



# Cancer in adolescents and young adults in Australia





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## **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

CI confidence interval

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, 3rd edition

NCI National Cancer Institute

NHMD National Hospital Morbidity Database

NMD National Mortality Database

NSW New South Wales

NT Northern Territory

Qld Queensland

SA South Australia

SEER Surveillance, Epidemiology, and End Results

SIR standardised incidence ratio

Tas Tasmania

Vic Victoria

WA Western Australia

YLD years lost due to 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

## **Summary**

This is the second national report to present comprehensive national statistics on cancer in adolescents and young adults aged 15–24 (also referred to as young Australians in this report). 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 cancers in young Australians.

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

In 2010–2014, 4,843 new cases of cancer (excluding basal and squamous cell carcinoma of the skin) were diagnosed in young Australians—an average of 2–3 cases per day.

In 2011–2015, cancer accounted for 8.8% of all deaths of young Australians. In 2011, cancer was the 7th leading cause of overall disease burden in young people, and the 2nd leading cause of fatal burden. Young Australians lost 6,850 disability-adjusted life years from cancer, with most of the burden due to dying prematurely (94%).

# Melanoma was the most common cancer, and brain cancer was the leading cause of cancer mortality

In 2010–2014, melanoma was the most commonly diagnosed cancer in young Australians, accounting for 15% of all cancers diagnosed. But age-standardised incidence rates for melanoma fell from 96 new cases per 1 million young Australians in 1985–1989 to 44 new cases per 1 million in 2010–2014.

In 2011–2015, brain cancer was the leading cause of cancer mortality in young Australians, accounting for 18% of all cancer deaths. But age-standardised mortality rates from brain cancer fell from 7.6 deaths per 1 million young Australians in 1981–1985 to 5.8 deaths per 1 million in 2011–2015.

## Cancer survival is high

In 2010–2014, young Australians diagnosed with cancer had, on average, an 89% chance of surviving for 5 years. Relative survival from all cancers combined for young Australians rose from 80% in 1985–1989 to 89% in 2010–2014, though changes in 5-year relative survival varied between cancer types.

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

In 1982–2014, 725 second cancers were diagnosed in those who had their first cancer diagnosed when aged 15–24, representing about 3% of all young cancer survivors.

For cancer survivors who had been diagnosed as an adolescent or young adult, the risk of developing a second cancer was 1.9 times as high as for the general population (2.2 times for males; 1.8 times for females).

The majority of second cancers had an initial diagnosis of Hodgkin lymphoma, followed by melanoma, gonadal germ cell cancer, and non-Hodgkin lymphoma.

## 1 Introduction

Cancers in adolescents and young adults aged 15–24 (referred to as young Australians in this report) are uncommon, but can have far-reaching consequences, and contribute a substantial disease burden—in 2011, cancers accounted for about 8% of the fatal burden in young Australians (AIHW 2016a).

There is also growing recognition that young people with cancer have distinct biological, psychosocial, and information needs (Bleyer 2009; Palmer & Thomas 2008; 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 & CanTeen Australia 2009). The 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 second 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).

This report presents updated national incidence and survival data for young Australians with cancer for 2010–2014, with trends dating back to 1985–1989. National mortality data are presented for 2011–2015, with trends dating back to 1981–1985.

This report also presents trends in cancer-related hospitalisations for 2001–02 to 2015–16, and the burden of cancer in 2011. 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)
- How many young Australians were hospitalised with a cancer-related illness, and what services are most commonly accessed? (Chapter 3)
- What are the survival figures for young Australians diagnosed with cancer, and is survival from cancer improving for young Australians? (Chapter 4)
- How many young Australians died from cancer each year, and what are the trends in cancer mortality? (Chapter 5)
- What is the burden of cancer in young Australians? (Chapter 6)

- 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 7)
- What is the risk of developing a second cancer for young Australians who survived their initial cancer diagnosis? (Chapter 8).

#### Box 1.1: Definitions and terminology in this report

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

Adult: An individual aged 25-39.

Age-specific: See Rate.

**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. In this report, age-standardised rates for incidence and mortality are expressed per 1 million population.

**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 follows often 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.

**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 million population.

**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.

## 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 malianant 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 (Palmer & Thomas 2008).

There is no universally accepted age group to define adolescence and young adulthood (Geiger & 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 Canadian Cancer Society report on ages 15–29, while the National Cancer Institute reports on ages 15–39 (Albritton et al. 2006; Canadian Cancer Society 2017).

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 (also referred to as young Australians), 'children' refers to individuals aged 0–14, and 'adults' refers to individuals aged 25–39.

To help inform service delivery for Youth Cancer Services, cancer incidence, mortality, and survival for individuals aged 15–25 are also included in online supplementary tables.

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

In 2016, there were close to 3.2 million adolescents and young adults in Australia, representing about 13% of the total population (ABS 2017a). Males (51%) made up a slightly higher proportion than females (49%). Those aged 20–24 accounted for 53% of the total population of young Australians, slighter higher than those aged 15–19 (47%).

In 2015, the majority of adolescents and young adults in Australia lived in *Major cities* (73% compared with 71% for the total population).

# 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 (Palmer & Thomas 2008). 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 2017).

Additionally, as relative survival from all cancers combined tends to be high for this population (88% 5-year relative survival in 2004–2010 for those aged 15–29), the number of years lived post-cancer is higher than many other age groups, resulting in a higher lifelong impact from cancer (AIHW 2011). For those aged 15–25 who are diagnosed with cancer in Australia in 2016, the total lifetime costs are estimated to be \$1.4 billion (CanTeen Australia 2017).

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 2015).

# 1.5 How are cancers in adolescents and young adults classified?

In this report, the Surveillance, Epidemiology and End Results (SEER) adolescent and young adult site recode was used as the basis to classify and report incidence and survival statistics. The 10th revision of the International Statistical Classification of Disease and Related Health Problems (ICD-10) was used to classify and report treatment, mortality, and burden of disease statistics (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 (SEER 2010). 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, 3rd edition (Steliarova-Foucher et al. 2005).

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

The classification system defines 10 major cancer groups, which are:

- leukaemias
- lymphomas
- · central nervous system cancers
- bone cancers
- soft-tissue sarcomas
- germ cell cancers
- melanomas
- carcinomas
- · miscellaneous specified neoplasms, not otherwise specified
- unspecified cancers.

All but 1 of these major cancer groups are divided further into subgroups. The codes for each group and subgroup are presented in Appendix A1. Further information about each of the 10 major cancer groups is provided in this section.

#### Leukaemias

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) (NCI 2011). There are 4 main types of leukaemia in the SEER recode: acute myeloid leukaemia; acute lymphoid leukaemia; chronic myeloid leukaemia; and other and unspecified leukaemia.

#### Lymphomas

Lymphomas are cancers arising in the lymphatic cells of the immune system. They often present as solid tumours, originating in 1 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 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 (ACS 2017a; 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 2015a; NCI 2008).

#### 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 2017b). 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 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. Germ cell cancers that form in the testicles or ovaries are referred to as gonadal germ cell cancers, while those that form in other parts of the body are referred to as non-gonadal germ cell cancers (MacMillan Cancer Support 2016).

#### **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 2015b).

#### Carcinomas

Carcinomas are cancers arising in the epithelial cells covering the outside of the body and the body's organs.

#### 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 9 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, 3rd 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 is preparing a childhood cancer report that will contain detailed information on childhood cancers classified by the International Classification of Childhood Cancer, 3rd edition.

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-0-3.

As a result, the SEER adolescent and young adult site recode could not be used as the basis for reporting treatment, mortality and burden of disease statistics. Treatment, mortality and burden of disease statistics 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 the same as those in the treatment, mortality, and burden of disease chapters. For example, the cancer group *melanoma* in the incidence and survival chapters differs slightly from *melanoma of the skin* in the mortality chapter, as it includes melanomas originating at sites other than the skin, which generally have a poorer prognosis. Similarly, *acute lymphoid leukaemia* in the incidence chapter might not be the same as *acute lymphoblastic leukaemia* in the mortality chapter.

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

#### Periods for reporting

This report presents:

- incidence and survival trends for 1985–2014
- mortality trends for 1981–2015
- cancer-related hospitalisations for 2001–02 to 2015–16
- burden of disease data for 2011.

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 an individual year.

#### Rates

This report presents information on the number of cancer cases and deaths, together with rates and age-standardised rates.

Rates (often referred to as 'crude rates') reflect the number of cancers diagnosed relative to the total population of interest in a specified period. However, as age structures and the size of the population can change over time and vary between population groups, this measure may not be appropriate when making comparisons. Age-standardised rates account for differences in the age structure and size of the population over time.

Both measures are included in the report to reflect the impact of cancer in a specified period, and to allow for comparisons over time and between groups. Age-standardised rates have been standardised to the Australian population at 30 June 2001. In this report, both rates and age-standardised rates are expressed per 1 million population.

## **Data variability**

The number 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 in 5-year periods.
- Larger categories have been used to present small groups (for example, combining Remote and Very remote geographic areas in Chapter 7).
- Cancers with fewer than 25 new cases/deaths per 5-year period have not been presented in the incidence (Chapter 2) and mortality (Chapter 5) chapters.
- A note has been included to interpret mortality rates with caution for special population groups (Chapter 7) that contain fewer than 25 cancer deaths during 2011–2015.

## Statistical significance

Confidence intervals (at the 95% level) are presented for standardised incidence ratios in the spotlight chapter (Chapter 8) and are included for relative survival in online appendix tables. Confidence intervals can be used as a guide when considering whether differences in rates may be a result of chance variation. While differences might be regarded as 'statistically significant', they may or may not be 'significant' from a practical or clinical perspective. Where differences across time or between groups have been highlighted throughout the report (for example, when it is stated that cancer incidence rates increased over time) they represent a change that is statistically significant.

## 2 Incidence of cancer

#### **Key findings**

#### In 2010-2014:

- 4,843 new cases of cancer were diagnosed in young Australians
- males contributed more than half (53%) of all cancers diagnosed in young Australians
- melanoma was the most commonly diagnosed cancer in young Australians, followed by gonadal germ cell cancer, Hodgkin lymphoma, thyroid carcinoma, and colorectal carcinoma
- adolescents and young adults generally had a lower incidence rate of cancer compared with adults aged 25–39. However, they had a higher incidence rate than adults for acute lymphoid leukaemia, Hodgkin lymphoma, and Ewing tumour.

