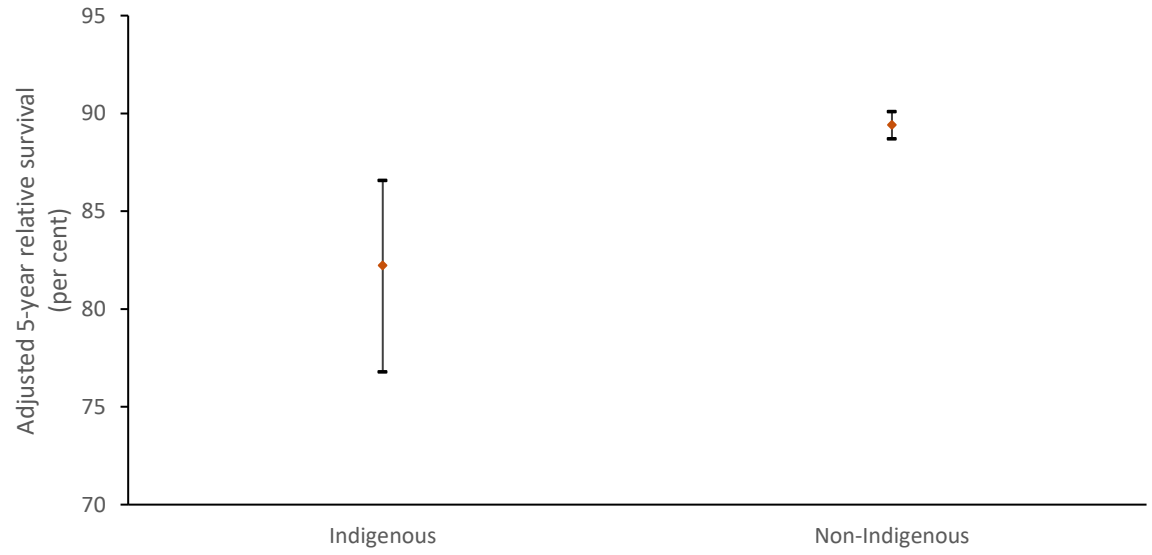
However, the effect of adjustment was found to be small.

Both adjusted and unadjusted survival are reported in the online tables.

In 2009–2020, survival was significantly lower for Indigenous people aged 15–24 than for non-Indigenous people aged 15–24.

In this period, adjusted 5-year relative survival was 82% for Indigenous people aged 15–24 compared with 89% for non-Indigenous people of the same age (Figure 5.5).

Figure 5.4: Adjusted 5-year relative survival, all cancers combined, 2009–2018, by Indigenous status, 15–24 years



Notes

1. Survival has been adjusted to the national incidence distribution by site.
2. 95% confidence intervals reflect the level of certainty around the survival estimate. The estimate for Indigenous people aged 15–24 is less certain than for non-Indigenous people aged 15–24 because the former is based upon a relatively small number of cases and deaths.

Source: AIHW ACD 2018.

Survival for individual cancer groups has not been presented because of the small number of cases diagnosed, which would make calculated survival especially unreliable.

5.2 State and territory

New cases

In the 9-year period 2010–2018, the average annual number of new cases of cancer in people aged 15–24 ranged from 332 in New South Wales to 9 in the Northern Territory.

In the period 2010–2018, cancer incidence rates tended to be broadly similar across most of the states and territories, perhaps slightly higher in Queensland and Tasmania, and tended to be slightly lower in Victoria, South Australia, the Australian Capital Territory and the Northern Territory. Incidence rates in Queensland (324 cases per 1,000,000 population) were significantly higher than the Australian average (292), while rates in Victoria (266) and the Northern Territory (217 cases per 1,000,000 population) were lower than the Australian average (Table 5.1).

The diagnosis rate of melanoma was higher in Queensland than in any of the other states. When melanoma is excluded from the comparison, overall cancer incidence rates tended to be broadly similar across the states and territories (237 to 283 cases per 1,000,000 population), but lower (195 cases per 1,000,000 population) in NT.

Table 5.1: Incidence of cancer in people aged 15–24, by jurisdiction, 2001–2009 and 2010–2018

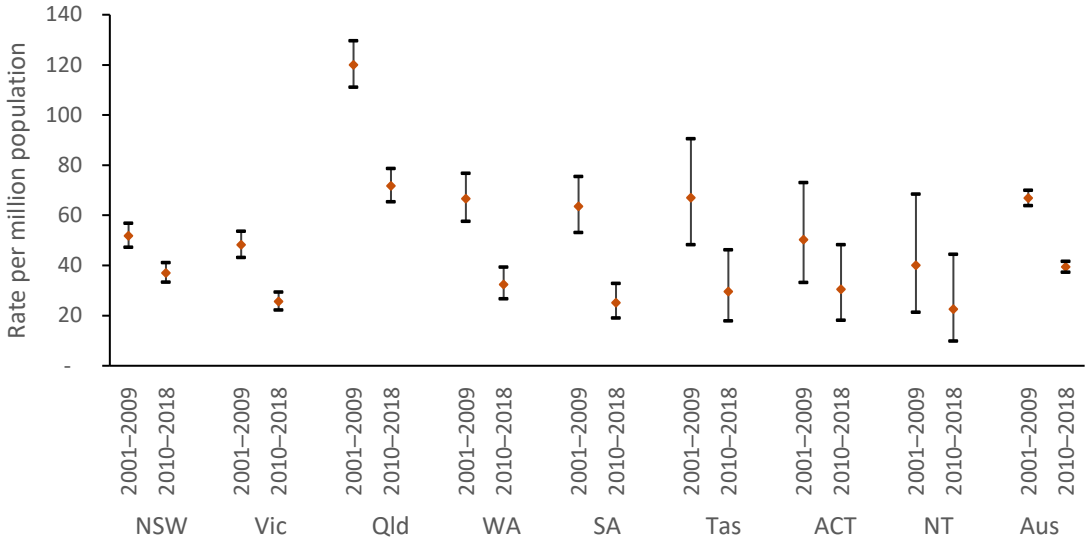
	Count		Rate (all cancers)		Rate (all cancers excluding melanoma)	
	2001–2009	2010–2018	2001–2009	2010–2018	2001–2009	2010–2018
New South Wales	2,605	2,991	288	305	236	268
Victoria	1,836	2,129	266	266	217	240
Queensland	2,010	2,067	368	324	248	252
Western Australia	843	940	292	282	226	250
South Australia	599	579	292	264	229	239
Tasmania	163	200	260	312	193	283
Australian Capital Territory	142	158	264	268	214	237
Northern Territory	56	77	172	217	132	195
Australia	**8,254**	**9,142**	**296**	**292**	**230**	**252**

Note: Rates are expressed per 1,000,000 population.

Source: AIHW ACD 2018.

There is no significant difference between state incidence rates in 2001–2009 and 2010–2018, apart from in Queensland, where rates decreased from 368 to 324 cases per 1,000,000 population. This reflects a decrease in melanoma incidence rates in Queensland from 120 to 70 cases per 1,000,000 population between 2001–2009 and 2010–2018. This decrease in Queensland has also been identified by others (Holland et al. 2021). Decreases in melanoma rates were also apparent in New South Wales, Victoria, Western Australia, South Australia and Tasmania with rates in some states less than half what they were in the previous period, and a tendency to be lower in the Australian Capital Territory and Northern Territory (Figure 5.5).

Figure 5.5: Incidence rates for melanoma, by jurisdiction, 2001–2009 and 2010–2018, 15–24 years



Source: AIHW ACD 2018.

More detailed data is available in the online tables.

Deaths

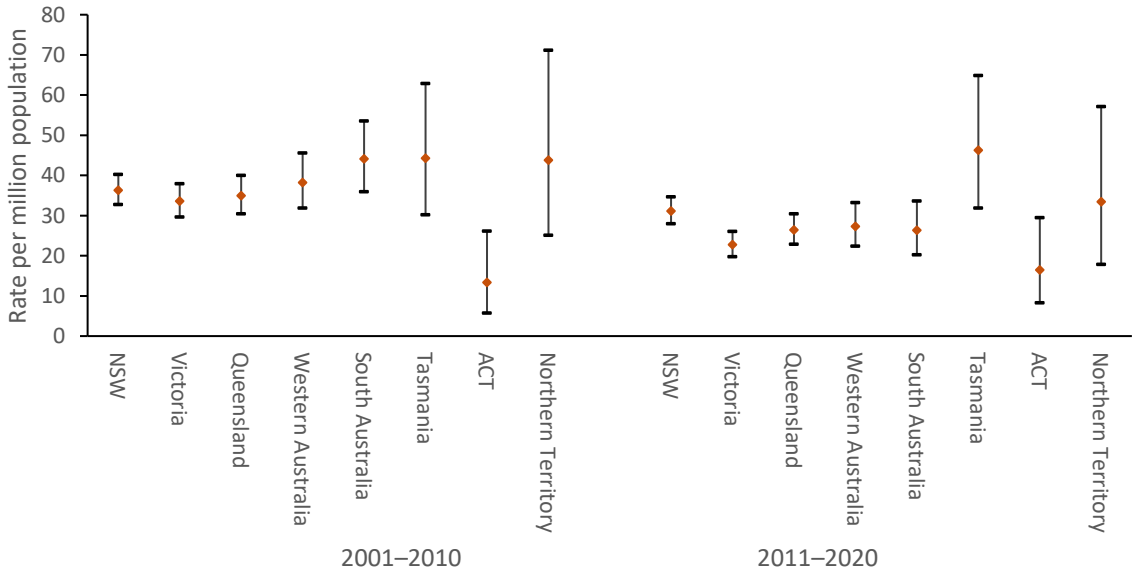
In the 10-year period 2011–2020, the average annual number of deaths of people aged 15–24 due to cancer ranged from 34 in New South Wales to 1 in both the Australian Capital Territory and Northern Territory.

There were some inter-jurisdictional differences in death rate, with rates in Victoria (23 deaths per 1,000,000 population) being lower than in New South Wales (31 deaths per 1,000,000 population) and Tasmania (46 deaths per 1,000,000 population), and rates in the Australian Capital Territory (16 deaths per 1,000,000 population) also being lower than in Tasmania (Figure 5.7).

Rates in Tasmania were higher than the Australian average (27 deaths per 1,000,000 population).

Between 2001–2010 and 2011–2020, cancer death rates have decreased in most jurisdictions. Cancer death rates decreased in Victoria (from 34 deaths per 1,000,000 population in 2001–2009 to 23 in 2010–2018) and Queensland (from 35 to 26 deaths per 1,000,000 population), and trended lower in New South Wales, Western Australia, South Australia and the Northern Territory, with rates remaining similar in Tasmania and the Australian Capital Territory.

Figure 5.6: Mortality rate for all cancers combined, by jurisdiction, 2001–2010 and 2011–2020, 15–24 years



Notes

1. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.

2. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.

3. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

Source: NMD 2020.

More detailed data is available in the online tables.

Survival

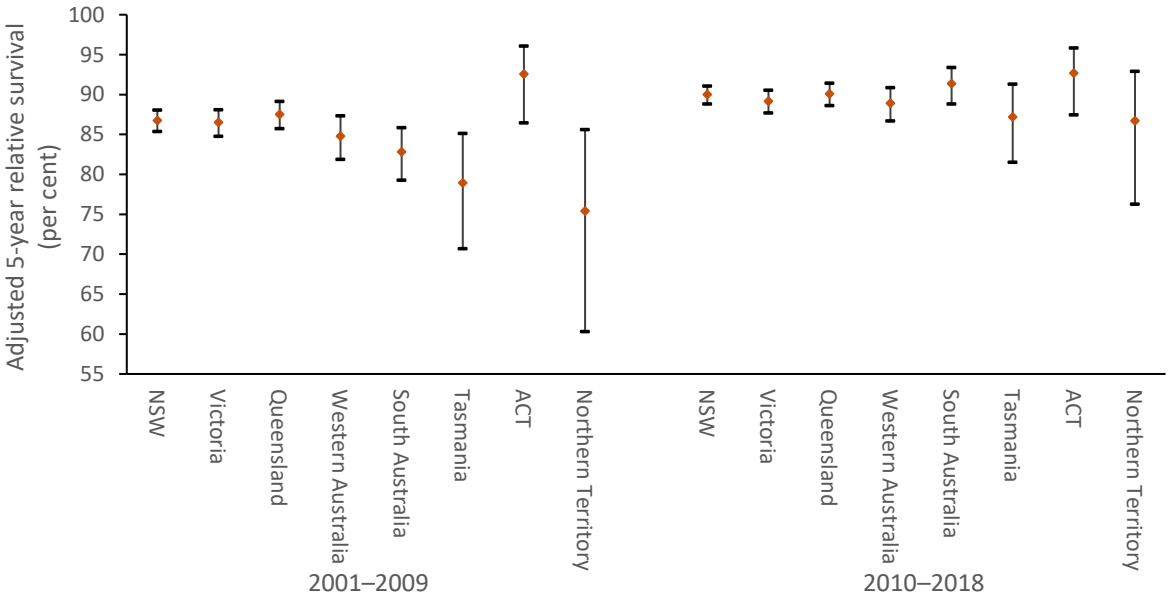
Cancer death rates, discussed earlier, reflect both the number of cases of cancer in the population and the capacity of the health system to treat cancer. Relative survival provides a clearer understanding of the probability of surviving a cancer diagnosis for a specified time, given the background mortality (from any cause of death) within the population.

All-cancer 5-year relative survival reported here has been adjusted to reflect the national distribution of cancer types. The mix of cancers differs between states, with Queensland having a higher incidence of high-survival cancers than many of the other states. Adjusting survival largely removes this influence and makes comparison between jurisdictions more valid (see Appendix E2).

In the period 2010–2018, there was no significant difference between survival in any of the jurisdictions. Point estimates for Tasmania and the Northern Territory tended to be a little lower than for other jurisdictions, while the estimate for Australian Capital Territory was a little higher than for other jurisdictions. These tendencies are also reflected in data for 2001–2009 (Figure 5.7).

There was a general tendency for survival in all jurisdictions to be higher in 2010–2018 than in 2001–2009.

Figure 5.7: Adjusted 5-year relative survival, all cancers combined, 2001–2009 and 2010–2018, by jurisdiction, 15–24 years



Notes

1. Survival has been adjusted to the national incidence distribution by site.
2. The estimate of survival is accompanied by lower and upper 95% confidence limits. Data are used to estimate the underlying rates in the population. The confidence interval indicates the degree of certainty that the estimate is close to the true rate.
3. Jurisdiction is based on area of usual residence (statistical local area, level 2) at time of diagnosis.

Source: AIHW ACD 2018.

More detailed data is available in the online tables.

5.3 Remoteness area

People living in regional and remote areas of Australia are often disadvantaged in terms of access to primary health-care services, educational and employment opportunities, and income. They are also more likely to have higher rates of risky health behaviours, such as smoking, heavy alcohol use, and poor nutrition (AIHW 2016b).

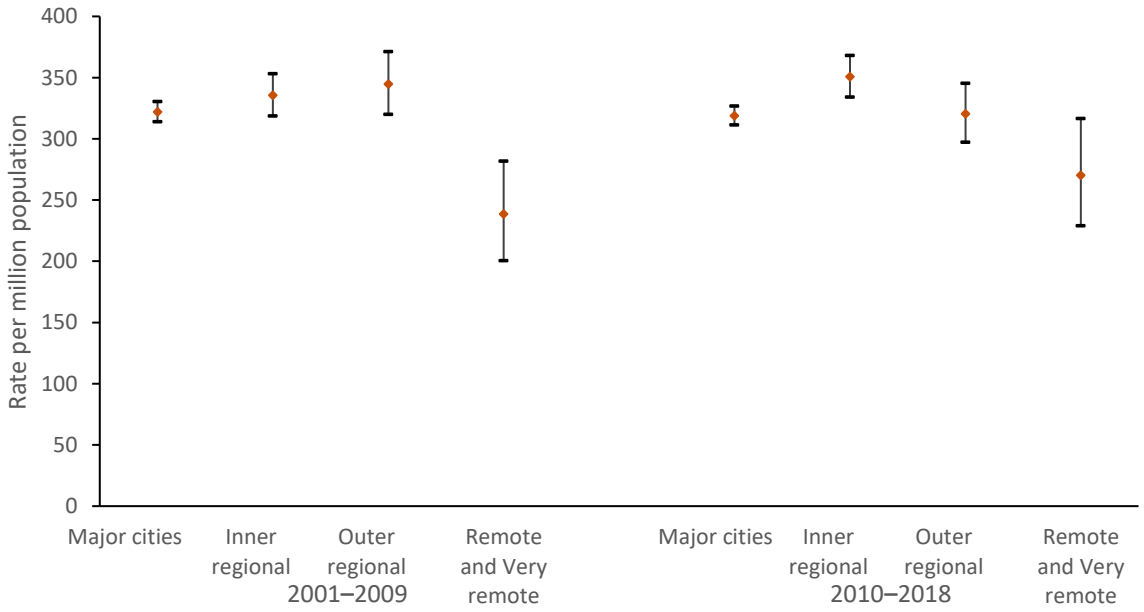
Incidence and mortality rates were calculated according to remoteness area of residence at the time of diagnosis for cancer incidence, and at the time of death for cancer mortality. Remoteness areas divide Australia into broad geographic regions that share common characteristics of remoteness for statistical purposes; being *Major cities*, *Inner regional* areas, *Outer regional* areas, *Remote* and *Very remote* areas (aggregated here and referred to as '*Remote and Very remote*' areas).

New cases

Due to the relatively small numbers of cases in some areas, and to boost statistical power, incidence data reported here for people aged 15–24 relate to an expanded 9-year time-period (2010–2018), with data also reported for the preceding 9-year period 2001–2009.

In the 9-year reporting period 2010–2018, there was an average of 736 people aged 15–24 diagnosed with cancer in *Major cities* per year, and 183, 77 and 17 diagnosed per year in *Inner regional*, *Outer regional* and *Remote and Very remote* areas respectively.

Figure 5.8: Incidence of all cancers combined, 2001–2009 and 2010–2018, by remoteness area, 15–24 years



Note: Geography is based on area of usual residence (statistical local area, level 2) at time of diagnosis. The area of usual residence was then classified according to remoteness area 2016.

Source: AIHW ACD 2018.

Compared with *Major cities* in 2010–2018 (319 cases per 1,000,000 persons), the incidence rate of all cancers combined was significantly higher in *Inner regional* areas (351 per 1,000,000), similar in *Outer regional* areas (321 per 1,000,000), and possibly lower in *Remote and Very remote* areas (270 cases per 1,000,000 persons). This is broadly similar to 2001–2009, when rates in *Inner regional* and *Outer regional* areas were slightly higher

(but not significantly) compared with *Major cities*, with rates in *Remote and Very remote* areas significantly lower than in *Major cities* (Figure 5.8).

Contributing factors to this pattern appear to be:

- broadly similar rates of blood cancers across remoteness areas
- a tendency for similar or lower rates of carcinoma as remoteness increases
- higher rates of melanoma in regional areas compared with *Major cities* (but not necessarily *Remote and Very remote* areas)
- a tendency for lower rates of germ cell cancers in *Outer regional* and *Remote and Very remote* areas
- broadly similar rates of other Tier 1 cancers (for example, bone, central nervous system, soft tissue sarcomas) across remoteness areas.

Confidence intervals around estimates tend to be wide, which makes it difficult to be definite about inter-regional comparisons (that is, some rate differences between areas could be due to chance alone). However, there are clear decreases in the incidence rates for melanoma between the 2 time periods, but the general tendency for rates of melanoma to be higher in regional areas remains (Figure 5.9).

Figure 5.9: Incidence of melanoma, 2001–2009 and 2010–2018, by remoteness area, 15–24 years

Note: Geography is based on area of usual residence (statistical local area, level 2) at time of diagnosis. The area of usual residence was then classified according to remoteness area 2016.

Source: AIHW ACD 2018.

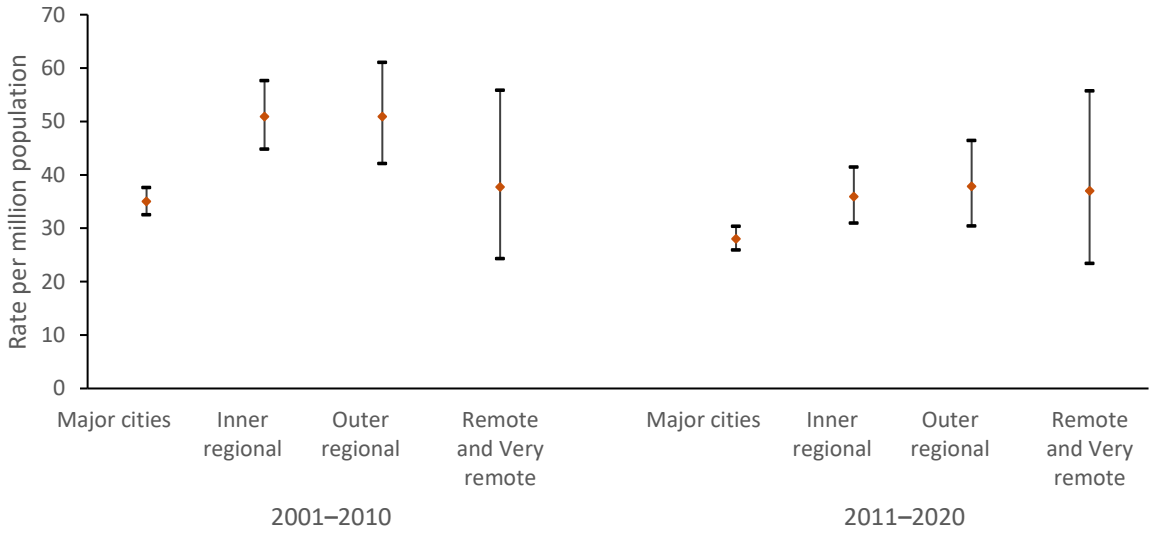
Deaths

In the 10-year reporting period 2011–2020, there was an average of 65 deaths of people aged 15–24 per year in *Major cities*, and 19, 9 and 2 per year in *Inner regional*, *Outer regional* and *Remote and Very remote* areas, respectively.

In the period 2011–2020, death rates for people aged 15–24 due to all cancers combined were higher in *Inner regional* and *Outer regional* areas (36 and 38 deaths per 1,000,000 population, respectively) than in *Major cities* (28 deaths per 1,000,000 population). Death rates in *Remote and Very remote* areas were similar to those in *Major cities* (Figure 5.10).

This general pattern of higher death rates in regional areas is similar to that in the preceding period (2001–2010). However, death rates in *Major cities* and *Inner regional* areas have decreased over this period (from 35 to 28 deaths per 1,000,000 population and from 51 to 36 deaths per 1,000,000 population, respectively). Rates in *Outer regional* areas may have decreased over this period, but the evidence is less clear. Mortality rates in *Remote and Very remote* areas did not clearly change over this period.

Figure 5.10: Mortality rate due to all cancers combined, 2001–2010 and 2011–2020, by remoteness area, 15–24 years



Notes

1. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.

2. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.

3. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

4.Geography is based on area of usual residence (statistical local area, level 2) at time of death. The area of usual residence was then classified according to remoteness area 2016.

Source: AIHW NMD.

Due to data constraints, SEER-based categorisation has been possible for only the 5 years 2013–2017, which is insufficient to clearly identify any inter-regional mortality differences. Even with the expanded time periods (2001–2010 and 2011–2020) available for describing ICD-based categorised cancers, there were no clearly visible inter-regional differences in

even the 3 highest mortality cancers (bone cancer, brain cancer and acute lymphoblastic leukaemia).

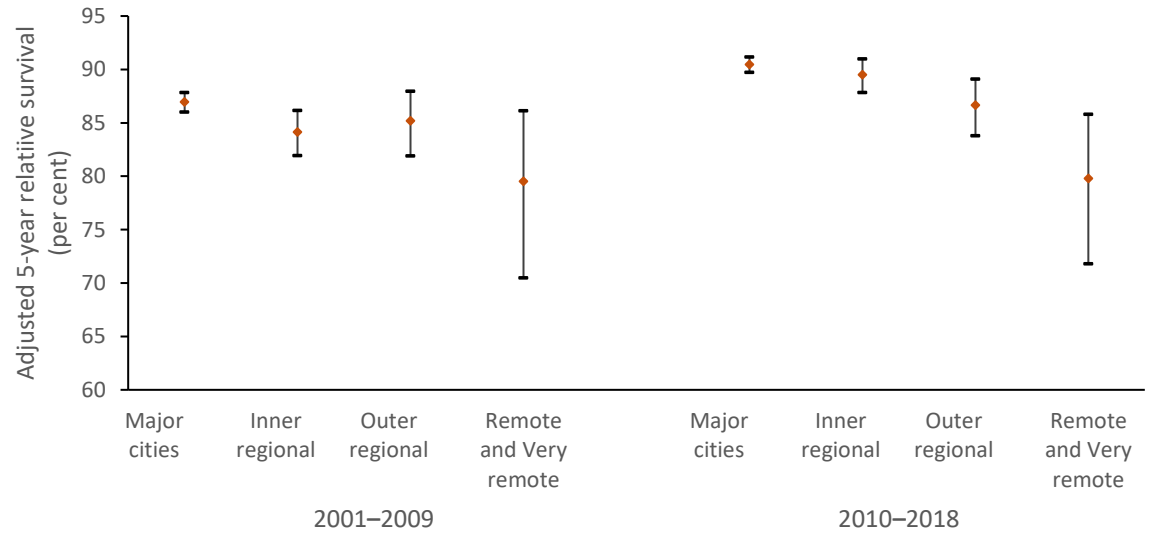
Survival

Survival decreases with increasing remoteness. Survival is strongly dependant on the type of cancer diagnosed, and the mix of cancers in each regional population can be different. Unadjusted, differences in survival may simply reflect a higher incidence of higher-survival cancers in one population compared with another. Consequently, relative survival has been adjusted to reflect survival had the national mix of cancers been present in each area (see Appendix E2).

In 2010–2018, adjusted 5-year survival for all cancers combined in people aged 15–24 was lower in *Outer regional* (86.8%) and *Remote and Very remote* (81.3%) areas compared with *Major cities* (90.4%). Survival in *Inner regional* areas was similar to that in *Major cities* (Figure 5.11).

Survival in *Major cities* and *Inner regional* areas had increased since the preceding period (2001–2009) from 87% to 90%, and from 84% to 90% respectively, but remained similar in *Outer regional* and *Remote and Very remote* areas.

Figure 5.11: Adjusted 5-year relative survival, all cancers combined, 2001–2009 and 2010–2018, by remoteness area, 15–24 years



Notes

1. Survival has been adjusted to the national incidence distribution by site.
2. Geography is based on area of usual residence (statistical local area, level 2) at time of diagnosis. The area of usual residence was then classified according to remoteness area 2016.

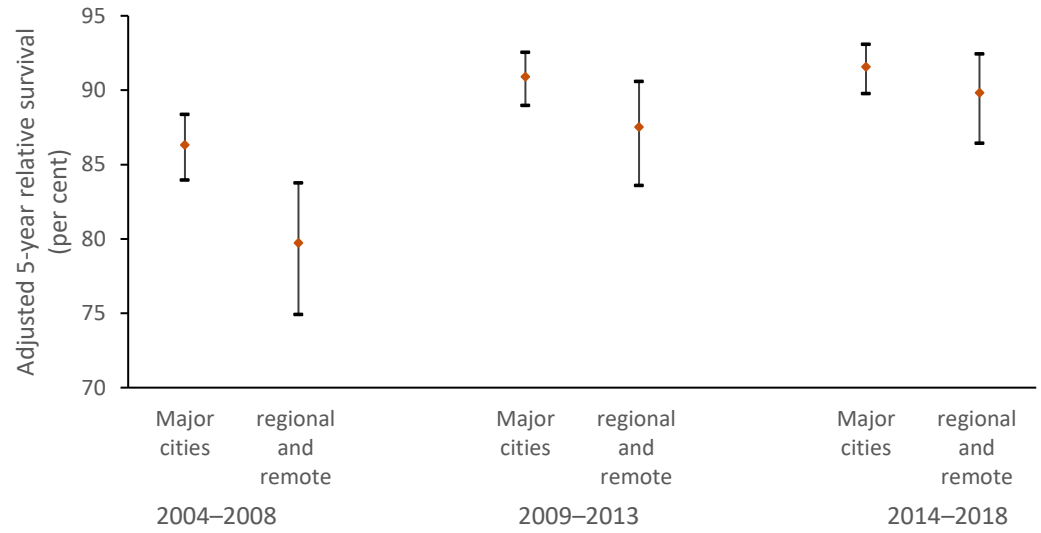
Sources: AIHW ACD 2018; AIHW NMD.

In the three 5-year periods, 2004–2008, 2009–2013 and 2014–2018, there was no clear inter-regional difference between survival inside and outside *Major cities* for soft tissue sarcomas, germ cell cancers, central nervous system cancers and melanoma.

There was non-significantly lower survival from bone cancer and carcinomas outside *Major cities* in each of these 3 periods. There have been improvements in survival both inside and outside *Major cities* for carcinomas and blood cancers over this period. Whereas survival for blood cancers appeared lower outside *Major cities* in 2004–2008, survival both inside and

outside *Major cities* was higher in 2014–2018, with no significant difference between them during that latest period (Figure 5.12).