#### Between 1985-1989 and 2010-2014:

- age-standardised incidence rates for all cancers combined in young Australians increased from 283 new cases per 1 million young Australians in 1985–1989 to 330 new cases per 1 million in 1995–1999, before decreasing to 308 new cases per 1 million in 2010–2014
- age-standardised incidence rates in young Australians for glioblastoma and anaplastic astrocytoma, thyroid carcinoma, and colorectal carcinoma increased by over 100%
- age-standardised incidence rates in cervical carcinoma and melanoma decreased by over 25%.

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

The main data source for this chapter was the Australian Cancer Database (ACD) 2014. 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 2014 (2013 for New South Wales).

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

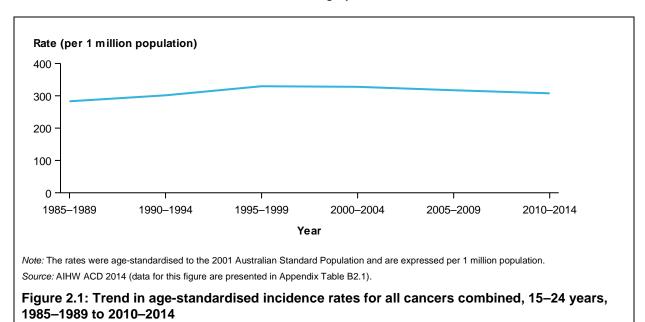
This chapter presents incidence for cancer in adolescents and young adults in 2010–2014, including differences by sex, and comparisons with other age groups.

Trends in age-standardised incidence rates from 1985–1989 are also presented.

## 2.1 Incidence of all cancers combined

In 2010–2014, 4,843 new cases of cancer were diagnosed in young Australians (0.8% of all cancers diagnosed in 2010–2014)—an average of 2–3 young people per day. The incidence rate for all cancers combined in the period 2010–2014 was 313 new cases per 1 million young Australians (308 per 1 million when age-standardised).

The number of new cases of cancer diagnosed in young Australians increased from 3,836 in 1985–1989 to 4,843 in 2010–2014. However, the age-standardised incidence rate for all cancers combined in young Australians increased from 283 new cases per 1 million young people in 1985–1989 to 330 new cases per 1 million in 1995–1999, before decreasing to 308 new cases per 1 million in 2010–2014 (Figure 2.1). The decrease in age-standardised incidence rates for AYA since 1995–1999 is largely attributable to a decline in melanoma.



## 2.2 Incidence by cancer type

In 2010–2014, melanoma was the most commonly diagnosed cancer (707 new cases) among young Australians, followed by gonadal germ cell cancer (666) and Hodgkin lymphoma (661). These 3 cancers each had incidence rates of over 40 new cases per 1 million young Australians.

The 5 most commonly diagnosed cancers during this period accounted for 58% of all cancers diagnosed in young Australians (Table 2.1).

Table 2.1: The 10 most commonly diagnosed cancers, 15-24 years, 2010-2014

Cancer	Number	% of new cancers	Rate	ASR
Melanoma	707	14.6	45.6	44.1
Gonadal germ cell cancer	666	13.8	43.0	41.7
Hodgkin lymphoma	661	13.6	42.7	42.5
Thyroid carcinoma	445	9.2	28.7	28.1
Colorectal carcinoma	351	7.2	22.7	22.3
non-Hodgkin lymphoma	293	6.0	18.9	18.7
Acute lymphoid leukaemia	186	3.8	12.0	12.3
Acute myeloid leukaemia	162	3.4	10.5	10.5
Other specified soft tissue sarcoma	111	2.3	7.1	7.0
Ewing tumour	86	1.8	5.5	5.7
All cancers combined	4,843	100.0	312.8	307.6

Note: Rate is the number of cancers diagnosed per 1 million population. ASR stands for age standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Source: AIHW ACD 2014.

Table B2.2 presents trends in cancers that averaged at least 5 new cases per year in young Australians during 1985–1989 to 2010–2014.

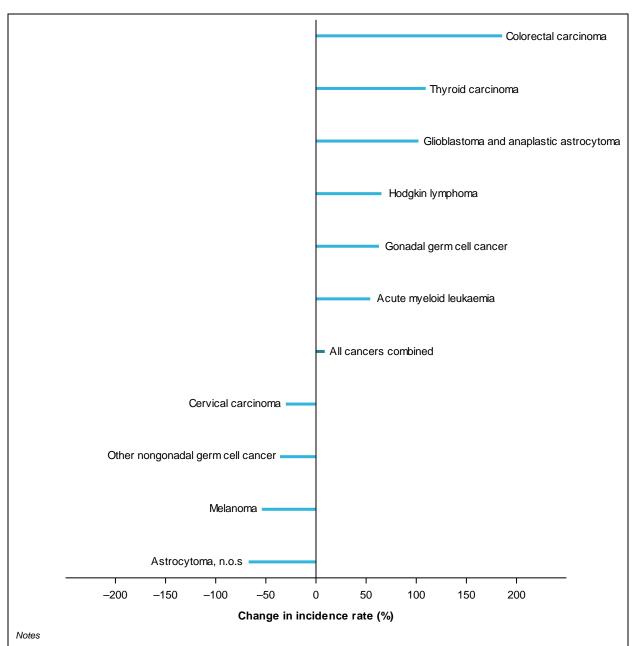
Figure 2.2 presents cancers which demonstrated an increase in age-standardised incidence rates of at least 50%, or a decrease in incidence rates of at least 25% between 1985–1989 and 2010–2014. Colorectal carcinoma showed the largest increase in incidence rates (186%), followed by thyroid carcinoma (109%), glioblastoma and anaplastic astrocytoma (102%), Hodgkin lymphoma (65%), gonadal germ cell cancer (63%), and acute myeloid leukaemia (54%).

Increased incidence rates of thyroid carcinoma in young Australians might, in part, be explained by improved diagnostic tools (Barr et al. 2016; Vergamini et al. 2014). Increases in incidence rates for colorectal carcinoma and testicular cancer (a common form of gonadal germ cell cancer) among young people have occurred internationally (Barr et al. 2016).

While the reasons for increased testicular cancers in young people are not well understood, some of the known risk factors include testicular atrophy, maternal exposures, and cryptorchidism (that is, an undescended testicle). Similarly, increased incidence of colorectal carcinoma among young Australians might be related to risk factors including hereditary predisposition, and environmental factors, such as poor nutrition, smoking, and alcohol consumption (Haggar et al. 2012).

Four cancers had a decrease of at least 25% in age-standardised incidence rates since 1985–1989. Unspecified astrocytoma showed the biggest decrease (67%), followed by melanoma (54%), other non-gonadal germ cell cancer (36%), and cervical carcinoma (30%).

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). Similarly, the decrease in cervical cancer incidence rates might be partly due to early detection through the National Cancer Screening Program (Brotherton et al. 2011).



The bars indicate the percentage change in incidence rates between 1985–1989 and 2010–2014. This summary measure enables the use of a single number to describe the change over multiple years. However, it is not always reasonable to expect that a single measure can accurately describe the trend over the entire period.

Figure 2.2: Percentage change in age-standardised incidence rates for specific cancers and all cancers combined, 15–24 years, 1985–1989 to 2010–2014

<sup>2.</sup> The rates were age-standardised to the 2001 Australian Standard Population and are expressed per 1 million population. Source: AIHW ACD 2014 (data for this figure are presented in Appendix Table B2.2).

## 2.3 Incidence of cancer by sex

In 2010–2014, males accounted for about 53% of all cancers diagnosed in young Australians (2,544 new cases). The proportion of male cancer diagnoses in young people is similar to that of male cancer diagnoses in the wider Australian population (54%) (AIHW 2017a).

For males, gonadal germ cell cancer was the most commonly diagnosed cancer (597 new cases), followed by Hodgkin lymphoma (315), melanoma (305), non-Hodgkin lymphoma (182), and colorectal carcinoma (145). These 5 cancers accounted for 63% of all cancers diagnosed in young males (Table 2.2).

For females, melanoma was the most commonly diagnosed cancer (401 new cases), followed by Hodgkin lymphoma (345), thyroid carcinoma (344), colorectal carcinoma (206), and non-Hodgkin lymphoma (111). Together, these cancers accounted for 61% of all cancers diagnosed in young females.

Table 2.2: The 10 most commonly diagnosed cancers, 15-24 years, by sex, 2010-2014

Male					Fema	ale			
Cancer	Number	% of new cancers	Rate	ASR	Cancer	Number	% of new cancers	Rate	ASR
Gonadal germ cell cancer	597	23.5	75.3	72.9	Melanoma	401	17.5	53.1	51.2
Hodgkin lymphoma	315	12.4	39.7	39.4	Hodgkin lymphoma	345	15.0	45.7	45.8
Melanoma	305	12.0	38.5	37.4	Thyroid carcinoma	344	15.0	45.5	44.3
non-Hodgkin lymphoma	182	7.2	22.9	22.8	Colorectal carcinoma	206	8.9	27.2	26.7
Colorectal carcinoma	145	5.7	18.3	18.0	non-Hodgkin lymphoma	111	4.8	14.7	14.5
Acute lymphoid leukaemia	131	5.1	16.5	16.8	Acute myeloid leukaemia	78	3.4	10.4	10.3
Thyroid carcinoma	101	4.0	12.7	12.6	Cervical carcinoma	75	3.3	10.0	9.4
Acute myeloid leukaemia	84	3.3	10.6	10.6	Gonadal germ cell cancer	70	3.0	9.2	9.1
Osteosarcomas	62	2.4	7.8	8.1	Acute lymphoid leukaemia	55	2.4	7.3	7.5
Other specified soft tissue sarcoma	60	2.4	7.6	7.5	Other specified neoplasms, n.o.s.	54	2.3	7.1	6.9
All cancers combined	2,544	100.0	320.9	316.2	All cancers combined	2,299	100.0	304.4	298.5

Note: Rate is the number of cancers diagnosed per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Source: AIHW ACD 2014.

## 2.4 Incidence of cancer by age

In 2010–2014, cancer incidence rates generally increased with age (Figure 2.3). Children (aged 0–14) had the lowest incidence rate (160 new cases per 1 million children; 158 per 1 million when age-standardised), followed by adolescents and young adults (313 new cases per 1 million young people; 308 per 1 million when age-standardised), and adults (aged 25–39) (1,036 new cases per 1 million adults; 1,055 per 1 million when age-standardised).