Figure 5.12: Adjusted 5-year relative survival, blood cancers, Major cities and regional/remote areas, 2004–2008, 2009–2013 and 2014–2018, 15–24 years



Notes

1. Survival has been adjusted to the national age-sex incidence distribution.
2. Geography is based on area of usual residence (statistical local area, level 2) at time of diagnosis. The area of usual residence was then classified according to remoteness area 2016.

Source: AIHW ACD 2018.

5.4 Socioeconomic group

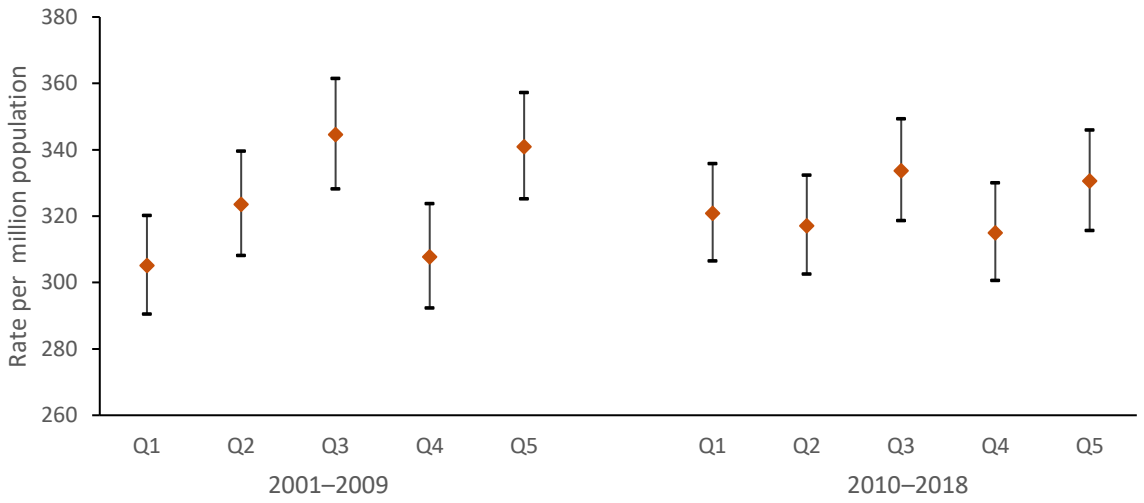
The Index of Relative Socio-economic Disadvantage is used to indicate socioeconomic groups based on where people live. It scores each geographic area, by summarising attributes of the population, such as low income, low educational attainment, high unemployment, and jobs in relatively unskilled occupations. This index is an area-based measure of socioeconomic group, not a person-based measure (Pink 2013).

New cases

In 2010–2018, incidence rates for all cancers combined for people aged 15–24 varied little across socioeconomic groups – ranging between 316 and 334 cases per 1,000,000 population (Figure 5.13). In the previous period 2001–2009, incidence rates were lower for the first (most disadvantaged) quintile and the fourth quintile, and highest for the third and the fifth (least disadvantaged) quintile.

This pattern is not clearly influenced by cancer incidence for any particular cancer groups.

Figure 5.13: Incidence of all cancers combined, 2001–2009 and 2010–2018, by SEIFA quintile, 15–24 years



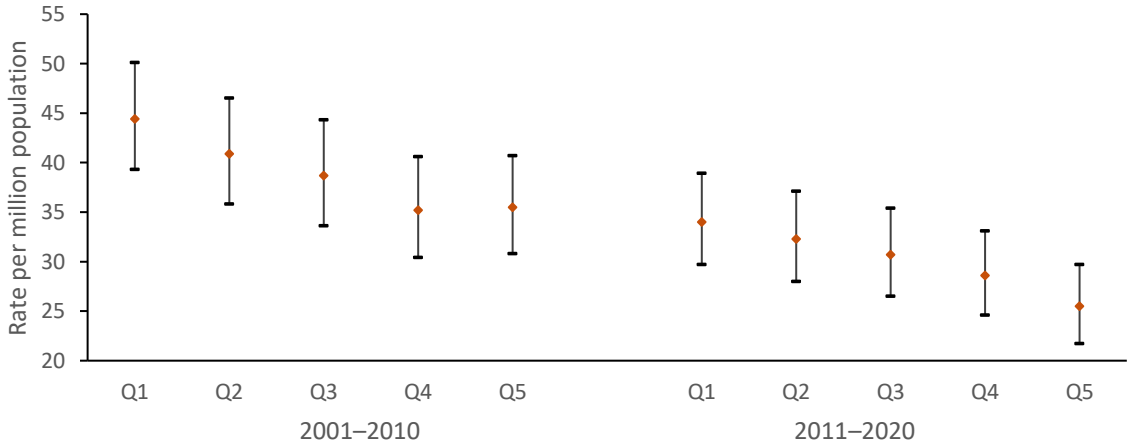
Note: Q1 is the most disadvantaged SEIFA quintile; Q5 is the least disadvantaged quintile.

Source: AIHW ACD 2018.

Deaths

In the period 2011–2020 (similar to the previous period 2001–2010) cancer death rates tended to be higher in areas with greater socioeconomic disadvantage. (Figure 5.14).

Figure 5.14: Mortality rate due to all cancers combined, 2001–2010 and 2011–2020, by SEIFA quintile, 15–24 years



Notes

1. Q1 is the most disadvantaged SEIFA quintile; Q5 is the least disadvantaged quintile.

2.. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.

3. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.

4. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

Source: AIHW NMD.

Even though rates were not statistically significantly lower in successive SEIFA quintiles, there appears to be a consistent pattern indicating a tendency for death rates to increase with increasing disadvantage. For example, in 2011–2020 the cancer death rate for the least and most disadvantaged SEIFA quintiles are 26 and 34 deaths per 1,000,000 population, respectively.

Death rates in all SEIFA quintiles have decreased over time, being clearly lower in the second period (2010–2020) than in the first (2001–2009).

Death rates for SEER-categorised cancers are available only for the period 2013–2017. Cancer-group specific death rates are based on relatively small numbers and hence have considerable volatility. Of these cancer groups, only carcinoma shows clear differences in death rate between SEIFA quintiles, with lower death rates in the least disadvantaged SEIFA quintile compared with the most disadvantaged SEIFA quintile (7 compared with 30 deaths per 1,000,000 population, respectively).

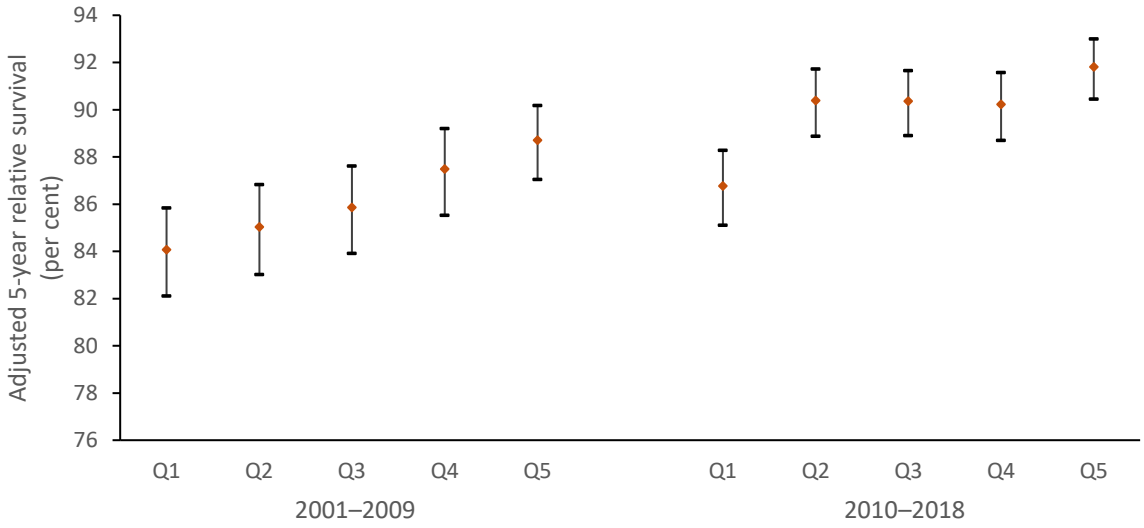
Survival

Relative survival has been adjusted to reflect survival had the national mix of cancers been present in each area (see Appendix E2).

In 2010–2018, adjusted 5-year relative survival for people aged 15–24 was lower in the most disadvantaged SEIFA quintile (87%) than in the other SEIFA quintiles, including the least disadvantaged SEIFA quintile where survival was 92% (Figure 5.15).

In 2010–2018, survival had generally improved since 2001–2009, with clear improvements in the second, third and fifth (least-disadvantaged) SEIFA quintiles (from 85% to 90%, from 86% to 90% and from 89% to 92%, respectively).

Figure 5.15: Adjusted 5-year relative survival, all cancers combined, 2001–2009 and 2010–2018, by SEIFA quintile, people aged 15–24 years



Notes

1. Survival has been adjusted to the national incidence distribution by site.

2. Q1 is the most disadvantaged SEIFA quintile; Q5 is the least disadvantaged quintile.

Sources: AIHW ACD 2018; AIHW NMD.

In the most recent period for which reporting has been possible for specific cancer groups (2014–2018), there are no clear differences in survival evident between SEIFA quintiles. However, there is a tendency for higher survival for carcinoma and blood cancers in less disadvantaged SEIFA quintiles, a pattern that is reflected in previous time periods (2004–2008 and 2009–2013) for these cancer groups.

6 Subsequent cancers and deaths

Key findings

Being diagnosed with cancer when aged 15–24 approximately doubles the risk of being diagnosed with another cancer in the future.

This risk varies between cancers, from no additional risk associated with a diagnosis of melanoma, to over 3 times the risk for several blood cancers, and over 5 times the risk for some rarer cancers.

By the end of December 2018, 1,009 individuals were diagnosed with a second cancer out of 31,246 individuals previously diagnosed with cancer (while they were aged 15–24) between 1984 and 2018.

Of these 1,009 individuals, 76 were later diagnosed with a third cancer by 2018, and of these 76 individuals, 3 were later diagnosed with a fourth cancer.

The percentage of each cohort still alive after a given period of time has increased for cancers generally, and for a number of specific cancers, including some previously low survival cancers (for example, acute lymphoblastic leukaemia/lymphoma, acute myeloid leukaemia, chronic myeloid leukaemia and breast carcinoma). There has been little change for some low-survival cancers (for example, central nervous system and bone cancers).

Deaths predominantly occur in the first few years after diagnosis.

Up to 30% of subsequent deaths overall were due to unknown or non-cancer causes, and this varies from cancer to cancer and depends on time after initial diagnosis.

There were also a number of deaths due to subsequent cancers, and again, the proportion varies from cancer to cancer and depends on time after initial diagnosis.

The available data shows little change in the ratio of subsequent cancers to initial cancers with each successive cohort (given similar follow-up time), suggesting that the risk of developing a second cancer has remained similar over time.

Specific details are described in the online tables.

The previous edition of this report (AIHW 2018) described the additional risk of developing a second cancer for those people who had been diagnosed with a first cancer when aged 15 to 24 years. The main findings of that work are presented again in this chapter, while more detail can be accessed in the previous edition and associated online tables.

New work presented in this chapter describes the number of subsequent cancers and deaths experienced by historic cohorts of people aged 15–24 for the most common cancers diagnosed in this age group.

Background

While many young Australians survive their first diagnosis of cancer, their life is often disrupted during treatment, and they face subsequent late effects (for example, issues with fertility because of treatment) (Patterson et al. 2015). While these issues are important for young cancer survivors, the ACD does not hold information on patient outcomes and experience. An additional risk that young cancer survivors face, which is recorded in the

ACD, is that of developing a second primary malignancy (referred to as a second cancer in this report) or dying.

Inherited gene mutations, the effects of cancer treatments (see Box 6.1), and exposure to certain risk factors, including tobacco smoke, may increase the risk of a second cancer (NCI n.d.).

Box 6.1: Contribution of chemotherapy and radiotherapy to the late effects of cancer

Chemotherapy and radiotherapy treatments have helped improve cancer survival, but these treatments are not without risk. Child and adolescent cancer survivors might have an increased risk of developing a second cancer following treatment and successful cancer remission (Carver et al 2007; Mertens et al. 2001; Nass et al. 2015).

Improvements are constantly being made to chemotherapy and radiotherapy to minimise harmful side effects, and accurately target cancer cells. As the ACD does not contain information on cancer treatments, the impact of radiotherapy and chemotherapy on young Australians developing a second cancer cannot be directly calculated.

About the data

The main data source used for this chapter was the ACD 2014 (for second cancers reported in the previous edition) and the ACD 2018 (for subsequent cancers and deaths). The ACD consists of data provided to the AIHW by state and territory cancer registries and contains data on all primary, invasive tumours (excluding basal cell and squamous cell carcinoma of the skin) diagnosed in Australia from 1982 up to and including 2018.

It also contains cause of death information, linked to the National Death Index dataset up to 31 December 2018.

The cancer classification used in this chapter was based on the SEER adolescent and young adult site recode (see Chapter 1 for more detail).

The method used to calculate additional risk of a second cancer is described in Appendix E4.

The method used to calculate subsequent cancers and deaths for each cohort of people aged 15–24 from 1984–1988 is relatively simple and is described below.

All people aged 15–24 diagnosed with each in-scope cancer, in each successive 5-year period from 1984–1988 to 2014–2018, were followed until December 2018, and all subsequent (second, third and so on) cancers and deaths in the cohort counted. Any cancers diagnosed before the age of 15 years were recorded as ‘previous cancers’. Subsequent cancers and deaths were then reported for each 5-year period following recruitment. The total number of subsequent cancers for each cohort were also reported as second, third and fourth cancers as appropriate.

Summary results for each cohort are presented in this chapter and all details for each cancer are presented in the online tables associated with this report.

6.1 Additional risk of developing a second cancer

The additional risk of being diagnosed with a second cancer was calculated in the previous edition of this report and the findings are summarised in this section. More detailed information is available in *Cancer in adolescents and young adults in Australia 2018* (AIHW 2018).

The method used to describe the additional risk of developing a second cancer, follows people aged 15–24 who were diagnosed with a first cancer, for as many years as possible, and then compares the number of second cancers that were subsequently diagnosed with the number that would be expected in similar people who had not been previously diagnosed with a first cancer. The ratio of observed to expected cancers is a measure of the additional risk. The method is described in Appendix E4.

Table 6.1: Ratio of observed to expected second cancers after diagnosis of first cancer as a child (0–14), adolescent or young adult (15–24) and as an older young adult (25–39), 1982–2014

	Age at diagnosis of first cancer		
	0–14	15–24	25–39
First cancer	**Ratio of observed to expected second cancers**		
Leukaemias	4.77*	3.53*	1.39*
Acute lymphoid leukaemia	5.02*	3.95*	1.20
Acute myeloid leukaemia	3.38*	3.77*	1.33
Chronic myeloid leukaemia	n.p.	2.61	1.70*
Lymphomas	5.87*	3.89*	2.17*
Non-Hodgkin lymphoma	5.45*	3.12*	2.08*
Hodgkin lymphoma	6.37*	4.20*	2.31*
CNS and other intracranial and intraspinal neoplasms	5.54*	2.24*	1.45*
Osseous & chrondromatous neoplasms	6.98*	3.13*	1.45*
Soft tissue sarcomas	11.44*	2.14*	2.05*
Germ cell and trophoblastic neoplasms	3.06*	1.97*	1.39*
Melanoma and skin carcinomas	0.97	1.06	0.98
Carcinomas	3.24*	1.66*	1.32*
Thyroid carcinoma	n.p.	1.77*	1.38*
Carcinoma of breast	–	2.28	1.03
Carcinoma of the colon and rectum	n.p.	1.78*	1.71*
Miscellaneous specified neoplasms, NOS	4.60*	1.65	1.55*
Unspecified malignant neoplasms	n.p.	2.27	1.53*
All cancers combined	**5.16***	**1.93***	**1.28***

Notes

n.p. indicates not published.

1. Cancer categorisation is based on the previous version of the SEER recode. Cancer groups are similar to those used in the rest of this report.

2. Osseous and chrondromatous neoplasms are broadly synonymous with bone cancers described elsewhere in this report.

3. Asterisks (*) indicate that the additional risk was found to be statistically significantly greater than 1.

Source: AIHW ACD 2014.

Table 6.1 summarises findings from *Cancer in adolescents and young adults in Australia 2018* (AIHW 2018) for the more common cancers in people aged 15–24. Cancers categorised in that edition were based on the previous SEER recode, whereas those

described in this edition are based on the revised SEER recode. While the categorisations are similar, they are not exactly the same and consequently some cancers in this table will be defined slightly differently compared with those in other sections of this report (including the next section of this chapter).

From Table 6.1, the risk of developing a future second cancer is about twice (1.9 times) as high for someone who was diagnosed with a cancer when they were aged 15–24, as it would be for a similar person (who had never been previously diagnosed) to be diagnosed with (their first) cancer.

A cancer diagnosis at a younger age (0–14) is associated with a higher risk (5.2 times higher) of developing a second cancer, while a cancer diagnosis when aged 25–39 years is slightly (1.3 times) more likely to be associated with a second future cancer.

The additional risk for people aged 15–24 varies substantially between cancers. There appears to be no additional risk of a second cancer after a diagnosis of melanoma when aged 15–24.

Those people aged 15–24 diagnosed with carcinomas, soft tissue sarcomas, central nervous system cancers and germ cell and trophoblastic neoplasms (most of which will have been testicular cancer) were about twice as likely to be diagnosed with a second cancer.

People aged 15–24 diagnosed with bone cancer, leukaemias and lymphomas were over 3 times as likely to be diagnosed with a second cancer in the future. The cancer associated with the highest additional risk in Table 6.1 is Hodgkin lymphoma (4.2 times higher risk).

Two less common cancers, not specifically included in Table 6.1, were found to be associated with even higher additional risk. The additional risk of being diagnosed with a future second cancer after a first diagnosis (at age 15–24 years) of glioblastoma and anaplastic astrocytoma or Ewing tumour (respectively, types of central nervous system neoplasms and osseous and chrondromatous neoplasms mentioned in Table 6.1) was found to be about 5.5 times greater than for a similar person who had never been diagnosed before (AIHW 2018).

6.2 Subsequent cancers and deaths, by cohort

Subsequent cancers and deaths are described for people aged 15–24 for the 15 highest incidence cancers listed in Table 2.1, as well as all other cancers combined and all cancers combined.

Table 6.2 summarises the main findings.

The online tables describe the number of subsequent cancers diagnosed and deaths that occurred for each 5-year cohort of people aged 15–24 diagnosed with each of the 15 reported cancers, for each 5-year follow-up period until 2018.

An advantage of this analysis over that in the previous section is that it describes both deaths and subsequent cancers as they occur over time. A disadvantage of this analysis is that it does not as precisely describe the additional risk for individuals, and summary results such as those in Table 6.2 are limited by the fact that they are a composite of results from 7 separate cohorts each with different follow-up periods.

From Table 6.2, between 1984 and 2018, 31,428 cancers were diagnosed amongst people aged 15–24 at the time, of which 182 were second cancers diagnosed while within the 15–24 year age range. This leaves 31,246 individuals who were diagnosed with cancer while aged 15–24, between 1984 and 2018.

Table 6.2: Subsequent cancers and deaths for highest incidence cancers that were diagnosed in people aged 15–24, 1984–2018

	Number of diagnoses 1984–2018		Subsequent cancer diagnoses 1984–2018			Died 1984–2018	Still alive at end of second period after diagnosis		
	All cancer diagnoses	First cancer diagnoses	Total	Second cancers	Third cancers	Total	Cohort 1984–1988	Cohort 2009–2013	1984–1988 to 2009–2013
First diagnosed cancer	Count		Count	Per cent of first cancers diagnosed	Per cent of second cancers diagnosed	Per cent	Per cent	Per cent	Percentage point increase
Melanoma of the skin	7,455	7,438	204	3	5	8	92	96	4
Hodgkin lymphoma	3,542	3,533	220	6	11	9	85	96	11
Testicular germ cell cancer	3,195	3,186	89	3	7	6	89	97	8
Thyroid carcinoma	2,195	2,183	66	3	12	2	97	99	2
Colorectal carcinoma	1,761	1,752	37	2	6*	11	80	90	10
Non-Hodgkin lymphoma	1,398	1,378	53	3	10	19	71	91	20
Central nervous system	1,734	1,726	44	2	10*	45	58	60	2
Soft tissue sarcomas	1,387	1,371	51	4	4*	37	56	67	11
Acute lymphoblastic leukaemia	1,311	1,308	45	3	5*	42	36	81	45
Bone cancers	1,203	1,196	51	4	6*	41	57	61	4
Acute myeloid leukaemia	967	942	30	3	3*	45	27	71	43
Chronic myeloid leukaemia	657	651	18	3	6*	22	57	91	33
Ovarian germ cell cancer	398	398	21	5	5*	9	91	93	1
Major salivary glands	206	203	1	0*	0*	4	100	97	–3
Breast carcinoma	287	282	9	3	13*	32	46	89	43
All other cancers	3,732	3,699	149	4	7	23	73	80	6
All cancers combined	31,428	31,246	1,088	3	3	18	77	88	10

(continued)

Table 6.2 (continued): Subsequent cancers and deaths for highest incidence cancers that were diagnosed in people aged 15–24, 1984–2018

Notes

1. Asterisks (*) indicate that numerator is based on fewer than 5 counts. Caution is advised.

2. The number of cancer diagnoses 1984–2018 is the total number of cases diagnosed between January 1984 and December 2018. The number of first cancer diagnoses is the number of people diagnosed with cancer for the first time while aged 15–24 between January 1984 and December 2018. The difference between the 2 numbers reflects the number of people who had been diagnosed with another cancer first (while aged 15–24), and then with the specified cancer (while still in the 15–24 age range).

3. Second cancers are expressed as the percentage of people aged 15–24 diagnosed with cancer between January 1984 and December 2018, who were subsequently diagnosed with a second cancer in this period.

4. Third cancers are expressed as the percentage of those diagnosed with a second cancer between January 1984 and December 2018 who were then diagnosed with a third cancer in this period.

5. Deaths are expressed as the percentage of people aged 15–24 diagnosed with cancer between January 1984 and December 2018, who then died in this period.

6. The last 3 columns describe the percentage of the first (1984–1988) and the second last (2009–2013) cohorts who were still alive at the end of the second 5-year period after their initial diagnosis (which is an average 7.5 year follow-up for each cohort). The last column describes the improvement in the percentage who were still alive 7.5 years on average after their initial diagnosis.

Source: AIHW ACD 2018

The number of individuals diagnosed with cancer increased from 3,803 in the period 1984–1988 to 5,254 in the period 2014–2018.

Of the 31,246 individuals diagnosed with cancer between 1984 and 2018:

- 1,009 were later diagnosed with a second cancer by 2018 (including the 182 who were diagnosed with a subsequent cancer while still within the 15–24 year age range). Of these 1,009 individuals, 76 were later diagnosed with a third cancer, and of these, 3 were later diagnosed with a fourth cancer by 2018. This is a total of 1,088 subsequent cancer diagnoses amongst those who received an initial cancer diagnosis while aged 15–24.
- 5,519 (18%) had died (of any cause) by December 2018. Being diagnosed with another cancer and dying are not mutually exclusive, and so some of those diagnosed with another cancer will also be amongst those who died.

The available data show little change in the ratio of second cancers to initial cancers with each successive cohort (given similar follow-up time). This suggests that the risk of developing a second cancer has remained similar over time.

The percentage of each cohort still alive has improved over time (see Figure 6.1):

- While 86% of the 1984–1988 cohort were still alive at the end of their first 5-year follow-up period (2.5 years (assuming first case diagnoses are uniformly distributed throughout this period, with about a fifth being diagnosed in the first year, and a fifth being diagnosed in the fifth year)), 94% of the 2014–2018 cohort were still alive after a similar period.
- While 77% of the 1984–1988 cohort were still alive at the end of their second 5-year follow-up period (7.5 years), 88% of the 2009–2013 cohort were still alive after a similar period.
- While 74% of the 1984–1988 cohort were still alive at the end of their fourth 5-year follow-up period (17.5 years), 82% of the 1999–2003 cohort were still alive after a similar period.

Improvements in the percentage still alive vary from cancer to cancer.

For cancers which had very low apparent survival when diagnosed in 1984–1988 (acute lymphoblastic leukaemia/lymphoma, acute myeloid leukaemia, and breast carcinoma), there have clearly been large improvements in the percentage still alive for those diagnosed in 2009–2013.

For those cancers which had slightly better (but still relatively low) apparent survival when diagnosed in 1984–1988, there have been large improvements for chronic myeloid leukaemia, some improvement for soft tissue sarcomas, and little change for central nervous system and bone cancers for those diagnosed in 2009–2013.

For those cancers with moderate apparent survival when diagnosed in 1984–1988, there have been substantial improvements for non-Hodgkin lymphoma, and some improvement for Hodgkin lymphoma, testicular germ cell cancer and colorectal carcinoma for those diagnosed in 2009–2013.

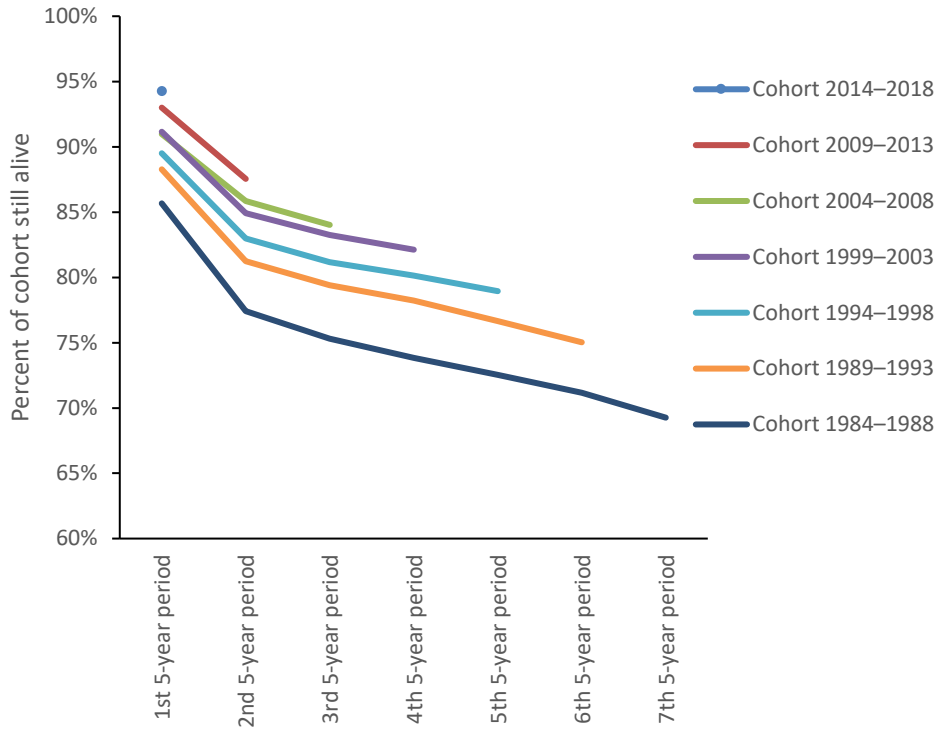
For those cancers with high apparent survival when diagnosed in 1984–1988 (melanoma of the skin, ovarian germ cell cancer, thyroid carcinoma and major salivary gland carcinoma), there has been little change in the proportion still alive for those diagnosed in 2009–2013.

Deaths predominantly occur in the first few years after diagnosis (Figure 6.1).

While the initial diagnosed cancer is responsible for a substantial proportion of subsequent deaths, up to 30% of these deaths were due to unknown or non-cancer causes, and this varies from cancer to cancer and from period to period.

More detailed data is available in the online tables.

Figure 6.1: Percentage of people still alive at the end of each 5-year period after diagnosis of cancer when aged 15–24, successive 5-year cohorts, 1984 to 2018



Note: The first 5-year period is the period in which diagnosis occurred.

Source: AIHW ACD 2018

Appendix A: Cancer classification systems

A SEER-based classification system has been used in this report where the data contains details of cancer histology and topography (incidence, survival, and for mortality where possible). Where these are not available (hospital data, mortality, burden of disease), classification systems based on ICD-10 have been used.

A1 Classification of cancers for incidence, survival and mortality (where possible)

The system of grouping cancers for incidence, survival, and for mortality where possible, was based primarily on the revised SEER adolescent and young adult site recode (NCI 2020), adjusted to the Australian context.

The classification comprises 51 Tier 2 cancer sub-groups distributed amongst 9 higher-level Tier 1 cancer groups. There are insufficient cases to warrant a third Tier in this classification. This improved classification is similar to but differs slightly from the SEER-based classification used in the previous edition of this work.