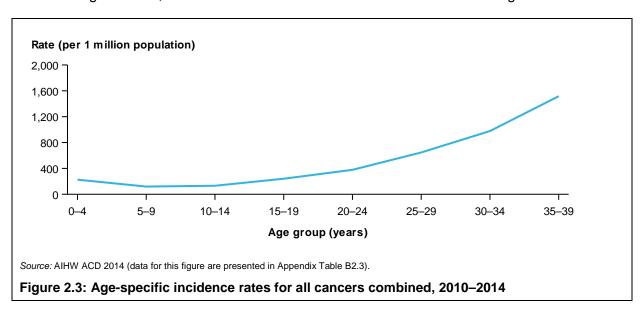
Incidence rates for the 10 cancers most commonly diagnosed among young Australians differed between the age groups. Compared with adults, young Australians had higher incidence rates for:

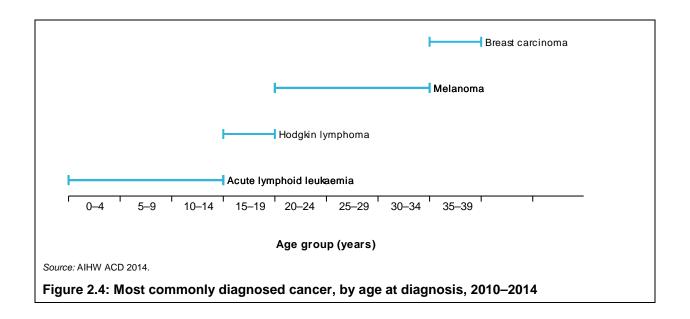
- acute lymphoid leukaemia (12 new cases per 1 million young Australians, compared with 6.5 new cases per 1 million adults)
- Hodgkin lymphoma (43 per 1 million, compared with 34 per 1 million)
- Ewing tumour (5.5 per 1 million, compared with 1.6 per 1 million).

Compared with children, young Australians had lower incidence rates for:

 acute lymphoid leukaemia (12 new cases per 1 million young people, compared with 45 new cases per 1 million children).

The pattern of cancer incidence differed across age groups (Figure 2.4). Acute lymphoid leukaemia was the most commonly diagnosed cancer for children aged 0–14, while Hodgkin lymphoma was most common for those aged 15–19, melanoma was most common for those aged 20–34, and breast carcinoma was most common for those aged 35–39.





## 3 Treatment for cancer

#### **Key findings**

In 2015–16, for adolescents and young adults:

- there were 10,638 cancer-related hospitalisations (1.7% of all hospitalisations in young Australians)
- about two-thirds (65%) of cancer-related hospitalisations were for same-day care
- chemotherapy was the most common treatment recorded as a principal diagnosis, and for these hospitalisations, Hodgkin lymphoma was the most common additional diagnosis
- Hodgkin lymphoma and other soft tissue cancers were the most common principal diagnoses for radiotherapy courses.

Data for this chapter are mainly sourced from the National Hospital Morbidity Database (NHMD), which is a compilation of episode-level records from admitted morbidity data collection systems in Australian hospitals.

For more information about the NHMD, see Appendix C and Admitted patient care 2015–16: Australian hospital statistics (AIHW 2017c). In this report, cancer-related hospitalisations are defined as those where at least 1 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.

## 3.1 Hospitalisations for all cancers combined

In 2015–16, there were 611,711 hospitalisations of adolescents and young adults in Australia. About 1.7% (10,638) of these were cancer-related (Table 3.1). Less than half (38%) of all cancer-related hospitalisations of young Australians had a principal diagnosis of cancer. The remainder had an additional diagnosis of cancer, or a principal diagnosis related to the treatment of cancer (and cancer was not an additional diagnosis).

For hospitalisations with a principal diagnosis of cancer, 66% were overnight, with an average length of stay (ALOS) of 7.4 days (Table 3.2). In contrast, 16% of hospitalisations with an additional diagnosis of cancer were overnight.

Table 3.1: Cancer-related hospitalisations, 15–24 years, 2015–16

	Number	%	Rate	ASR
Principal diagnosis of cancer	4,084	38.4	12.8	13.0
Additional diagnosis of cancer	6,307	59.3	19.8	19.9
Principal diagnosis of cancer-related service	247	2.3	0.8	0.7
All cancer-related hospitalisations	10,638	100.0	33.4	33.6

#### Notes

- 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. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 10,000 population.

Source: AIHW NHMD.

Table 3.2: Average length of stay for cancer-related hospitalisations, 15-24 years, 2015-16

	Same-day	Overnight	
	Number	Number	ALOS (days)
Principal diagnosis of cancer	1,383	2,701	7.4
Additional diagnosis of cancer	5,300	1,007	6.0
Principal diagnosis of cancer-related service	235	12	2.8
All cancer-related hospitalisations	6,918	3,720	7.0

#### Notes

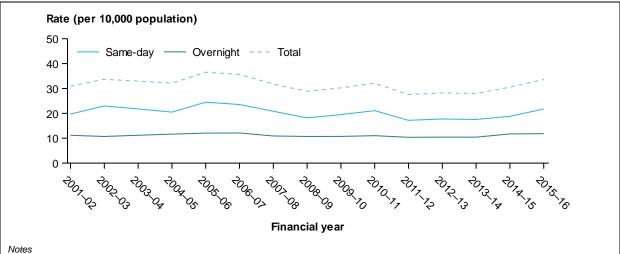
- Hospitalisations for which the care type was reported as 'Newborn with no qualified days', and records for 'Hospital boarders' and 'Posthumous organ procurement' have been excluded from the analysis.
- 2. Number represents the frequency of episodes. ALOS stands for average length of stay.

Source: AIHW NHMD.

Trends in hospitalisations for young Australians are presented from 2001–02 to 2015–16. Changes in hospital admission policies and practices might affect comparisons over time.

Between 2001–02 and 2015–16, there was no clear trend in total cancer-related hospitalisations for young Australians (Figure 3.1).

The age-standardised cancer-related hospitalisation rate ranged from 37 per 10,000 young Australians in 2005–06 to 28 per 10,000 in 2011–12. The age-standardised rate of cancer-related hospitalisations in young Australians was largely influenced by same-day hospitalisations.



- 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 were age-standardised to the 2001 Australian Standard Population, and are expressed per 10,000 population.

Source: AIHW NHMD (data for this figure are presented in Appendix Table B3.1).

Figure 3.1: Trend in age-standardised cancer-related hospitalisations for all cancers combined, by admission type, 15-24 years, 2001-02 to 2015-16

#### By sex

In 2015–16, males accounted for 55% (5,856) of all cancer-related hospitalisations of young Australians, while only accounting for 38% of all hospitalisations of young Australians. The average length of stay for overnight cancer-related hospitalisations for young males was 7.4 days, compared with 6.6 days for young females (Table 3.3).

For overnight hospitalisations where the principal diagnosis was cancer, young males had an ALOS of 7.9 days, compared with 6.8 days for young females. Young males had an ALOS of 1.8 days for overnight hospitalisations where the principal diagnosis was a cancer-related service, compared with 3.6 days for young females. The ALOS for young females was attributable to prophylactic surgeries for risk factors related to malignant neoplasms (ICD-10-AM codes Z40.00 and Z40.01).

Table 3.3: Average length of stay for cancer-related hospitalisations, by sex, 15–24 years, 2015–16

		Male			Female			
	Same-day	Overnight		Same-day	Overnight			
	Number	Number	ALOS (days)	Number	Number	ALOS (days)		
Principal diagnosis of cancer	738	1,438	7.9	645	1,262	6.8		
Additional diagnosis of cancer	3,028	554	6.1	2,272	453	5.9		
Principal diagnosis of cancer-related service (and cancer was not an additional diagnosis)	93	5	1.8	142	7	3.6		
All cancer-related hospitalisations	3,859	1,997	7.4	3,059	1,722	6.6		

#### Notes

Source: AIHW NHMD.

<sup>1.</sup> 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.

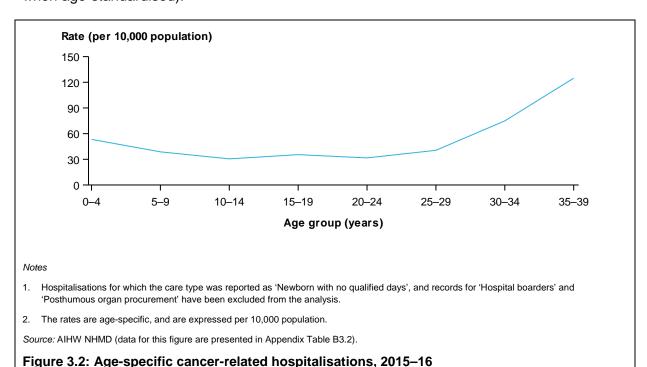
<sup>2.</sup> Number represents the frequency of episodes. ALOS stands for average length of stay.

#### By age

In 2015–16, the age-specific cancer-related hospitalisation rate decreased with increasing age—from 53 hospitalisations per 10,000 persons aged 0–4, to 31 per 10,000 persons aged 10–14 (Figure 3.2).

The age-specific rate was similar (between 31 and 41 per 10,000 persons) for those aged between 10–14 and 25–29, but increased to 125 per 10,000 persons aged 35–39.

Adolescents and young adults had an age-specific cancer-related hospitalisation rate of 33 hospitalisations per 10,000 young people (34 per 10,000 when age-standardised), compared with 41 hospitalisations per 10,000 children aged 0–14 (also 41 per 10,000 when age-standardised), and 78 hospitalisations per 10,000 adults aged 25–39 (81 per 10,000 when age-standardised).



## 3.2 Hospitalisations by cancer type

In 2015–16, acute lymphoblastic leukaemia was the most common cancer recorded as a principal diagnosis for young Australians (688 hospitalisations), followed by bone cancer (622), Hodgkin lymphoma (375), acute myeloid leukaemia (319), and non-Hodgkin lymphoma (306). The 10 most common cancers recorded as a principal diagnosis accounted for 81% of all hospitalisations with a principal diagnosis of cancer (Table 3.4).