Tier 1 cancer groups

Abbreviations for topography codes:

Bone = C40–C41

Central nervous system (CNS) = C70–C72, C75.1–C75.3

Tier 1	Histology codes	Topography codes
1. Blood cancers	9590–9993	All
2. Central nervous system cancers	9350–9352, 9360–9362, 9380–9472, 9474–9480, 9530–9539	All
	8000–8005, 8680–8700, 8963, 9363–9365, 9473, 9490–9509	CNS
3. Bone cancers	8812, 9180–9250, 9260–9342, 9370–9372	All
	8000–8005, 8800–8803, 8805–8806, 9363–9365, 9473	Bone
4. Soft tissue sarcomas	8710–8714, 8804, 8810–8811, 8813–8921, 8930–8931, 8935–8936, 8982–8983, 8990–8991, 9040–9045, 9120–9175, 9251–9252, 9540–9581	All
	8800–8803, 8805–8806	All except bone
	9363–9365, 9473	All except bone and CNS
5. Germ cell and trophoblastic cancers	9060–9105	All
6. Melanomas	8720–8790	All
7. Carcinomas	8010–8589	All
8. Miscellaneous specified cancers	8590–8671, 8932–8934, 8940–8941, 8950–8951, 8959–8960, 8964, 8970–8973, 8980–8981, 9000–9030, 9050–9053, 9110–9111, 9510–9523	All
	8680–8700, 8963, 9490–9509	All except CNS
9. Unspecified cancers	8000–8005	All except bone and CNS

Note: ‘Carcinomas’ excludes basal and squamous cell carcinomas of the skin.

Tier 2 cancer groups

1. Blood cancers

The topography codes are the same for every Tier 2 group: All.

Tier 2	Histology codes
1.1 Acute myeloid leukaemia	9727[a], 9840, 9861, 9865–9867, 9869–9874, 9877–9879, 9891, 9895–9898, 9910–9912, 9920, 9930–9931, 9984
1.2 Chronic myeloid cancers	9740–9742, 9863, 9875–9876, 9945–9946, 9950, 9960–9968, 9975, 9980, 9982–9983, 9985–9987, 9989, 9993
1.3 Acute lymphoblastic leukaemia/lymphoma	9727[a], 9811–9819, 9835, 9837
1.4 Hodgkin lymphoma	9650–9655, 9659, 9661–9665, 9667
1.5 Mature non-Hodgkin lymphomas and related cancers	9596–9597, 9671, 9673, 9675, 9678–9680, 9684, 9687–9691, 9695, 9698–9702, 9705, 9708–9709, 9712, 9714–9719, 9724, 9726, 9731–9735, 9737–9738, 9760–9762, 9764, 9766, 9823, 9827, 9831–9834, 9940, 9948
1.6 Histiocytic and dendritic cell cancers	9749–9751, 9755–9759
1.7 Other and unspecified blood cancers	9590–9591, 9800–9801, 9805–9809, 9820, 9860

a. 9727 belongs to ‘acute lymphoblastic leukaemia/lymphoma’ for diagnosis years 1982 to 2010 and ‘acute myeloid leukaemia’ for 2011 onwards.

2. Central nervous system cancers

Tier 2	Histology codes	Topography codes
2.1 Oligodendrogliomas	9382, 9385, 9450–9451, 9460	All
2.2 Glioblastomas	9440–9442, 9445	All
2.3 Ependymomas	9383, 9391–9394, 9396	All
2.4 Other astroglial neoplasms	9380–9381, 9384, 9400–9401, 9410–9412, 9420–9421, 9424–9425, 9431–9432	All
2.5 Medulloblastomas and other embryonal CNS cancers	9470–9472, 9474–9478, 9480	All
	8963, 9364–9365, 9473, 9508	CNS
2.6 Other specified CNS cancers	9350–9352, 9360–9362, 9390, 9395, 9413, 9423, 9430, 9444, 9530–9535, 9537–9539	All
	8680–8700, 9363, 9490–9507, 9509	CNS
2.7 Unspecified CNS cancers	8000–8005	CNS

3. Bone cancers

Tier 2	Histology codes	Topography codes
3.1 Osteosarcomas	9180–9187, 9192–9195	All
3.2 Chondrosarcomas	9220–9221, 9230–9231, 9240, 9242–9243	All
3.3 Ewing family of bone sarcomas	9364–9365, 9473	Bone
3.4 Other specified bone cancers	8812, 9250, 9261, 9270–9342, 9370–9372	All
	9363	Bone
3.5 Unspecified bone cancers	8000–8005, 8800–8803, 8805–8806	Bone

4. Soft tissue sarcomas

Tier 2	Histology codes	Topography codes
4.1 Fibromatous sarcomas	8810–8811, 8813–8814, 8816–8818, 8820–8828, 8830–8836, 9252	All
4.2 Liposarcomas	8850–8858, 8860–8862, 8870, 8880–8881	All
4.3 Rhabdomyosarcomas	8900–8905, 8910, 8912, 8920–8921	All
4.4 Synovial sarcomas	9040–9043	All
4.5 Ewing family of soft tissue sarcomas	9364–9365, 9473	All except bone and CNS
4.6 Nerve sheath tumours	9540–9571	All
4.7 Other specified soft tissue sarcomas	8710–8714, 8815, 8840–8842, 8890–8898, 8930–8931, 8935–8936, 8982–8983, 8990–8991, 9044–9045, 9120–9175, 9251, 9580–9581	All
	9363	All except bone and CNS
4.8 Unspecified soft tissue sarcomas	8804	All
	8800–8803, 8805–8806	All except bone

5. Germ cell and trophoblastic cancers

The histology codes are the same for every Tier 2 group: 9060–9105.

Tier 2	Topography codes
5.1 Testicular germ cell cancers	C62
5.2 Ovarian germ cell cancers	C56
5.3 CNS germ cell cancers	CNS
5.4 Mediastinal germ cell cancers	C38.1–C38.3
5.5 Germ cell cancers of other and unspecified sites	All except the above

6. Melanomas

The histology codes are the same for every Tier 2 group: 8720–8790.

Tier 2	Topography codes
6.1 Melanoma of skin	C44
6.2 Melanoma of other and unspecified sites	All except C44

7. Carcinomas

The histology codes are the same for every Tier 2 group: 8010–8589.

Tier 2	Topography codes
7.1 Carcinomas of tongue	C01–C02
7.2 Carcinomas of major salivary glands	C07–C08
7.3 Carcinomas of other and unspecified sites in head and neck	C00, C03–C06, C09–C14, C30–C32, C76.0
7.4 Carcinomas of stomach	C16
7.5 Carcinomas of colon and rectum	C18–C20
7.6 Carcinomas of liver and intrahepatic bile ducts	C22
7.7 Carcinomas of pancreas	C25
7.8 Carcinomas of other and unspecified sites in gastrointestinal tract	C15, C17, C21, C23–C24, C26
7.9 Carcinomas of lung, bronchus and trachea	C33–C34
7.10 Carcinomas of breast	C50
7.11 Carcinomas of cervix	C53
7.12 Carcinomas of ovary	C56
7.13 Carcinomas of kidney	C64
7.14 Carcinomas of thyroid	C73
7.15 Carcinomas of other and unspecified sites	All except the above

Note: 'Carcinomas of other and unspecified sites' excludes basal and squamous cell carcinomas of the skin.

8. Miscellaneous specified cancers

Tier 2	Histology codes	Topography codes
8.1 Other paediatric and embryonal cancers	8959–8960, 8964, 8970–8973, 8981, 9510–9523	All
	8963, 9490–9509	All except CNS
8.2 Other specified cancers	8590–8671, 8932–8934, 8940–8941, 8950–8951, 8980, 9000–9030, 9050–9053, 9110–9111	All
	8680–8700	All except CNS

A2 Classification used to define cancers in hospital admissions data

The system of grouping cancers for treatment was based on the International Statistical Classification of Diseases and Related Health Problems 10th revision.

Table A2: Classification of cancers for treatment

Cancer site/type	ICD-10 codes
Lip, oral cavity and pharynx	
Lip	C00
Tongue	C01–C02
Mouth	C03–C06
Salivary glands	C07–C08
Oropharynx	C09–C10
Nasopharynx	C11
Hypopharynx	C12–C13
Other and ill-defined sites in the lip, oral cavity and pharynx	C14
Digestive organs	
Oesophagus	C15
Stomach	C16
Small intestine	C17
Colorectal	C18–C20
Anus	C21
Liver	C22
Gallbladder and extrahepatic bile ducts	C23–C24
Pancreas	C25
Other digestive organs	C26
Respiratory system and intrathoracic organs	
Nasal cavity, middle ear and accessory sinuses	C30–C31
Larynx	C32
Lung	C33–C34
Other thoracic and respiratory organs	C37–C39
Bone	C40–C41
Skin	
Melanoma of the skin	C43
Non-melanoma of the skin	C44

(continued)

Table A2 (continued): Classification of cancers for treatment

Cancer site/type	ICD-10 codes
Mesothelial and soft tissue	
Mesothelioma	C45
Kaposi sarcoma	C46
Peritoneum	C48
Other soft tissue	C47, C49
Breast	**C50**
Female genital organs	
Vulva	C51
Vagina	C52
Cervix	C53
Uterus	C54–C55
Ovary	C56
Other female genital organs	C57
Placenta	C58
Male genital organs	
Penis	C60
Prostate	C61
Testis	C62
Other male genital organs	C63
Urinary tract	
Kidney	C64
Bladder	C67
Other urinary organs	C65–C66, C68
Eye, brain and other parts of the central nervous system	
Eye	C69
Brain	C71
Other central nervous system	C70, C72, C751–C753
Thyroid and other endocrine glands	
Thyroid	C73
Other endocrine glands	C74, C750, C754–C759

(continued)

Table A2 (continued): Classification of cancers for treatment

Cancer site/type	ICD-10 codes
Blood and lymphatic system	
Hodgkin lymphoma	C81
non-Hodgkin lymphoma	C82–C86
Immunoproliferative cancers	C88
Multiple myeloma	C90.0
Other plasma cell	C90.1–C90.9
Acute lymphoblastic leukaemia	C91.0
Chronic lymphocytic leukaemia	C91.1
Other and unspecified lymphoid leukaemia	C91.2–C91.9
Acute myeloid leukaemia	C92.0, C92.3–C92.6, C92.8, C93.0, C94.0, C94.2, C94.4–C94.5
Chronic myelogenous leukaemia	C92.1
Other and unspecified myeloid leukaemia	C92.2, C92.7, C92.9, C93.1–C93.9, C94.6–C94.7
Other and unspecified leukaemia	C94.3, C95
Myelodysplastic syndromes	D46
Other cancers of the blood and lymphatic system	C941, C96, D45, D47.1, D47.3–D47.5
Other	
Other and ill-defined sites	C76
Unknown primary site	C77, C78, C79, C80, C97
All cancers combined	**C00–C97, D45, D46, D47.1, D47.3–D47.5**

Note: For mortality data before 2008, unknown primary site is coded as C77–C80. For mortality data before 2013, C97 was an applicable code.

A3 Classification of cancers for mortality

The system of grouping cancers for treatment was based on the International Statistical Classification of Diseases and Related Health Problems 10th revision.

This table is very similar to A2, with a small number of code adjustments applicable to mortality data, and a reduced range of cancers in line with relatively small numbers of deaths amongst people aged 15–24 years.

Table A3: Classification of cancers for mortality

Cancer site/type	ICD-10 codes
Lip	C00
Tongue	C01–C02
Mouth	C03–C06
Oesophagus	C15
Stomach	C16
Colorectal	C18–C20, C26
Anus	C21
Liver	C22
Gallbladder and extrahepatic bile ducts	C23–C24
Pancreas	C25
Larynx	C32
Lung	C33–C34
Bone	C40–C41
Skin	
Melanoma of the skin	C43
Non-melanoma of the skin	C44
Mesothelioma	C45
Other soft tissue	C47, C49
Breast	C50
Cervix	C53
Uterus	C54–C55
Ovary	C56
Prostate	C61
Testis	C62
Kidney	C64
Bladder	C67
Brain	C71
Thyroid	C73

(continued)

Table A3 (continued): Classification of cancers for mortality

Cancer site/type	ICD-10 codes
Hodgkin lymphoma	C81
non-Hodgkin lymphoma	C82–C86
Multiple myeloma	C90.0
Acute lymphoblastic leukaemia	C91.0
Chronic lymphocytic leukaemia	C91.1
Acute myeloid leukaemia	C92.0, C92.3–C92.6, C92.8, C93.0, C94.0, C94.2, C94.4–C94.5
Chronic myelogenous leukaemia	C92.1
Myelodysplastic syndromes	D46
Unknown primary site	C80
All cancers combined	**C00–C97, D45, D46, D47.1, D47.3–D47.5**

Note: For mortality data before 2008, unknown primary site is coded as C77–C80. For mortality data before 2013, C97 was an applicable code.

A4 Classification of cancers for burden of disease

The system of grouping cancers for the burden of disease chapter was based on the International Statistical Classification of Diseases and Related Health Problems, 10th revision.

Table A4: Burden of cancer codes

Australian Burden of Disease Study 2022 cause	ICD-10 codes
Malignant neoplasms	
Lip and oral cavity cancer	C00, C01, C02, C03, C04, C05, C06, C07, C08
Nasopharyngeal cancer	C11
Other oral cavity and pharynx cancers	C09, C10, C12, C13, C14
Oesophageal cancer	C15
Stomach cancer	C16
Bowel cancer	C18, C19, C20, C26.0
Liver cancer	C22
Gallbladder cancer	C23, C24
Pancreatic cancer	C25
Laryngeal cancer	C32
Lung cancer	C33, C34
Melanoma of the skin	C43
Non-melanoma skin cancers	C44
Mesothelioma	C45
Breast cancer	C50
Cervical cancer	C53
Uterine cancer	C54, C55
Ovarian cancer	C56
Prostate cancer	C61
Testicular cancer	C62
Bladder cancer	C67
Kidney cancer	C64
Brain and central nervous system cancer	C70, C71, C72
Thyroid cancer	C73
Hodgkin lymphoma	C81
Non-Hodgkin lymphoma	C82, C83, C84, C85, C86
Myeloma	C90
Acute myeloid leukaemia (AML)	C92.0, C92.3, C92.4, C92.5, C92.6, C92.8, C93.0, C94.0, C94.2, C94.4, C94.5
Chronic myeloid leukaemia (CML)	C92.1
Acute lymphoblastic leukaemia (ALL)	C91.0

(continued)

Table A4: Burden of cancer codes (continued)

Australian Burden of Disease Study 2022 cause	ICD-10 codes
Chronic lymphocytic leukaemia (CLL)	C91.1
Other leukaemias	C91.2, C91.3, C91.4, C91.5, C91.6, C91.7, C91.8, C91.9, C92.2, C92.7, C92.9, C93.1, C93.2, C93.3, C93.7, C93.9, C94.1, C94.3, C94.6, C94.7, C95
Other blood cancers	C88, C96, D45, D46, D47.1, D47.3, D47.4, D47.5
Unknown primary	C39, C97
Other malignant neoplasms (cancers)	C17, C21, C30, C31, C37, C38, C40, C41, C46, C47, C48, C49, C51, C52, C57, C58, C60, C63, C65, C66, C68, C69, C74, C75
Benign, in situ and uncertain neoplasms	
Benign and uncertain brain tumours	D32, D33, D42, D43
Ductal carcinoma in situ (breast)	D05
Other benign, in situ and uncertain neoplasms	D00, D01, D02, D03, D04, D06, D07, D09, D10, D11, D12, D13, D14, D15, D16, D17, D18, D19, D20, D21, D22, D23, D24, D26, D27 , D28, D29, D30, D31, D34, D35, D36, D37, D38, D39, D40, D41, D44, D47.0, D47.2, D47.7, D47.9, D48

Source: Australian Burden of Disease Study 2022

Appendix B: Supplementary data tables

Comprehensive supplementary data tables, as well as tables describing data used in figures in this report, are available in the online tables associated with this report (https://www.aihw.gov.au/reports/cancer/cancer-in-adolescents-young-adults-australia-2023/contents/summary).