Table 3.4: The 10 most common cancers recorded as a principal diagnosis, 15–24 years, 2015–16

Principal diagnosis	Number	%
Acute lymphoblastic leukaemia	688	16.8
Bone cancer	622	15.2
Hodgkin lymphoma	375	9.2
Acute myeloid leukaemia	319	7.8
non-Hodgkin lymphoma	306	7.5
Unknown primary site	215	5.3
Thyroid cancer	207	5.1
Brain cancer	191	4.7
Testicular cancer	190	4.7
Other soft tissue cancers	182	4.5
All cancers combined	4,084	100.0

*Note:* 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.

Source: AIHW NHMD.

## By sex

Acute lymphoblastic leukaemia and bone cancer were the most common principal diagnoses for young males and females. For males, this was followed by non-Hodgkin lymphoma, testicular cancer, and acute myeloid leukaemia, while for females, it was followed by Hodgkin lymphoma, thyroid cancer, and other soft tissue cancers (Table 3.5).

## By age

Although young Australians had lower cancer-related hospitalisation rates than children and adults, the hospitalisation rates for the 10 most common cancers recorded as a principal diagnosis for young Australians was similar to that of both children and adults in 2015–16.

Table 3.5: The 10 most common cancers recorded as a principal diagnosis, by sex, 15-24 years, 2015-16

Males			Females		
Principal diagnosis	Number	%	Principal diagnosis	Number	%
Acute lymphoblastic leukaemia	385	17.7	Acute lymphoblastic leukaemia	303	15.9
Bone cancer	377	17.3	Bone cancer	245	12.8
non-Hodgkin lymphoma	207	9.5	Hodgkin lymphoma	194	10.2
Testicular cancer	189	8.7	Thyroid cancer	162	8.5
Acute myeloid leukaemia	185	8.5	Other soft tissue cancers	135	7.1
Hodgkin lymphoma	181	8.3	Acute myeloid leukaemia	134	7.0
Unknown primary site	120	5.5	non-Hodgkin lymphoma	99	5.2
Brain cancer	108	5.0	Unknown primary site	95	5.0
Other soft tissue cancers	47	2.2	Brain cancer	83	4.4
Colorectal cancer	46	2.1	Colorectal cancer	70	3.7
All cancers combined	2,176	100.0	All cancers combined	1,907	100.0

*Note:* 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.

Source: AIHW NHMD.

## 3.3 Hospitalisations for chemotherapy

This section explores the number of admitted-patient hospitalisations for chemotherapy. The principal diagnosis recorded is usually a disease, but can also be a specific treatment of an already diagnosed condition, such as chemotherapy for cancer.

In public hospitals, admission practices for same-day chemotherapy vary across states and territories. The number of hospitalisations for chemotherapy is likely to be an under-count, because the NHMD does not include chemotherapy provided to non-admitted patients in public hospitals. For more information on variations in chemotherapy in hospitals, see *Variations in hospital admission policies and practices: Australian hospital statistics* (AIHW 2017e).

In 2015–16, there were 6,554 hospitalisations for young Australians where the additional diagnosis was cancer or the principal diagnosis was a cancer-related treatment (and cancer was not an additional diagnosis).

For these hospitalisations, pharmacotherapy (chemotherapy) was the most common principal diagnosis (4,853 hospitalisations; 74%), and, of these, Hodgkin lymphoma was the most common additional cancer diagnosis (1,029 hospitalisations; 21% of all chemotherapy hospitalisations for young Australians), followed by acute lymphoblastic leukaemia (908 hospitalisations; 19%), and testicular cancer (583 hospitalisations; 12%).

#### By sex

A larger number of pharmacotherapy (chemotherapy) hospitalisations for young Australians were for males (2,754 hospitalisations; 57%) than for females (2,099; 43%).

For young males, where the principal diagnosis was chemotherapy, testicular cancer was the most common additional cancer diagnosis (583 hospitalisations; 21% of all chemotherapy hospitalisations for young males), followed by Hodgkin lymphoma (571 hospitalisations; 21%), and acute lymphoblastic leukaemia (364 hospitalisations; 13%).

For young females, where the principal diagnosis was chemotherapy, acute lymphoblastic leukaemia was the most common additional cancer diagnosis (544 hospitalisations; 26% of all chemotherapy hospitalisations for young females), followed by Hodgkin lymphoma (458 hospitalisations; 22%), and acute myeloid leukaemia (210 hospitalisations; 10%).

## By age

Adults (aged 25–39) accounted for the largest number of hospitalisations where the principal diagnosis was chemotherapy (21,208 hospitalisations), followed by children (aged 0–14) (6,636), and adolescents and young adults (4,853).

The reasons for chemotherapy varied by age group. Children predominantly had an additional diagnosis of acute lymphoblastic leukaemia (4,350 hospitalisations; 66%), while breast cancer was the most common additional diagnosis in adults (7,455 hospitalisations; 35%), followed by colorectal cancer (2,685 hospitalisations; 13%).

## 3.4 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 often provided on a non-admitted basis, so limited information is available in the NHMD.

An alternative source is the National Radiotherapy Waiting Times Database, which provides key information on the number of radiotherapy courses that began in the reporting period, key characteristics of the patients who undertook a course of treatment, and the waiting times associated with these courses. Coverage of radiotherapy courses in Australia for 2015–16 across both public and private sectors was effectively 100%.

The database contains data about the principal diagnosis (the diagnosis established after study to be chiefly responsible for causing a patient's need for a course of treatment). In the case of radiotherapy treatment, the principal diagnosis is most typically a type of cancer.

Data reported for principal diagnosis might not reflect the incidence of certain cancers in the Australian population. The differences in principal diagnosis activity in this section might indicate data quality issues; for example, some providers, such as Victoria, are reporting the primary site of the cancer, rather than the diagnosis code associated with the health condition being treated in the specific course of radiotherapy. For this reason, comparisons with incidence data should be made with caution. For more detail, see *Radiotherapy in Australia 2015–16* (AIHW 2017d).

In 2015–16, 363 courses of radiotherapy were recorded for young Australians in the National Radiotherapy Waiting Times Database. Of these, 335 (92%) were for a principal diagnosis of cancer. The most commonly diagnosed cancers for which a course of radiotherapy was administered to young Australians were Hodgkin lymphoma (49 courses; 13%), and other soft tissue cancers (49 courses; 13%).

## By sex

Young males (193 courses) accounted for a larger proportion of radiotherapy courses where cancer was a principal diagnosis than young females (142 courses).

For young males, the most common courses of radiotherapy for cancers were for Hodgkin lymphoma (31 courses; 16%), other soft tissue cancers (22 courses; 11%), and bone cancer (22 courses; 11%). For young females, the most common courses of radiotherapy for cancers were for other soft tissue cancers (27 courses; 19%), followed by Hodgkin lymphoma (18 courses; 13%), and brain cancer (15 courses; 11%).

## By age

The number of radiotherapy courses administered increased with increasing age group. Adults (aged 25–39) had the largest number of radiotherapy courses (1,821 total; 1,712 cancer-related), followed by young Australians (363 total; 335 cancer-related), and children (aged 0–14) (265 total; 246 cancer-related).

Children received radiotherapy courses primarily for brain cancer (72 courses; 27%), followed by other soft tissue cancers (35 courses; 13%), and kidney cancer (23; 8.7%). Adults received radiotherapy courses primarily for breast cancer (572 courses; 31%), followed by brain cancer (152 courses; 8.3%), and colorectal cancer (109 courses; 6.0%).

## 4 Survival from cancer

#### **Key findings**

In 2010-2014:

- 5-year relative survival for young Australians was 89% for all cancers combined
- for cancers commonly diagnosed in young Australians, 5-year relative survival was highest for those diagnosed with thyroid carcinoma, gonadal germ cell cancer, and melanoma, and it was lowest for those diagnosed with Ewing tumour
- adolescents and young adults had a higher overall 5-year relative survival compared with children (aged 0–14), and similar overall 5-year relative survival compared with adults (aged 25–39).

Between 1985–1989 and 2010–2014, 5-year relative survival of young Australians for all cancers combined increased from 80% to 89%.

At the end of 2013:

- 4,412 people who were diagnosed with cancer as adolescents or young adults in the previous 5 years were still alive
- for people who were diagnosed with cancer as adolescents or young adults in the previous 5 years, survivorship was highest for melanoma, followed by Hodgkin lymphoma, and gonadal germ cell cancer.

Data for this section are sourced from the 2014 ACD, and focus on 5-year relative survival. Data from the National Death Index on deaths (from any cause) that occurred up to 31 December 2014 were used to determine which people with cancer had died, and when this occurred.

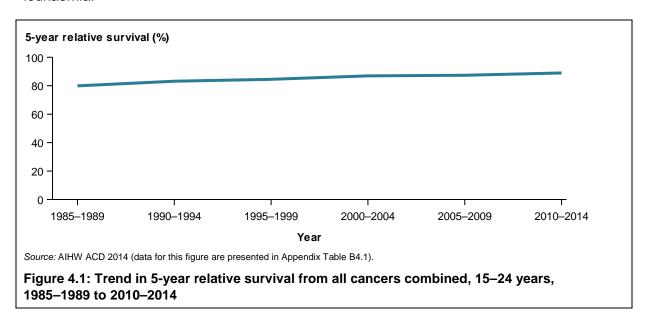
Relative survival refers to the probability of being alive for a given amount of time after diagnosis compared with the general population. A 5-year relative survival figure of 100% means that the cancer has no impact on the person's chance of still being alive 5 years after diagnosis, whereas a figure 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. Various 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)
- 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; WCRF & AICR 2007).

## 4.1 Survival from all cancers combined

In 2010–2014, 5-year relative survival from all cancers combined in young Australians was 89%, an increase from 80% in 1985–1989 (Figure 4.1). The increase in survival for all cancers combined has been largely driven by improved relative survival for lymphoma and leukaemia.



# 4.2 Survival by cancer type

In 2010–2014, 5 of the 10 most commonly diagnosed cancers among young Australians had 5-year relative survival of 90% or higher (Table 4.1).

Thyroid carcinoma had the highest 5-year relative survival (almost 100%), followed by gonadal germ cell cancer (97%), and melanoma (96%).

Acute lymphoid leukaemia (79%), acute myeloid leukaemia (77%), and Ewing tumour (46%) had the lowest 5-year relative survival.