Data is presented in 6 Excel workbooks:

- Supplementary tables for Chapter 2: Cancer incidence, survival and mortality
- Supplementary tables for Chapter 3: Cancer treatment
- Supplementary tables for Chapter 4: Burden of disease
- Supplementary tables for Chapter 5: Focus on key population groups
- Supplementary tables for Chapter 6: Subsequent cancers and deaths, by cohort
- Supplementary tables: Data for figures.

Appendix C: Data sources

AIHW Australian Cancer Database

All forms of cancer, except basal and squamous cell carcinomas of the skin, are notifiable diseases in each Australian state and territory. This means there is legislation in each jurisdiction that requires hospitals, pathology laboratories, and various other institutions to report all cases of cancer to their central cancer registry.

An agreed subset of the data collected by these cancer registries is supplied annually to the AIHW, where it is compiled into the ACD. The ACD currently contains data on all cases of cancer diagnosed from 1982 to 2018 for all states and territories.

Cancer reporting and registration is a dynamic process, and records in the state and territory cancer registries may be modified if new information is received. As a result, the number of cancer cases reported by the AIHW for any particular year might change slightly over time and might not always align with state and territory reporting for that same year.

The data quality statement for the ACD 2018 can be found at https://meteor.aihw.gov.au/content/757686.

AIHW National Mortality Database

The AIHW NMD contains information provided by the Registries of Births, Deaths and Marriages and the National Coronial Information System – and coded by the ABS – for deaths from 1964 to 2020. Registration of deaths is the responsibility of each state and territory Registry of Births, Deaths and Marriages. These data are then collated and coded by the ABS and are maintained at the AIHW in the NMD.

In the NMD, both the year in which the death occurred and the year in which it was registered are provided. For this report, actual mortality data are shown based on the year the death occurred, except for the most recent year (namely 2020), where the number of people whose death was registered is used.

Previous investigation has shown that the year of death and its registration coincide for the most part. However, in some instances, deaths at the end of each calendar year might not be registered until the following year. As a result, year-of-death information for the latest available year is generally an underestimate of the actual number of deaths that occurred in that year.

In this report, deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 are based on the revised version; deaths registered in 2020 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the ABS.

The data quality statements underpinning the AIHW NMD can be found on the following webpages:

- ABS quality declaration summary for Deaths, Australia (ABS cat. no. 3302.0) https://www.abs.gov.au/methodologies/deaths-australia-methodology/2020#quality-declaration-summary.
- ABS quality declaration summary for Causes of death, Australia (ABS cat. no. 3303.0) https://www.abs.gov.au/methodologies/causes-death-australia-methodology/2018#explanatory-notes.

For more information on the AIHW NMD, see www.aihw.gov.au/about-our-data/our-data-collections/national-mortality-database.

AIHW National Hospital Morbidity Database

The AIHW NHMD is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals. The data supplied are based on the Admitted Patient Care National Minimum Data Set, and include demographic, administrative, and length-of-stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital, and external causes of injury and poisoning.

The purpose of the Admitted Patient Care National Minimum Data Set is to collect information about care provided to admitted patients in Australian hospitals. Its scope is episodes of care for admitted patients in all public acute hospitals, private acute hospitals, psychiatric hospitals, free-standing day hospital facilities, and alcohol and drug treatment centres in Australia.

Hospitals operated by the Australian Defence Force, corrections authorities, and in Australia's offshore territories are not in scope, but some are included.

The data quality statement for the AIHW NHMD 2020–21 can be found at http://meteor.aihw.gov.au/content/index.phtml/itemId/638202.

National Death Index

The National Death Index is a database, housed at the AIHW, that contains records of all deaths occurring in Australia since 1980. The data are obtained from the Registrars of Births, Deaths and Marriages in each state and territory. The National Death Index is designed to support epidemiological studies, and its use is strictly confined to medical research. Cancer incidence records from the ACD were linked to the National Death Index, and used to calculate the survival and prevalence data presented in this report.

The data quality statement for the National Death Index can be found at http://meteor.aihw.gov.au/content/index.phtml/itemId/480010.

Australian Burden of Disease Study

Data to develop the Australian Burden of Disease Study estimates for cancer were obtained from many different sources. Deaths data for the fatal burden were sourced from the NMD, while data for the non-fatal burden came from various administrative sources, including the NMD, the ACD, the NHMD, and Medicare Benefits Schedule claims data, as well as epidemiological studies.

Full details on the various methods, data sources, and standard inputs are available in the *Australian Burden of Disease Study: methods and supplementary material 2018* (AIHW 2021c).

Non-admitted patient databases

The aim of the Non-admitted Patient Care data collections is to report episode-level data on non-admitted activity in Australia's public hospital system. Data suppliers report non-admitted patient activity in either aggregate or episode-level format.

Each year the collection increasingly reports on episode-level data, however, not all data suppliers are able to report data in this format. In 2020–21, 75% of non-admitted patient service events were recorded at the episode-level and 25% of service events were recorded at the aggregate-level.

The National Non-admitted Patient Care (aggregate) Database (NNAPC(agg)D) holds aggregated clinic-level data on:

- the type of outpatient clinic
- counts of individual and group service events
- the funding source for the service events
- whether the service involved care from multiple health-care providers.

The National Non-admitted Patient (episode-level) Database (NNAP(el)D) holds episode-level data including:

- selected patient characteristics
- the type of outpatient clinic
- whether the episode was an individual or a group service event
- the source of the request for service
- the service delivery setting
- the service delivery mode
- the type of care provided
- whether the service involved care from multiple health-care providers
- the funding source for the service event.

Data quality summaries and additional detailed information relevant to interpretation of non-admitted patient care data collections can be found at https://www.aihw.gov.au/getmedia/8a2ac60d-2d20-4561-a29b-68fd367ed56c/Non-admitted-patient-care-2020-21-Appendixes.pdf.aspx.

Complete data quality statements for the National Non-admitted Patient Care (aggregate) Database (NNAPC(agg)D) and the National Non-admitted Patient (episode-level) Database (NNAP(el)D) are available online at meteor.aihw.gov.au.

Medicare Benefits Schedule database

Medicare provides free or subsidised access to a range of medical services. The Medicare Benefits Schedule (MBS) database is maintained by the Australian Government Department of Health and is compiled from data supplied by the Department of Health. The database includes services that qualify for a Medicare benefit under the Health Insurance Act 1973, and for which a claim has been processed by Services Australia (and its predecessors) from February 1984 onwards. These data are generated as an administrative by-product of the processing of MBS claims and payments. Information is collected about patients, providers, the type of service provided (MBS item number) and the amount of benefit paid for that service (based on the schedule fee). The database does not include information on public patients in public hospitals or services that are not listed on the MBS. Services rendered free of charge in recognised hospitals, services that qualified for a benefit under the Department of Veterans' Affairs National Treatment Account and services rendered under other publicly funded programs such as breast screening services are also excluded.

The MBS lists services that are subsidised by the Australian Government under Medicare. Each professional service (consultation, procedure, test) contained in the schedule has a unique item number and a set schedule fee. Services listed in the MBS must be rendered according to the provisions of the relevant Commonwealth, state and territory laws. The MBS claims database is maintained by the Department of Health and sourced from Services Australia. For more information on the specific MBS item numbers used in this report, see Appendix D. More information on MBS item numbers in general can be found on the MBS Online website.

Population data

Throughout this report, population data have been used to derive rates of cancer incidence and mortality. The population data are sourced from the ABS, using the most up-to-date estimates available at the time of analysis.

To derive its estimates of the resident populations, the ABS uses data from the 5-yearly Census of Population and Housing, and adjusts them as follows:

- All respondents in the Census are placed in their state or territory, statistical local area, and postcode of usual residence. Overseas visitors are excluded.
- An adjustment is made for people missed in the Census.
- Australians temporarily overseas on Census night are added to the usual residence Census count.

Estimated resident populations are then updated each year from the Census data, using indicators of population change, such as births, deaths, and net migration. More information is available from the ABS website at www.abs.gov.au.

Appendix D: Definition of cancer-related hospitalisations, and of chemotherapy and radiotherapy services

A separation is the term used to refer to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer, or death) or a portion of a hospital stay, starting or ending in a change of type of care (for example, from acute care to rehabilitation). In this report, a separation is also referred to as a hospitalisation.

Due to coding methods, it is insufficient to simply select hospitalisations for which cancer was recorded as the principal diagnosis – it must also include those hospitalisations where a treatment relating to cancer was recorded as the principal diagnosis. These treatments are usually coded using Z-codes defined in the ICD-10-AM.

Based on the definition of cancer-related hospitalisations, data presented in this report might have included a small number of some treatments and services provided to non-cancer patients. For example, Z51.0 'Radiotherapy session' services are not entirely cancer specific but may be provided to a small number of non-cancer patients, although the majority of these interventions are cancer related.

Table D1: Definition of cancer-related hospitalisations

	ICD-10-AM codes	
Definition	**Principal diagnosis**	**Additional diagnosis**
Principal diagnosis of cancer	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	
Additional diagnosis of cancer		C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5
Principal diagnosis is a cancer-related treatment (and cancer was not an additional diagnosis)	Z08 (Follow-up examination after treatment for malignant neoplasms) Z40.00 (Breast prophylactic surgery for risk-factors related to malignant neoplasms) Z40.01 (Ovary prophylactic surgery for risk-factors related to malignant neoplasms) Z51.0 (Radiotherapy session) Z51.1 (Pharmacotherapy session for neoplasm) Z54.1 (Convalescence following radiotherapy) Z54.2 (Convalescence following chemotherapy)	Not a cancer code (C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5)

Note: Codes were sourced from the ninth edition of the Australian Classification of Health Interventions (ACCD 2014, 2015).

Definition of chemotherapy procedures for admitted patients

For earlier editions of this report, cancer-related hospitalisations for which a chemotherapy session was performed included only chemotherapy sessions with a principal diagnosis of Z51.1 and an additional diagnosis of cancer. From the previous edition of this report, *Cancer in adolescents and young adults in Australia 2018*, the scope has been expanded to include hospitalisations where a procedure block code related to pharmacotherapy was assigned and cancer was a principal and/or additional diagnosis. Consequently, the results presented in this report are not directly comparable to results presented in *Cancer in adolescents and young adults in Australia 2018*.

Table D2: Definition of chemotherapy procedures for cancer-related hospitalisations

Block codes	Block Name
1920	Administration of pharmacotherapy
1922	Other procedures related to pharmacotherapy

Note: Codes were sourced from the 11th edition of the Australian Classification of Health Interventions (ACHI) (ACCD 2019).

Table D3: Definition of cancer-related hospitalisations where a chemotherapy procedure was performed

	ICD-10-AM codes		
Definition	**Principal diagnosis**	**Additional diagnosis**	**Block Code**
Principal diagnosis of a cancer	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5		1920, 1922
Additional diagnosis of a cancer	Z51.1 (Pharmacotherapy session for neoplasm)	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	1920, 1922
	Codes excluding C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	1920, 1922

Note: Codes were sourced from the eighth edition of the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), and the Australian Classification of Health Interventions (ACHI) (ACCD 2019).

Definition of radiotherapy procedures for admitted patients

This is the first time that the admitted patient data on radiotherapy procedures are included in *Cancer in adolescents and young adults in Australia*. Radiotherapy data in this report include hospitalisations where a procedure block code related to radiotherapy was assigned and cancer was a principal and/or additional diagnosis. Radiation oncology procedures were assigned as one of the block codes 1786–1800 in the NHMD.

Table D4: Definition of cancer-related hospitalisations where a radiotherapy procedure was performed

	ICD-10-AM codes		
Definition	**Principal diagnosis**	**Additional diagnosis**	**Block Code**
Principal diagnosis of a cancer	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5		1786–1800
Additional diagnosis of a cancer	Z51.0 (Radiotherapy session)	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	1786–1800
	Codes excluding C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5	1786–1800

Note: Codes were sourced from the 11th edition of the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM), and the Australian Classification of Health Interventions (ACHI) (ACCD 2019).

Definition of MBS-subsidised chemotherapy services

Codes used to identify chemotherapy services: prior to 1 November 2020: 13915, 13918, 13921, 13924, 13927, 13930, 13933, 13936, 13939, 13942, 13945, 13948; on and after 1 November 2020: 13950.

Definition of MBS-subsidised radiation therapy services

Codes used to identify radiotherapy services: 15000, 15003, 15006, 15009, 15012, 15100, 15103, 15106, 15109, 15112, 15115, 15211, 15214, 15215, 15218, 15221, 15224, 15227, 15230, 15233, 15236, 15239, 15242, 15245, 15248, 15251, 15254, 15257, 15260, 15263, 15266, 15269, 15272, 15275, 15303, 15304, 15307, 15308, 15311, 15312, 15315, 15316, 15319, 15320, 15323, 15324, 15327, 15328, 15331, 15332, 15335, 15336, 15338, 15339, 15342, 15345, 15348, 15351, 15354, 15357, 15500, 15503, 15506, 15509, 15512, 15513, 15515, 15518, 15521, 15524, 15527, 15530, 15533, 15536, 15539, 15550, 15553, 15555, 15556, 15559, 15562, 15565, 15600, 15700, 15705, 15710, 15715, 15800, 15850, 15900.

Appendix E: Methods

E1 Estimating confidence bounds for crude incidence and mortality rates

Introduction

Incidence and mortality rates are expressed per 1,000,000 population members. The estimated resident populations we use, constructed by demographic methods, are not accompanied with standard errors. Consequently, they are regarded as known constants and this section is primarily concerned with estimating confidence bounds for the counts corresponding to these rates.

Method

A cancer incidence (or mortality) count *X* is conventionally assumed to follow a Poisson distribution with (unknown) mean parameter θ. By equation (1) of Dobson et al. (1991), lower and upper 95% confidence limits for this parameter, X_L and X_U, are given by

$$X_L = 0.5 * C(0.025|2X)$$

and

$$X_U = 0.5 * C(0.975|2X + 2)$$

where $C(\alpha|\mu)$ is quantile α of the cumulative Chi-squared distribution with μ degrees of freedom.

Suppose incidence count *X* is observed in a population of size *N*. Then the crude rate *R*, per 1,000,000 population, is given by

$$R = \frac{X}{N} \times 10^6$$

This measure has mean parameter

$$\frac{\theta}{N} \times 10^6$$

The 95% confidence limits for this parameter, R_L and R_U, are given by

$$R_L = \frac{500{,}000 * C(0.025|2X)}{N}$$

$$R_U = \frac{500{,}000 * C(0.975|2X + 2)}{N}$$

E2 Method of adjusting relative survival to the national site incidence distribution

Introduction

Relative survival estimates for remoteness areas, SEIFA quintiles and Indigenous and non-Indigenous Australians, for a specific cancer patient intake period, have been adjusted to the national incidence distribution, across cancer sites, of that period. Since survival varies considerably with the site of the cancer, survival for these national subpopulations is highly dependent on their individual incidence distributions. When comparing survival between subpopulations, adjustment to a standard incidence distribution removes this confounding effect, allowing more valid comparisons between survival experiences than possible when comparing unadjusted relative survival.

Method

For a national subpopulation *i*, crude cancer survival for *T* years following diagnosis is given by

$$Pr(Crude\ survival\ for\ T\ years) = \exp\left(-(cumulative\ hazard\ to\ follow\text{–}up\ year\ T)\right)$$
$$= exp\left(-\sum_{t=1}^{T}\frac{d_{ti}}{y_{ti}}\right) \quad (1)$$

where

d_{ti} = number of cancer patient deaths in follow-up year *t* for subpopulation *i*
y_{ti} = observed cancer patient person-years in follow-up year *t* for subpopulation *i*

Details on the computation of crude survival probability estimates can be found in Dickman (2004).

To account for the difference in incidence distribution by cancer site, between subpopulations, this survival measure has been adjusted to the national person-time distribution across the following 3 broad cancer groups.

- acute lymphoid leukaemia, acute myeloid leukaemia and non-Hodgkin lymphoma
- other specified soft tissue sarcomas, germ cell and trophoblastic neoplasms of testicles/ovaries and melanoma
- other specified neoplasms and all other cancers.

This adjustment is made in each follow-up year by taking the mean of the hazards, for the 3 above-mentioned groups, weighted by their respective amounts of observed national person-time. That is, for subpopulation *i* the adjusted crude survival probability to year *T* is given by

Adjusted crude survival probability = $exp\left(-(standardised\ cumulative\ hazard\ to\ year\ T)\right)$
$= exp(-\sum_{t=1}^{T}(standardised\ hazard\ to\ year\ t))$
$= exp\left(-\sum_{t=1}^{T}\sum_{k=1}^{3} w_{tk}\frac{d_{tki}}{y_{tki}}\right)$ (2)

where

w_{tk}= proportion of national person-time for follow-up year *t* in cancer group *k*

d_{tki} = number of cancer patient deaths in follow-up year *t*, cancer group *k* and subpopulation *i*
y_{tki} = observed cancer patient person-years in follow-up year *t*, cancer group *k* and subpopulation *i*

To calculate the general population survival probability corresponding to that for cancer patients given in equation (1), we average the age-sex specific general population survival probabilities of the cancer patients in each follow-up year. Survival probabilities for distinct follow-up years are regarded as statistically independent. Hence, the general population survival probability for a follow-up period is obtained by multiplying the survival probabilities of the pertinent follow-up years.

That is, for subpopulation *i* the general survival probability (for follow-up year *T*) estimator is given by

$$Pr(General\ survival\ to\ follow\text{–}up\ year\ T) = \prod_{t=1}^{T} \bar{p}_{ti}$$

where

$\bar{p}_{ti}$ =average age-sex specific general survival probability corresponding to cancer patients in follow-up year *t* and subpopulation *i*

The estimation of general survival probabilities is also discussed in Dickman (2004).

This general survival probability is adjusted to the national incidence distribution (across the 3 cancer groups) by taking the mean of the group general survival probabilities weighted by their respective national cancer patient counts. That is, for subpopulation *i* the adjusted general survival probability to year *T* is given by

$$\text{Adjusted general survival probability} = \prod_{t=1}^{T} \sum_{k=1}^{3} \frac{n_{tk}}{n_{t.}} \bar{p}_{tki} \qquad (3)$$

where

$\bar{p}_{tki}$ = average age-sex general survival probability for follow-up year *t*, corresponding to cancer group *k* in subpopulation *i*
n_{tk} = number of national cancer patients for follow-up year *t* in cancer group *k*
$n_{t.}$ = number of national cancer patients for follow-up year *t*

Finally, adjusted relative survival is the ratio of the adjusted crude and general survival probabilities, given in equations (2) and (3).

E3 The impact of age-standardisation on rates for adolescents and young adults

Introduction

In this report, crude rates (as opposed to age-standardised rates) have been used when comparing between populations of people aged 15–24 years because this age-standardisation makes (as would be expected), very little difference to comparisons when working withing such a narrow age range. This section validates that approach.

This section summarises an investigation into the impact of age-standardisation on incidence and mortality rates of Australians aged 15–24 years. More specifically, we have considered graphs comparing the trajectories of these 2 cancer indicators, for the Indigenous and non-Indigenous subpopulations, over time.

We are considering a narrow age range of young individuals and so in any year, for the Indigenous, non-Indigenous and 2001 national (standard) populations, the population distribution will be evenly spread across the 2 constituent 5-year age groups, 15–19 and 20–24 years. In the large non-Indigenous subpopulation crude rates in these two 5-year age groups are similar in any given year, and so, the age-standardised and crude rates are bound to be numerically similar.

In the small Indigenous subpopulation, the 5-year age group rates are volatile and, for a given year, may be disparate. Consequently, there is greater discrepancy between annual age-standardised and crude rates. The aim of this study is to gauge the impact of these rate differences on the gap, in cancer incidence and mortality, between Indigenous and non-Indigenous Australians aged 15–24.

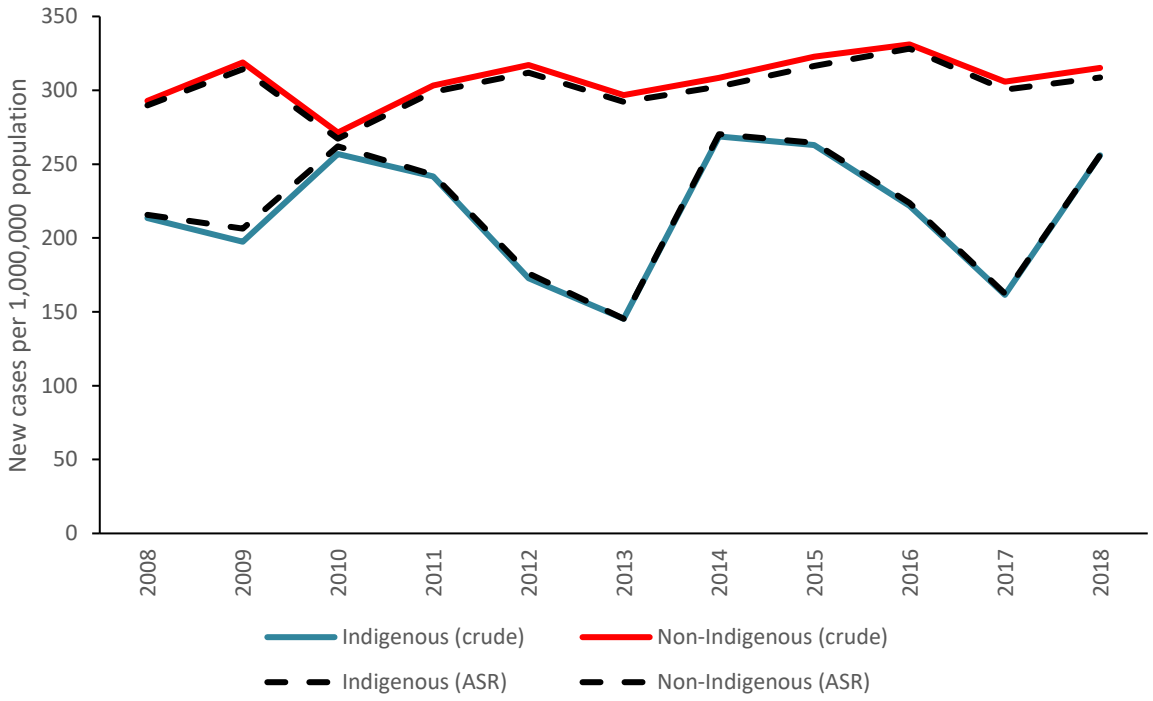
The next section presents graphs for both incidence and mortality, showing crude rates for both subpopulations and the corresponding age-standardised rates. Both the crude and age-standardised incidence and mortality rates for the Indigenous and non-Indigenous populations are seen to be similar in both figures.

Incidence

Figure E1 compares crude and age-standardised incidence rates per 1,000,000 population for Indigenous and non-Indigenous Australians aged 15–24, between 2008 and 2018. Figure E1 demonstrates the similarity of rates calculated using the 2 methods and shows the same pattern concerning the differences between these 2 subpopulations. Specifically, the non-Indigenous rate is always higher than the Indigenous rate with smallest differences (14.5 for crude and 5.2 for age-standardised rates (ASR)) and largest differences (151.4 for crude and 146.8 for ASR) occurring in 2010 and 2013, respectively.

In 2013, the Indigenous crude and age-standardised rates are both 145.3 and the non-Indigenous rates are 296.8 and 292.1. Hence, the within-subpopulation differences (0.0 and 4.7 in 2013) are of much smaller magnitude than the between-subpopulation differences (of approximately 150 in 2013).

Figure E1: Comparison of crude and age-standardised cancer incidence rates for Indigenous and non-Indigenous people aged 15–24, 2008 to 2018



Notes

1. Incidence data are for New South Wales, Victoria, Queensland, Western Australia, and the Northern Territory.
2. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.
3. Age-standardised rates (ASRs) have been age-standardised to the 2001 Australian Standard Population.

Source: AIHW ACD 2018.

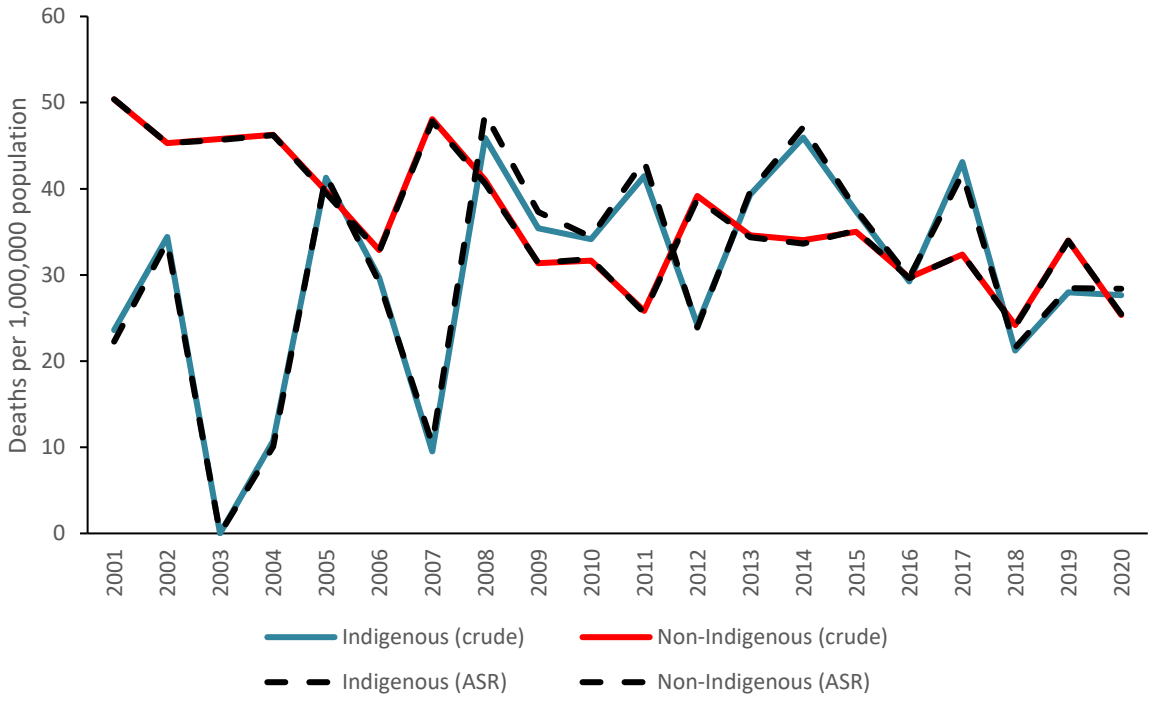
Mortality

Figure E2 compares crude and age-standardised mortality rates per 1,000,000 population for Indigenous and non-Indigenous Australians aged 15–24, between 2001 and 2020. Figure E2 demonstrates the similarity of rates calculated using the 2 methods and shows the same pattern concerning the differences between these 2 subpopulations.

In 2003, when the difference between the Indigenous and non-Indigenous rates were the largest, there were no Indigenous deaths in the 15–24 age range, and the within-subpopulation rate differences are much smaller than the between-subpopulation differences.

Furthermore, both measures show rates for the 2 groups were closest in 2016 when rate difference between Indigenous and non-Indigenous populations were 0.4 (crude) and 0.1 (ASR).

Figure E2: Comparison of crude and age-standardised cancer death rates for Indigenous and non-Indigenous people aged 15–24, 2001 to 2020



Notes

1. Mortality data are for New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory.

2. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 and 2020 are based on preliminary versions, and are subject to further revision by the ABS.

3. Mortality data from 2016 to 2019 are based on the year of occurrence of the death, and data for 2020 are based on the year of registration of the death.

4. All cancers combined includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1 and D47.3–D47.5.

5. Age-standardised rates (ASRs) have been age-standardised to the 2001 Australian Standard Population.

Source: AIHW NMD 2020.

Conclusion

Incidence and mortality rates can be described using either crude or age-standardised rates. The graphical analysis presented above indicates that, for the narrow age range 15–24 years, age-standardisation has negligible impact on the salient features of the differences in both incidence and mortality. Consequently, we have opted to use the simpler crude rate statistic for this report.

E4 Method to calculate second cancers

The cohort used to calculate second primary cancers included all Australians diagnosed with a first invasive primary cancer recorded on the ACD between 1 January 1982 and 31 December 2009 who survived for a minimum of 2 months after their diagnosis.

The cohort was followed up until 31 December 2014, allowing a potential minimum of 5 years, and potential maximum of 32 years after the initial diagnosis to ascertain the occurrence of second primary invasive cancers. Individuals who had 2 distinct primary diagnoses recorded on the same date were excluded from the analysis.