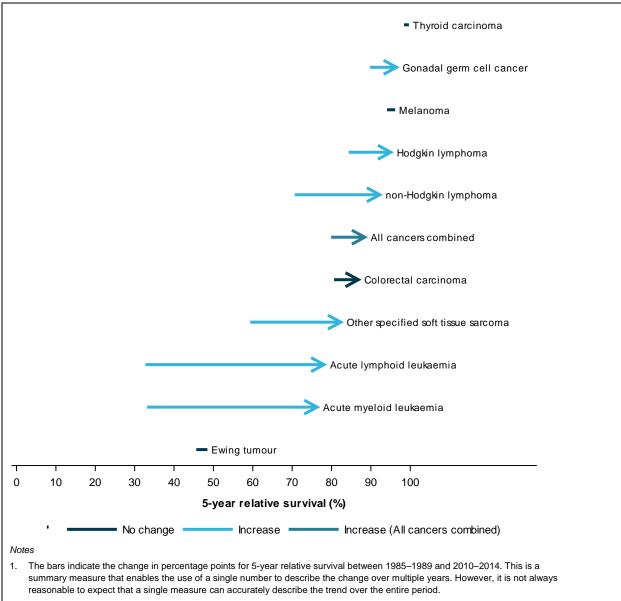
Between 1985–1989 and 2010–2014, increases in 5-year relative survival for young Australians were greatest for acute lymphoid leukaemia (46 percentage points), followed by acute myeloid leukaemia (44 percentage points), other specified soft tissue sarcoma (24 percentage points), non-Hodgkin lymphoma (22 percentage points), Hodgkin lymphoma (11 percentage points), and gonadal germ cell cancer (7.3 percentage points) (Figure 4.2).

Five-year relative survival for the remaining cancers most commonly diagnosed in young Australians did not change significantly between these 2 periods.

Table 4.1: Five-year relative survival from the 10 most commonly diagnosed cancers and all cancers combined, 15–24 years, 2010–2014

Cancer type	5-year relative survival (%)
Thyroid carcinoma	99.7
Gonadal germ cell cancer	97.0
Melanoma	96.2
Hodgkin lymphoma	95.6
non-Hodgkin lymphoma	92.8
Colorectal carcinoma	87.3
Other specified soft tissue sarcoma	82.9
Acute lymphoid leukaemia	78.6
Acute myeloid leukaemia	76.9
Ewing tumour	45.7
All cancers combined	89.0

Source: AIHW ACD 2014.



<sup>2.</sup> Five-year relative survival for Ewing tumour starts from 1990–1994 due to small numbers.

Source: AIHW ACD 2014 (data for this figure are presented in Appendix Table B4.2).

Figure 4.2: Trend in 5-year relative survival from the 10 most commonly diagnosed cancers and all cancers combined, 15–24 years, 1985–1989 to 2010–2014

# 4.3 Survival by sex

In 2010–2014, 5-year relative survival was similar for young males (88%) and young females (90%). Between 1985–1989 and 2010–2014, 5-year relative survival improved for both young males (from 76% to 88%) and young females (from 84% to 90%) (Figure 4.3).

For young males, of the 10 most commonly diagnosed cancers in 2010–2014, 5 cancers had 5-year relative survival greater than 90% (Table 4.2). Thyroid carcinoma (99%) had the highest 5-year relative survival, followed by gonadal germ cell cancer (98%), and Hodgkin lymphoma (96%). Acute lymphoid leukaemia (76%), acute myeloid leukaemia (75%), and osteosarcomas (65%) had the lowest 5-year relative survival.

For young females, of the 10 most commonly diagnosed cancers in 2010–2014, 6 cancers had 5-year relative survival greater than 90% (Table 4.2). Thyroid carcinoma (100%) had the highest 5-year relative survival, followed by melanoma (97%), and other specified neoplasms n.o.s (96%). Cervical carcinoma (89%), acute lymphoid leukaemia (86%), and acute myeloid leukaemia (79%) had the lowest 5-year relative survival.

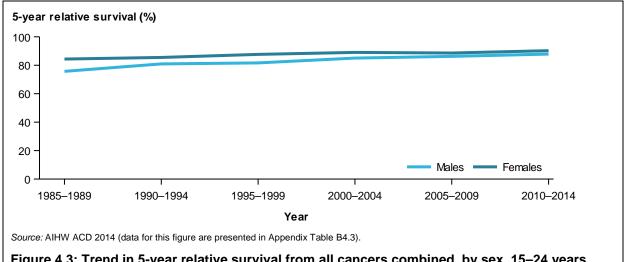


Figure 4.3: Trend in 5-year relative survival from all cancers combined, by sex, 15–24 years, 1985–1989 to 2010–2014

Table 4.2: Five-year relative survival for the 10 most commonly diagnosed cancers and all cancers combined, by sex, 15–24 years, 2010–2014

Males	Males		
Cancer type	5-year relative survival (%)	Cancer type	5-year relative survival (%)
Thyroid carcinoma	99.2	Thyroid carcinoma	99.8
Gonadal germ cell cancer	97.5	Melanoma	97.2
Hodgkin lymphoma	96.4	Other specified neoplasms, n.o.s.	96.3
Melanoma	94.8	Hodgkin lymphoma	94.8
non-Hodgkin lymphoma	94.4	Gonadal germ cell cancer	92.7
Other specified soft tissue sarcoma	84.7	non-Hodgkin lymphoma	90.1
Colorectal carcinoma	84.3	Colorectal carcinoma	89.9
Acute lymphoid leukaemia	75.7	Cervical carcinoma	89.1
Acute myeloid leukaemia	74.5	Acute lymphoid leukaemia	85.9
Osteosarcomas	64.8	Acute myeloid leukaemia	79.3
All cancers combined	87.8	All cancers combined	90.3

Source: AIHW ACD 2014.

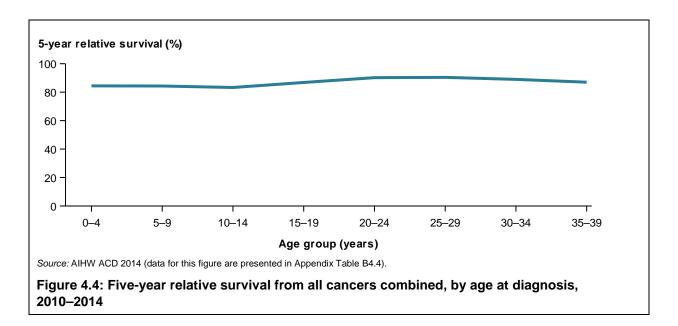
# 4.4 Survival by age

In 2010–2014, 5-year relative survival ranged from 83% in those aged 10–14 to 90% in those aged 25–29 (Figure 4.4). Adolescents and young adults had a higher overall 5-year relative survival (89%) compared with children (aged 0–14) (84%), and similar overall 5-year relative survival compared with adults (aged 25–39) (88%).

Between 1985–1989 and 2010–2014, children had a larger increase in 5-year relative survival (69% to 84%) compared with adults (77% to 88%) or adolescents and young adults (80% to 89%). However, adolescents and young adults had the highest 5-year relative survival from all cancers combined during the whole period.

While 5-year relative survival for all cancers combined was highest for young Australians in 2010–2014, 5-year relative survival for the 10 cancers most commonly diagnosed in young Australians differed between the age groups. Compared with children, young people had lower 5-year relative survival for:

- acute lymphoid leukaemia (79% for young people, compared with 92% for children)
- Ewing tumour (46% compared with 84%)
- gonadal germ cell cancer (97% compared with 100%).



# 4.5 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 2014 ACD, and are presented for limited-duration prevalence with an index date of 31 December 2013 (due to availability of actual cancer incidence data).

Data from the National Death Index on deaths (from any cause) that occurred up to 31 December 2014 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 2013, 4,412 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 in the previous 5 years.

Males made up 52% of 5-year prevalent cases. At the end of 2013, the 10-year prevalence of young Australians who had had cancer was 8,332, and the 32-year prevalence was 21,792 (Table 4.3). The 32-year prevalence has been used, because it is the maximum number of years for which prevalence can be calculated using the available data.

Table 4.3: Limited-duration prevalence of all cancers combined, by sex, 15–24 years, as at end of 2013

	Number	% of prevalent cases		
	5-year prevalence			
Males	2,296	52.0		
Females	2,116	48.0		
Persons	4,412	100.0		
10-year prevalence				
Males	4,361	52.3		
Females	3,971	47.7		
Persons	8,332	100.0		
	32-year prevalence			
Males	11,089	50.9		
Females	10,703	49.1		
Persons	21,792	100.0		

Note: The number of prevalent cases is based on the number of individuals diagnosed with a cancer as an adolescent or young adult, who were alive at the end of the period. It does not represent the total number of young Australians with a cancer history who were alive at the end of the period.

Source: AIHW ACD 2014.

## Survivorship by cancer type and sex

Among adolescents and young adults, melanoma had the highest 5-year prevalence (723), followed by Hodgkin lymphoma (644), and gonadal germ cell cancer (642) (Table 4.4).

For males, gonadal germ cell cancer had the highest 5-year prevalence (574), followed by Hodgkin lymphoma (315), and melanoma (308). For females, melanoma had the highest 5-year prevalence (415), followed by Hodgkin lymphoma (329), and thyroid carcinoma (322).

Table 4.4: Five-year prevalence of the 10 most prevalent cancers, by sex, 15–24 years at time of diagnosis, as at end of 2013

Males		Females		Persons	
Cancer type	Number	Cancer type	Number	Cancer type	Number
Gonadal germ cell cancer	574	Melanoma	415	Melanoma	723
Hodgkin lymphoma	315	Hodgkin lymphoma	329	Hodgkin lymphoma	644
Melanoma	308	Thyroid carcinoma	322	Gonadal germ cell cancer	642
non-Hodgkin lymphoma	169	Colorectal carcinoma	173	Thyroid carcinoma	409
Colorectal carcinoma	118	non-Hodgkin lymphoma	101	Colorectal carcinoma	291
Acute lymphoid leukaemia	104	Gonadal germ cell cancer	68	non-Hodgkin lymphoma	270
Thyroid carcinoma	87	Acute myeloid leukaemia	66	Acute lymphoid leukaemia	152
Acute myeloid leukaemia	67	Cervical carcinoma	66	Acute myeloid leukaemia	133
Other specified soft tissue sarcoma	51	Other specified neoplasms, n.o.s.	54	Other specified soft tissue sarcoma	92
Osteosarcomas	48	Acute lymphoid leukaemia	48	Other specified neoplasms, n.o.s.	80

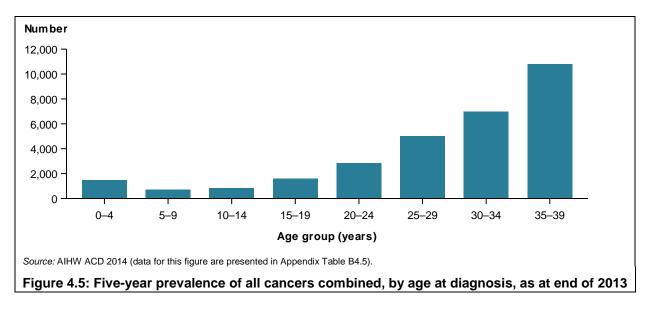
Source: AIHW ACD 2014.

## Survivorship by age

Five-year prevalence for all cancers combined generally increased with age (Figure 4.5). In the prevalence statistics presented in this report, age refers to the age of a person at diagnosis who was alive on the index date of 31 December 2013.

Five-year prevalence was greatest for people diagnosed with cancer as an adult (22,751), followed by adolescents and young adults (4,412), and children (2,987).

This pattern of prevalence by age was consistent for the 10 most commonly diagnosed cancers in young Australians in 2010–2014, except for: acute lymphoid leukaemia, which had the highest 5-year prevalence for children, followed by adults and young people; and soft tissue sarcoma, which had the highest 5-year prevalence in young people, followed by children, and adults.



# 5 Mortality from cancer

## **Key findings**

#### In 2011-2015:

- 499 adolescents and young adults died from cancer—8.8% of all deaths in this age group
- more than half (58%) of all young Australians who died from cancer were male
- brain cancer was the leading cause of cancer death among young Australians, followed by bone cancer, acute lymphoblastic leukaemia, other soft tissue cancer and acute myeloid leukaemia
- adolescents and young adults had a lower mortality rate due to cancer compared with adults, except for bone cancer and acute lymphoblastic leukaemia where young Australians had a higher mortality rate.

#### Between 1981-1985 and 2011-2015:

- age-standardised mortality rates in young Australians for melanoma of the skin, non-Hodgkin lymphoma, acute myeloid leukaemia, acute lymphoblastic leukaemia, Hodgkin lymphoma, and testicular cancer decreased by at least 50%
- age-standardised mortality rates for other soft tissue cancer decreased by less than 20%.

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 might 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.

The main data source for this chapter was the National Mortality Database (NMD). Since mortality data in the NMD are coded according to the International Statistical Classification of Diseases and Related Health Problems (ICD), and not to the International Classification of Diseases for Oncology (ICD-O), mortality data cannot be provided for the same groups that are used in the incidence and survival chapters. For this reason, the ICD-10 is used as the basis for reporting of mortality statistics (see Appendix A for codes used).

This chapter presents mortality from cancer in adolescents and young adults in 2011–2015, including differences by sex, and comparisons with other age groups.

Trends in age-standardised mortality rates from 1981–1985 are also presented.

## 5.1 Deaths from all cancers combined

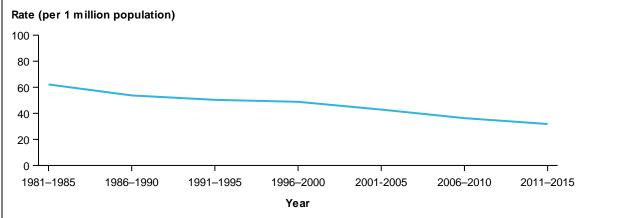
In 2011–2015, 499 young Australians died from cancer. This means that, on average, an adolescent and young adult died from cancer every 3–4 days in Australia.

While the number of deaths in young people was small relative to the total number of all deaths in Australia (0.8% of all deaths in 2011–2015), cancer accounted for about 8.8% of deaths of young Australians from all causes.

The mortality rate from all cancers combined was 32 deaths per 1 million young Australians in 2011–2015 (also 32 deaths per 1 million when age-standardised).

The number of cancer deaths among young Australians decreased from 820 in 1981–1985 to 499 in 2011–2015.

The age-standardised mortality rate from all cancers combined also decreased—from 62 deaths per 1 million young Australians in 1981–1985 to 32 deaths per 1 million in 2011–2015 (Figure 5.1).



#### Notes

- 1. Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.
- Mortality data from 1981 to 2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the death.
- 3. The rates were age-standardised to the 2001 Australian Standard Population and are expressed per 1 million population.
- 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 (data for this figure are presented in Appendix Table B5.1).

Figure 5.1: Trend in age-standardised mortality rates for all cancers combined, 15–24 years, 1981–1985 to 2011–2015

# 5.2 Deaths by cancer type

In 2011–2015, for adolescents and young adults, brain cancer was the most common cause of cancer death (90 deaths), followed by bone cancer (88 deaths), acute lymphoblastic leukaemia (48 deaths), other soft tissue cancers (42 deaths), and acute myeloid leukaemia (35 deaths). Together, these 5 cancers accounted for 61% of all deaths from cancer in young Australians (Table 5.1).

Figure 5.2 presents trends in cancers that averaged at least 5 deaths in young Australians per year in 1981–1985. Between 1981–1985 and 2011–2015, the age-standardised mortality rate decreased by at least 50% for 6 cancers. Melanoma of the skin had the greatest decrease fall in mortality (81%), followed by non-Hodgkin lymphoma (71%), acute myeloid leukaemia (69%), acute lymphoblastic leukaemia (65%), testicular cancer (60%), and Hodgkin lymphoma (57%).

Primary prevention campaigns about sun safety behaviours (such as the SunSmart media campaign) might be partly responsible for improved mortality outcomes in young Australians (Haggar et al. 2012; Whiteman et al. 2008). Additionally, improvements in treatments for testicular cancer, leukaemia, and lymphoma might also account for some of the decrease (Coory & Gill 2008).

The age-standardised mortality rates of other soft tissue cancers decreased by less than 20% since 1981–1985.

Table 5.1: The 10 most common causes of cancer death, 15-24 years, 2011-2015

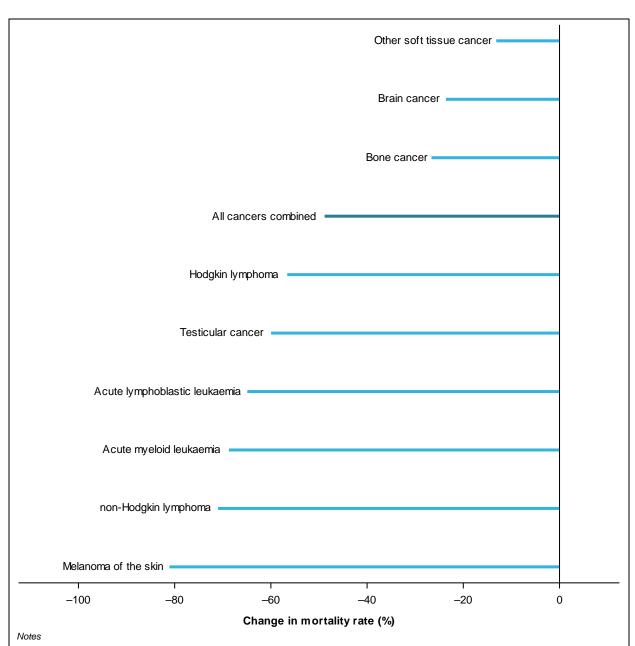
		0/ of oom		
Cancer type	Deaths	% of cancer deaths	Rate	ASR
Brain cancer	90	18.0	5.8	5.8
Bone cancer	88	17.6	5.7	5.7
Acute lymphoblastic leukaemia	48	9.6	3.1	3.2
Other soft tissue cancer	42	8.4	2.7	2.7
Acute myeloid leukaemia	35	7.0	2.2	2.2
Non-Hodgkin lymphoma	21	4.2	1.3	1.4
Hodgkin lymphoma	19	3.8	1.2	1.2
Colorectal cancer	18	3.6	1.2	1.1
Unknown primary site	15	3.0	1.0	0.9
Melanoma of the skin	14	2.8	0.9	0.9
All cancers combined	499	100.0	32.0	31.8

#### Notes

<sup>1.</sup> Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.

<sup>2.</sup> Mortality data for 2011–2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the death.

<sup>3. &#</sup>x27;All cancers combined' includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1, and D47.3–D47.5.



- The bars indicate the percentage change in age-standardised mortality rates between 1981–1985 and 2011–2015. This is a summary
  measure that enables the use of a single number to describe the change over multiple years. However, it is not always reasonable to expect
  that a single measure can accurately describe the trend over the entire period.
- 2. Cancers with less than 25 deaths during 1981–1985 were not considered suitable for the trend analysis, and are not included in the figure.
- 3. '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 (data for this figure are presented in Appendix Table B5.2).

Figure 5.2: Percentage change in age-standardised mortality rates for specific cancers and all cancers combined, 15–24 years, 1981–1985 to 2011–2015

# 5.3 Deaths from cancer by sex

In 2011–2015, of all adolescents and young adults who died from cancer, about 58% were male (290 deaths). This proportion is similar to the proportion of male cancer deaths in the wider Australian population (57%) (AIHW 2017a).

For young males, bone cancer was the most common cause of cancer death (62 deaths), followed by brain cancer (57 deaths), acute lymphoblastic leukaemia (30 deaths), other soft tissue cancers (25 deaths), and acute myeloid leukaemia (21 deaths) (Table 5.2). These 5 cancers accounted for about 67% of all cancer deaths in young males.

For young females, brain cancer was the most common cause of cancer death (33 deaths), followed by bone cancer (26 deaths), acute lymphoblastic leukaemia (18 deaths), other soft tissue cancer (17 deaths), Hodgkin lymphoma (14 deaths), and acute myeloid leukaemia (14 deaths). These cancers accounted for about 58% of all cancer deaths in young females.