Cancers that were histologically similar at the same site were included, unless the medical record indicated that the tumour was metastatic or recurrent. Synchronous primary cancers (those diagnosed within 2 months of the first primary cancer) were excluded, because they were more likely to be diagnosed as a result of detection bias. Third or subsequent primary cancers were not considered in the analysis.

Person-years at risk among people diagnosed with a first primary cancer were calculated as the time from 2 months after diagnosis until either 31 December 2014, date of death, or date of diagnosis of a second primary cancer, whichever came first. The data were then stratified by type of first primary cancer, sex and age at diagnosis.

The expected number of second primary cancers was calculated by multiplying the sum of the person-years at risk by the cancer incidence rate experienced by the general Australian population, matched by sex, age and year.

Standardised incidence ratios were then obtained by dividing the observed number of second cancers by the expected number. The ratio is therefore used to estimate the risk of a cancer survivor developing a second primary cancer relative to the incidence of cancer in the general population.

E5 Age-sex adjustment of relative survival estimates

Introduction

The general method for calculating 5-year relative survival is given by Dickman (2004).

In Chapter 5, 5-year relative survival estimates are presented for state/territory, remoteness category and SEIFA quintile. Inference concerning differences in survival between Australian subpopulations could be confounded by their differing age-sex distributions. Consequently, estimates that are adjusted to the national incidence distribution by age and sex have been provided. These synthetic estimates are calculated by applying survival probabilities, disaggregated by age and sex, to the corresponding national incidence proportions.

This appendix gives the methodological details of this adjustment process. The first section describes the crude survival probability estimator and its adjustment to the age-sex distribution of national person-time for cancer patients. In this report we have expressed crude survival relative to the corresponding *background survival probability* estimate, which is based on all-cause mortality. The second section presents the estimator of this probability and describes the process by which it is adjusted to age-sex distribution of national cancer patients.

Adjustment of the crude survival estimate

For cancer type *c* and Australian subpopulation *p*, the crude survival probability for *T* years follow-up is given by

$$\text{Unadjusted crude survival} = exp\left(-\sum_{t=1}^{T}\frac{d_{cpt}}{y_{cpt}}\right)$$

where

d_{cpt} = number of deaths among patients with cancer *c* in subpopulation *p* and follow-up year *t*

y_{cpt} = observed person-time for patients with cancer *c* in subpopulation *p* and follow-up year *t*

To adjust crude survival to the national person-time distribution for cancer type *c*, by sex and age groups 15–19 and 20–24 year, we proceed as follows.

Let

s = sex; *s* = 1, 2

a = age group; *a* = 1 (15–19 years), *a* = 2 (20–24 years)

y_{csat} = national observed person-years for cancer *c*, sex *s*, age group *a* and follow-up year *t*

$y_{ct} = \sum_{s=1}^{2}\sum_{a=1}^{2} y_{csat}$ = total national observed person-years for cancer *c* and follow-up year *t*

d_{cpsat} = death count for patients with cancer *c* in subpopulation *p*, sex *s*, age group *a and* follow-up year *t*

y_{cpsat}= observed person-years for cancer *c*, subpopulation *p*, sex *s*, age group *a* and follow-up year *t*

Then, for cancer *c*, subpopulation *p* and *T* years follow-up, we define

$$\text{adjusted crude survival} = exp\left(-\sum_{t=1}^{T}\sum_{s=1}^{2}\sum_{a=1}^{2}\frac{y_{csat}}{y_{ct}}\frac{d_{cpsat}}{y_{cpsat}}\right)$$

That is, in each follow-up year we adjust by applying the national proportions of observed person-years in each age-sex category to the corresponding deaths per person-year rates (known as *hazard rates*) in the subpopulation of interest.

We note that when *p* denotes the Australian population, we have the desirable result that the adjusted and unadjusted estimates coincide. To see this, we note that in this context $y_{csat} = y_{cpsat}$ and so

$$\text{adjusted crude survival} = exp\left(-\sum_{t=1}^{T}\frac{1}{y_{ct}}\sum_{s=1}^{2}\sum_{a=1}^{2} d_{cpsat}\right)$$

$$= exp\left(-\sum_{t=1}^{T}\frac{d_{csat}}{y_{csat}}\right)$$

= unadjusted crude survival

Adjustment of the background survival estimate

To obtain relative survival we divide crude survival by the background survival probability that is based on survival rates, in the entire Australian population, disaggregated by sex and single year age. More specifically, from their sex and age, cancer patients are assigned a *general survival rate* equal to one minus the pertinent all-cause mortality rate. Then, for cancer type *c*, subpopulation *p* and *T* years follow-up, unadjusted background survival is defined as

$\prod_{t=1}^{T}$(mean general survival rate for patients with cancer c in subpopulation p and follow-up year t)

That is,

unadjusted background survival =$\prod_{t=1}^{T}\frac{1}{n_{cpt}}\sum_{i\in C(p,t)}$(general survival rate for $patient\ i$)

where

n_{cpt} = number of patients with cancer c in subpopulation *p* and follow-up year *t*

$C(p,\ t)$ = set of patients with cancer *c* in subpopulation *p* and follow-up year *t*

We now consider the adjustment of the background survival probability for cancer *c*, subpopulation *p* and *T* follow-up years.

Let

n_{csat} = national patient count for cancer *c*, sex *s*, age group *a* and follow-up year *t*

$n_{ct} = \sum_{s=1}^{2}\sum_{a=1}^{2} n_{csat}$ = national patient count for cancer *c* and follow-up year *t*

n_{cpsat} = patient count for cancer *c*, subpopulation *p*, sex *s*, age group *a* and follow-up year *t*

C(c,p,s,a,t) = set of patients with cancer *c* in subpopulation *p* of sex *s* and age group *a* in follow-up year *t*

Then, for cancer *c*, subpopulation *p* and *T* follow-up years, the adjusted background survival probability is equal to

$$\prod_{t=1}^{T}\frac{1}{n_{ct}}\sum_{s=1}^{2}\sum_{a=1}^{2}\frac{n_{csat}}{n_{cpsat}}\sum_{i\in C(c,p,s,a,t)}(\text{general survival rate for patient } i)$$

That is, in each follow-up year we adjust by applying the national proportions of cancer patients in each age-sex category to the corresponding average general survival rates in the subpopulation of interest.

This adjustment process also has the property that when *p* denotes the Australian population the adjusted estimate equals the unadjusted estimate. In this case, $n_{cpsat} = n_{csat}$ and so the adjusted background survival probability is equal to

$\prod_{t=1}^{T}\frac{1}{n_{ct}}\sum_{s=1}^{2}\sum_{a=1}^{2}\sum_{i\in C(c,s,a,t)}(Australian\ survival\ rate\ for\ patient\ i)$

$$= \prod_{t=1}^{T} \frac{1}{n_{ct}} \sum_{i \in C(p,t)} (general\ survival\ rate\ for\ patient\ i)$$

which is the unadjusted background survival probability.

E6 Relative survival greater than 100%

Relative survival is a comparative statistic that divides the percentage of cancer patients who survive by the percentage who would be expected to survive if they were considered to be 'average' members of their age and sex in the general population. If the cancer being considered is rarely fatal and the number of cancer patients being considered is relatively small, sometimes the percentage of patients who survive can be 100%. As the expected survival is always less than 100% (because there is always some level of mortality in the general population), the relative survival comes out to be greater than 100% in this situation. For example, if 100 patients are diagnosed and all of them are still alive after 1 year (observed survival = 100%) and the expected survival of this group of people after 1 year is 99%, then 1-year relative survival will be 100/99 = 101%.

A relative survival figure of more than 100% can be interpreted as a statistical aberration due to the cancer being rarely fatal and the small number of patients in the calculation. However, another interpretation is possible. People who have been diagnosed with cancer tend to be more closely monitored by health professionals than the average person in the population, at least for the first few years after diagnosis. If the cancer is rarely fatal, this closer monitoring and/or voluntary lifestyle changes made by the patients could mean that they actually become healthier than the average members of the same age and sex in the general population, thus leading to better survival outcomes for them. In reality, both this effect and some statistical aberration due to small numbers could be at play. As it is not possible to determine how much each effect contributes to a relative survival figure of greater than 100%, such figures are reported as they are rather than rounded down to 100%.

Acknowledgments

Andrew Phillips, Carly Heyman, Brett Davis, Christina Hatzis, Henry Wong, Brent Bufton, Mark Short and Justin Harvey prepared this report under the direction of Richard Juckes.

The authors would like to thank all colleagues who commented on earlier drafts and provided expert advice and assistance in producing this document, and in particular Kristian Weissel, Caleb Leung, Jen Mayhew-Larsen, Julianne Garcia, Karen Bishop and Miriam Lum On for their specialised input around Hospital, MBS and Burden of Disease data.

The authors would like to thank Canteen for their support of this work.

The authors gratefully acknowledge the support of the Australasian Association of Cancer Registries who provide cancer incidence data to AIHW's Australian Cancer Database.

Abbreviations

ABS	Australian Bureau of Statistics
ACD	Australian Cancer Database
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ALOS	average length of stay
ASR	age-standardised rate
BOD	burden of disease
CNS	central nervous system
DALY	disability-adjusted life years
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th revision
ICD-10-AM	International Classification of Diseases, 10th revision, Australian modification
ICD-O-3	International Classification of Diseases for Oncology, third edition
MBS	Medicare Benefits Schedule
NCI	National Cancer Institute
NEN	neuroendocrine neoplasm
NHMD	National Hospital Morbidity Database
NMD	National Mortality Database
NNAPC(agg)D	National Non-admitted Patient Care (aggregate) Database
NNAP(el)D	National Non-admitted Patient (episode-level) Database
NSW	New South Wales
NT	Northern Territory
Qld	Queensland
SA	South Australia
SEER	Surveillance, Epidemiology, and End Results
SEIFA	Socio-Economic Indexes for Areas
Tas	Tasmania
Vic	Victoria
WA	Western Australia
YLD	years lived with disability

YLL	years of life lost

Symbols

n.o.s	not otherwise specified
n.p.	not publishable because of small numbers, confidentiality, or other concerns about the quality of the data

Glossary

additional diagnosis: A condition or complaint that either coexists with the principal diagnosis or arises during the episode of care. An additional diagnosis is reported if the condition affects patient management. Compare with **principal diagnosis**.

admitted patient: A person who undergoes a hospital's formal admission process to receive treatment and/or care. Such treatment or care can occur in hospital and/or in the person's home (as a 'hospital-in-the-home' patient).

age-standardisation: A method of removing the influence of age when comparing populations with different age-structures. This is usually necessary because the rates of many diseases vary strongly (usually increasing) with age. The age structures of the different populations are converted to the same 'standard' structure, and then the disease rates that would have occurred with that structure are calculated and compared.

age-standardised rate: A rate that results from removing the influence of age by converting the age structures of the different populations to the same 'standard' structure. This provides a more valid way of comparing rates from populations with different age structures.

benign: Non-cancerous tumours that might grow larger, but do not spread to other parts of the body.

cancer (or malignancy): Diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.

care type: The overall nature of a clinical service provided to an admitted patient during an episode of care (admitted care), or the type of service provided by the hospital for boarders or posthumous organ procurement (care other than admitted care).

chemotherapy: The use of drugs (chemicals) to prevent or treat disease, with the term usually being applied to treatment for cancer rather than for other uses.

children: People aged 0-14 years.

disability-adjusted life years (DALY): Years of healthy life lost, either through premature death, or through living with disability due to illness or injury. It is the basic unit used to estimate burden of disease and injury.

highest level diagnosis: The first mentioned cancer diagnosis in those recorded for a hospital admission. In this report, up to 10 diagnoses have been considered for each admission; the principal diagnosis, as well as 9 additional diagnoses that have been provided for the admission (with the majority of these being the second diagnosis). The majority of these admissions where the highest level additional diagnosis was cancer, also had a principal diagnosis of 'pharmacotherapy session for neoplasm'.

hospitalisation: An episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer, or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation care). Hospitalisation also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital, or changing type of care.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period. Compare with **prevalence**.

incidence rate: The number of diagnoses in a given period, expressed per 1,000,000 population in this report.

International Classification of Diseases (ICD): The World Health Organization's internationally accepted statistical classification of death and disease. The 10th revision (ICD-10) is currently in use. The Australian modification of the ICD-10 (ICD-10-AM) is used for diagnoses and procedures recorded for patients admitted to hospitals.

mortality: Death.

mortality rate: The number of deaths in a given period, adjusted to take account of population age structure, expressed per 1 million population in this report.

neuroendocrine neoplasm: See Box 2.4. Same as neuroendocrine tumour.

neoplasm: An abnormal ('neo', new) growth of tissue. Can be 'benign' (not a cancer) or 'malignant' (a cancer). Same as a **tumour**.

prevalence: The total number of people alive at a specific date who have been diagnosed with a particular disease, such as cancer, within a defined period.

principal diagnosis: The diagnosis established after study to be chiefly responsible for occasioning the patient's episode of admitted patient care.

radiotherapy: Radiation directed at a localised area to kill or damage cancer cells. There are several types of radiotherapy. This report focuses on megavoltage external beam radiotherapy delivered by linear accelerator machines.

relative survival: A measure of the average survival experience of a population of people diagnosed with cancer, relative to the 'average' Australian of the same sex and age, at a specified interval after diagnosis (usually 5 or 10 years).

second cancer: A new primary cancer that occurs in a person who has had cancer in the past.

tumour: An abnormal growth of tissue. Can be 'benign' (not a cancer) or 'malignant' (a cancer). Same as a **neoplasm**.

years lived with disability (YLD): Years lived with disability is calculated as the prevalence of a condition, multiplied by a disability weight for that condition. This is also sometimes referred to as years of healthy life lost due to disability.

years of life lost (YLL): For each new case, years of life lost equals the number of years between premature death and the standard life expectancy for the individual.

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Related publications

The following AIHW publications relating to cancer might be of interest:

- AIHW 2018. Cancer in adolescents and young adults in Australia. Cat. no. CAN 110. Canberra: AIHW.
- AIHW 2021. Cancer in Australia 2021. Cancer series no. 133. Cat. no. CAN 144. Canberra: AIHW.
- AIHW 2022. Cancer data in Australia. AIHW Cat.no. CAN 122.
- AIHW 2022. Australian Burden of Disease Study 2022.Cat. no. BOD 37. Canberra: AIHW.
- AIHW 2017. Brain and other central nervous system cancers. Cat. no. CAN 106. Canberra: AIHW.

This is the third national report to present data specific to cancer in adolescents and young adults in Australia. Cancer in this age group is rare and survival is high, with just over 1,000 diagnoses and 90 deaths per year. The report focuses on cancer incidence, survival, mortality, prevalence, treatment, disease burden, and second cancers for people aged 15–24, while also providing some data for children (0-14) and older young adults (25–39).

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