Table 5.2: The 10 most common causes of cancer deaths, by sex, 15-24 years, 2011-2015

Male			Female						
Cancer type	Deaths	% of cancer deaths	Rate	ASR	Cancer type	Deaths	% of cancer deaths	Rate	ASR
Bone cancer	62	21.4	7.8	7.8	Brain cancer	33	15.8	4.3	4.4
Brain cancer	57	19.7	7.2	7.1	Bone cancer	26	12.4	3.4	3.5
Acute lymphoblastic leukaemia	30	10.3	3.8	3.9	Acute lymphoblastic leukaemia	18	8.6	2.4	2.4
Other soft tissue cancer	25	8.6	3.1	3.1	Other soft tissue cancer	17	8.1	2.2	2.3
Acute myeloid leukaemia	21	7.2	2.6	2.6	Hodgkin lymphoma	14	6.7	1.8	1.7
Testicular cancer	13	4.5	1.6	1.6	Acute myeloid leukaemia	14	6.7	1.8	1.9
Unknown primary site	12	4.1	1.5	1.5	Ovarian cancer	12	5.7	1.6	1.5
Colorectal cancer	10	3.4	1.3	1.2	non-Hodgkin lymphoma	11	5.3	1.4	1.5
non-Hodgkin lymphoma	10	3.4	1.3	1.3	Colorectal cancer	8	3.8	1.1	1.0
Stomach cancer	7	2.4	0.9	0.9	Melanoma of the skin	8	3.8	1.1	1.0
All cancers combined	290	100.0	36.4	36.2	All cancers combined	209	100.0	27.5	27.2

#### Notes

<sup>1.</sup> Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.

<sup>2.</sup> Mortality data for 2011–2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the

Rate is the number of cancer deaths expressed per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

<sup>4. &#</sup>x27;All cancers combined' includes cancers coded in the ICD-10 as C00–C97, D45, D46, D47.1, and D47.3–D47.5.

# 5.4 Deaths from cancer by age

In 2011–2015, cancer mortality rates generally increased with age (Figure 5.3).

Children (aged 0–14) had the lowest mortality rate (21 deaths per 1 million children; also 21 deaths per 1 million when age-standardised), followed by adolescents and young adults (32 deaths per 1 million young Australians; also 32 deaths per 1 million when age-standardised), and adults (aged 25–39) (110 deaths per 1 million adults; 113 deaths per 1 million when age-standardised).

While the mortality rates for all cancers combined increased with increasing age group, mortality rates for individual cancers differed between the age groups.

Adolescents and young adults had higher mortality rates than adults for bone cancer (5.7 deaths per 1 million young Australians, compared with 1.9 deaths per 1 million adults), and acute lymphoblastic leukaemia (3.1 deaths per 1 million young Australians, compared with 2.1 deaths per 1 million adults). Conversely, young Australians had a lower age-standardised mortality rate than children for brain cancer (5.8 deaths per 1 million young Australians compared with 7.0 deaths per 1 million children).

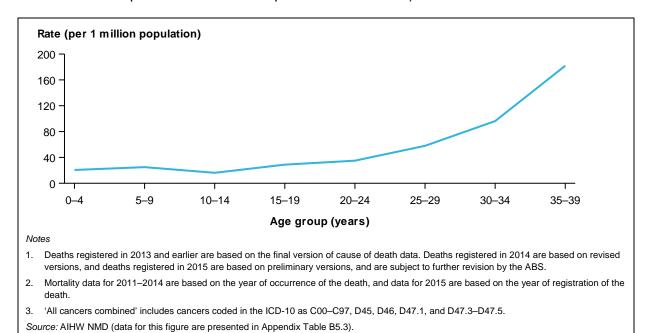


Figure 5.3: Age-specific mortality rates from all cancers combined, 2011-2015

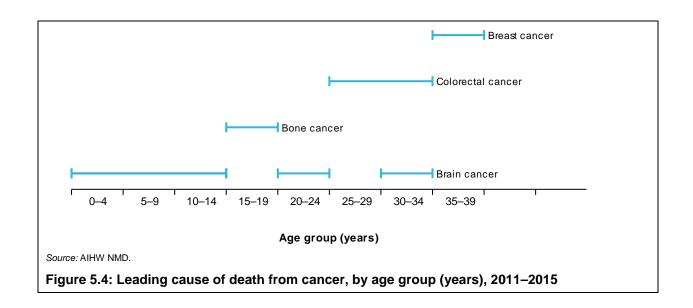
The pattern of cancer mortality also differed across age groups (Figure 5.4).

Brain cancer was the most common cause of cancer death for children aged 0-14.

Brain cancer and bone cancer were 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 25-29.

Colorectal cancer and brain cancer were both responsible for the greatest number of cancer deaths for those aged 30–34, and breast cancer was the most common cause of cancer death for those aged 35–39.



## 6 Burden of cancer

## **Key findings**

#### In 2011:

- adolescents and young adults in Australia experienced 6,850 disability-adjusted life years (DALY) due to premature death from cancer or living with cancer
- cancer was the 2nd highest disease group for fatal burden in young Australians, behind injuries
- the total cancer burden for young Australians was more pronounced in males (56%) than females (44%)
- leukaemia was associated with the highest proportion of the cancer burden in young Australians, followed by brain and central nervous system cancer, colorectal cancer and Hodgkin lymphoma.

Burden of disease 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 young Australians, based on the Australian Burden of Disease Study 2011. The study provides Australia-specific burden of disease estimates best matched to the Australian context for the total 2011 population.

In the Australian Burden of Disease Study 2011, the cancer and other neoplasms disease group also includes the impact of benign, in situ, and uncertain neoplasms (see Appendix A3 for a complete listing of ICD-10 codes for each site). For more information, see *Australian Burden of Disease Study: impact and causes of illness and death in Australia 2011* (AIHW 2016a) and *Burden of cancer in Australia: Australian Burden of Disease Study 2011* (AIHW 2017b).

Data are presented for the fatal burden, non-fatal burden, and the overall burden (fatal plus non-fatal) 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, the duration of its effects, and how severe those effects are.

The overall burden, which is expressed as disability-adjusted life years (DALY), is the sum of YLL and YLD. One DALY is 1 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.

## 6.1 Burden of all cancers combined

In 2011, adolescents and young adults in Australia lost 6,850 DALY due to premature death from, or living with, cancer. This burden was almost entirely due to dying prematurely (94%).

While cancer and other neoplasms was the 7th most burdensome disease group in young Australians overall, it was the 2nd highest 'disease group' in terms of fatal burden, behind injuries (AIHW 2016a).

Between 2003 and 2011, the number of DALY from cancer decreased from 8,622 (3.2 per 1,000 young Australians when age-standardised) to 6,850 (2.2 per 1,000 young Australians when age-standardised), suggesting that the total burden of cancer in young people has decreased over time.

## 6.2 Burden by cancer type

In 2011, leukaemia (1,268 DALY) contributed to the largest cancer burden for young Australians, followed by cancers of the brain and central nervous system (1,012 DALY), colorectal cancer (347 DALY), Hodgkin lymphoma (299 DALY), and non-Hodgkin lymphoma (226 DALY) (Figure 6.1). The burden from these 5 cancers was predominantly due to dying early.

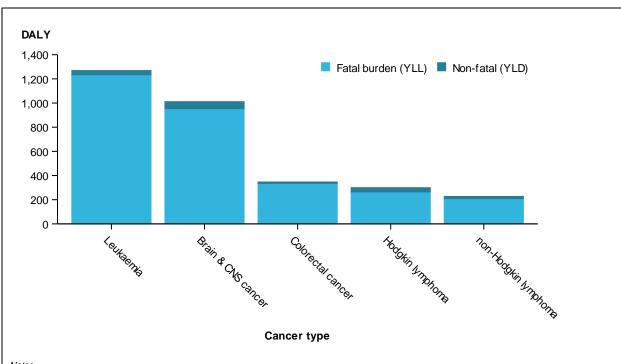
Together, these 5 cancers accounted for 46% of the total cancer burden in young Australians, with cancers of the brain and central nervous system and leukaemia accounting for 33% of the total cancer burden.

# 6.3 Burden of cancer by sex

In 2011, the total cancer burden in adolescents and young adults was greater in males (56%) than females (44%) (Table 6.1).

In 2011, leukaemia (920 DALY) contributed the greatest cancer burden in young males, followed by cancer of the brain and central nervous system (514 DALY), colorectal cancer (273 DALY), benign and uncertain brain tumours (153 DALY), and Hodgkin lymphoma (151 DALY). These 5 cancers represented about 52% of the total cancer burden in young males.

For young females, cancer of the brain and central nervous system (498 DALY) contributed the greatest cancer burden, followed by leukaemia (348 DALY), ovarian cancer (199 DALY), Hodgkin lymphoma (149 DALY), and melanoma of the skin (141 DALY). These 5 cancers represented about 40% of the total cancer burden in young females.



#### Notes

- The 5 leading causes of cancer burden exclude other malignant neoplasms (C17, C21, C26–C31, C37–C41, C46–C49, C51–C52, C57-C60, C63, C65-C66, C68-C69, C74-C75) and other benign, in situ and uncertain neoplasms (D00-D04, D06-D31, D34-D48).
- 2. CNS stands for central nervous system.
- 3. Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A3). Source: AIHW Burden of Disease Database 2011 (data for this figure are presented in Appendix Table B6.1).

Figure 6.1: Disability adjusted life years for the 5 leading causes of cancer burden, by fatal and non-fatal burden, 15-24 years, 2011

Table 6.1: Disability adjusted life years for the 5 most common causes of cancer burden, by sex, 15-24 years, 2011

Male	Male Female		
Cancer type	DALY	Cancer type	DALY
Leukaemia	920	Brain and central nervous system cancer	498
Brain and central nervous system cancer	514	Leukaemia	348
Colorectal cancer	273	Ovarian cancer	199
Benign and uncertain brain tumours	153	Hodgkin lymphoma	149
Hodgkin lymphoma	151	Melanoma of the skin	141
All cancers combined	3,842	All cancers combined	3,009

#### Notes

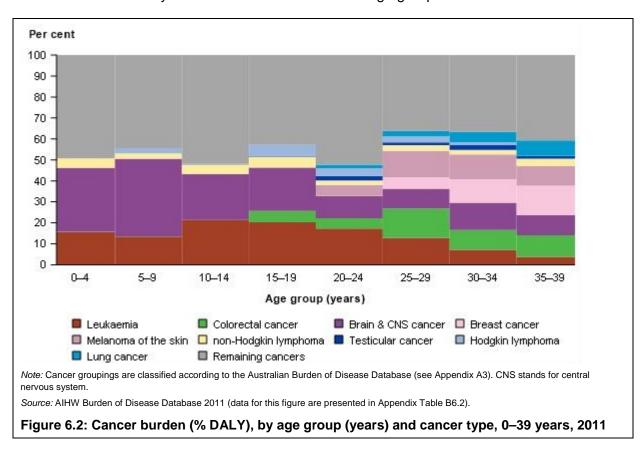
- The top 5 causes of burden exclude other malignant neoplasms (C17, C21, C26-C31, C37-C41, C46-C49, C51-C52, C57-C60, C63, C65-C66, C68-C69, C74-C75) and other benign, in situ and uncertain neoplasms (D00-D04, D06-D31, D34-D48).
- 2. Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A3).

Source: AIHW Burden of Disease Database 2011.

# 6.4 Burden of cancer by age

The pattern of cancer burden differed across the lifespan (Figure 6.2).

- For those aged 0–14, leukaemia, lymphoma, and brain and central nervous system cancer were the most common causes of cancer burden.
- For those aged 15–24, colorectal cancer and melanoma started contributing to the overall cancer burden.
- For those aged 25–39, lung cancer and breast cancer were substantial contributors to the overall cancer burden, while the relative burden due to leukaemia and brain and central nervous system cancer diminished in this age group.



# 7 Focus on key population groups

## **Key findings**

#### **Indigenous Australians**

 Cancer incidence rates were higher in non-Indigenous AYA: In 2009–2013, in New South Wales, Victoria, Queensland, Western Australia, and the Northern Territory combined, the age-standardised incidence rate for all cancers combined was lower for young Indigenous Australians (193 new cases per 1 million young Indigenous Australians) compared with young non-Indigenous Australians (261 new cases per 1 million young non-Indigenous Australians).

#### State and territory

Cancer incidence rates varied across jurisdictions: In 2009–2013, the age-standardised incidence rate for all cancers combined in adolescents and young adults varied across jurisdictions—from 185 new cases per 1 million young Australians in the Northern Territory to 336 new cases per 1 million young Australians in Queensland. The variations between jurisdictions was largely driven by differences in the incidence rates of melanoma.

#### Remoteness area

• Cancer incidence rates varied across geographic regions: In 2009–2013, the age-standardised incidence rate for all cancers combined varied across regions—from 268 new cases per 1 million young Australians living in *Remote/Very remote* areas to 328 new cases per 1 million young Australians living in *Inner regional* areas.

#### Socioeconomic group

 Cancer incidence rates were similar across socioeconomic groups: In 2009–2013, the age-standardised incidence rate for all cancers combined was similar across socioeconomic groups.

Data for this section are sourced from the 2014 ACD and the AIHW NMD. Incidence data are presented for 2009–2013, because 2013 is the most recent year for which actual data were available for all states and territories. Mortality data are presented for 2011–2015.

Data in this section are only provided for adolescents and young adults, and are not broken down by sex. Incidence and mortality counts and rates are relatively small in the population, particularly when broken down by Indigenous status, state, remoteness area, or socioeconomic group. As a result, data in this chapter are only provided for all cancers combined.

Differences by the characteristics presented in this section might be the result of various factors, including variations in:

- population characteristics (for example, a relatively greater proportion of young Indigenous Australians living in *Remote areas*)
- the availability and usage of diagnostic services.

# 7.1 Aboriginal and Torres Strait Islander people

Early access to cancer diagnosis and treatment services is key to improving outcomes, but 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 among Indigenous Australians can contribute to lower survival rates for some cancers, leading to higher mortality.

#### **New cases**

Reliable national data on the diagnosis of cancer for Indigenous Australians are not available. 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 2017b). However, it should be noted that New South Wales have identified an issue with their Indigenous data from 2008 onwards, which they are investigating. As a result, incidence rates by Indigenous status should be considered with caution.

For the 5 jurisdictions, 17% had an unknown Indigenous status for adolescents and young adults. It is not known how many young Indigenous Australians 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 likely to be underestimates.

In 2009–2013, an average of 23 young Indigenous Australians were diagnosed with cancer each year—2.7% of all cancer cases diagnosed in young Australians.

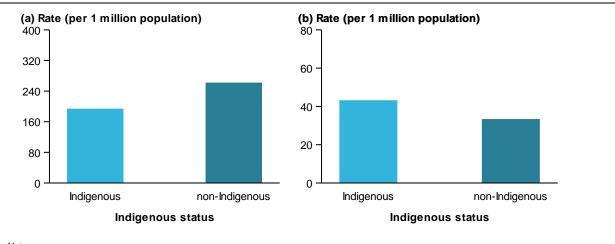
The incidence rate for all cancers combined was 190 new cases per 1 million young Indigenous Australians (193 per 1 million when age-standardised), compared with 264 new cases per 1 million young non-Indigenous Australians (261 per 1 million when age-standardised) (Figure 7.1).

#### **Deaths**

Information in the NMD on Indigenous status in 2011–2015 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. About 90% of all Indigenous Australians live in those jurisdictions (ABS 2017b). For these 5 jurisdictions, about 0.5% of adolescents and young adults recorded in the NMD who died from cancer had an unknown Indigenous status.

In 2011–2015, an average of 5 young Indigenous Australians per year died from cancer (6.9% of all deaths due to cancer in young Australians).

The mortality rate from all cancers combined was 42 deaths per 1 million young Indigenous Australians (43 per 1 million when age-standardised) compared with 33 deaths per 1 million young non-Indigenous Australians (also 33 per 1 million when age-standardised) (Figure 7.1). However, caution should be taken when interpreting age-standardised mortality rates for Indigenous Australians, as they are based on a small number of total deaths during this period.



#### Notes

- 1. The rates were age-standardised to the 2001 Australian Standard population, and are expressed per 1 million population.
- Some states and territories use an imputation method to determine Indigenous cancers, which might lead to differences in these data, and those shown in jurisdictional cancer incidence reports.
- Incidence data are for New South Wales, Victoria, Queensland, Western Australia, and the Northern Territory, New South Wales have identified an issue with their Indigenous data from 2008 onwards, which they are investigating. As a result, incidence rates by indigenous status should be considered with caution.
- Mortality data are for New South Wales, Queensland, Western Australia, South Australia, and the Northern Territory.

Sources: AIHW ACD 2014; AIHW NMD (data for this figure are presented in Appendix Table B7.1).

Figure 7.1: Incidence of cancer, 2009–2013(a), and mortality from cancer, 2011–2015(b), in selected jurisdictions, by Indigenous status, 15-24 years

# 7.2 State and territory

#### **New cases**

In 2009–2013, the average annual number of cancer cases diagnosed in young Australians ranged from 7 in the Northern Territory to 323 in New South Wales.

The incidence rates of all cancers combined varied across jurisdictions—from 195 new cases per 1 million young Australians in the Northern Territory (185 per 1 million when age-standardised) to 340 new cases per 1 million young Australians in Queensland (336 per 1 million when age-standardised) (Table 7.1). The variations between jurisdictions was largely driven by differences in the incidence rates of melanoma.

### **Deaths**

In 2011–2015, the average annual number of young Australians dying from cancer ranged from 1 in the Australian Capital Territory to 37 in New South Wales.

The mortality rates from all cancers combined ranged from 21 deaths per 1 million young Australians in the Australian Capital Territory (19 per 1 million when age-standardised) to 55 deaths per 1 million young Australians in Tasmania (also 55 per 1 million when age-standardised) (Table 7.2). However, caution should be taken when interpreting age-standardised mortality rates from Tasmania, the Australian Capital Territory, and the Northern Territory, as they are based on a small number of total deaths during this period (less than 5 deaths per year, on average).

Table 7.1: Incidence of all cancers combined, by state and territory, 15-24 years, 2009-2013

All cancers combined including melanoma			All cancers combined including melanoma			ıding
State/territory	Number	Rate	ASR	Number	Rate	ASR
New South Wales	1,617	335.1	330.7	1,426	295.5	292.1
Victoria	1,037	268.7	263.4	913	236.5	232.8
Queensland	1,065	339.9	335.8	768	245.1	242.8
Western Australia	524	315.4	310.3	465	279.9	276.2
South Australia	309	280.3	276.5	273	247.6	245.0
Tasmania	101	306.0	306.4	88	266.6	267.0
Australian Capital Territory	88	302.7	295.1	77	264.9	257.0
Northern Territory	35	195.1	185.1	29	161.7	152.6
Australia	4,776	310.4	305.7	4,039	262.5	259.2

Note: ASR stands for age standardised rates. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Source: AIHW ACD 2014.

Table 7.2: Mortality for all cancers combined, by state and territory, 15-24 years, 2011-2015

State/territory	Deaths	Rate	ASR
New South Wales	183	37.6	37.2
Victoria	100	25.5	25.6
Queensland	102	31.9	31.7
Western Australia	56	33.3	33.5
South Australia	25	22.7	22.2
Tasmania	18	55.1	55.1
Australian Capital Territory	6	20.6	18.8
Northern Territory	9	50.7	46.2
Australia	499	32.0	31.8

#### Notes

Source: AIHW NMD.

<sup>1.</sup> Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.

Mortality data for 2011–2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the death.

<sup>3. &#</sup>x27;All cancers combined' includes cancers coded in the ICD-10 as C00-C97, D45, D46, D47.1, and D47.3-D47.5.

ASR stands for age standardised rates. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

<sup>5. &#</sup>x27;Australia' includes records with unknown jurisdictions.

## 7.3 Remoteness area

People living in 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 2016c).

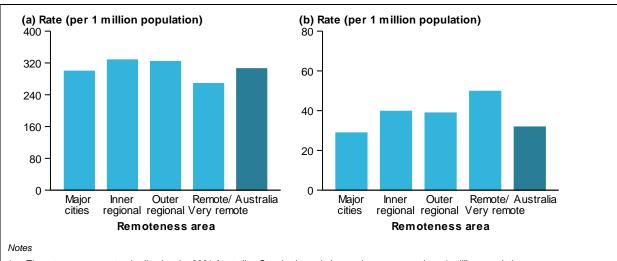
Incidence and mortality rates were calculated according to remoteness area of residence at diagnosis for cancer incidence, and at the time of death for cancer mortality. Remoteness areas divide Australia into broad geographic regions that share common characteristics of remoteness for statistical purposes.

#### New cases

In 2009–2013, the incidence rate of all cancers combined ranged from 276 new cases per 1 million young Australians (268 per 1 million when age-standardised) in *Remote/Very remote* areas to 323 new cases per 1 million young Australians (328 per 1 million when age-standardised) in *Inner regional* areas (Figure 7.2).

#### **Deaths**

In 2011–2015, the mortality rate from all cancers combined ranged from 29 deaths per 1 million young Australians (also 29 per 1 million when age-standardised) in *Major cities* to 51 deaths per 1 million young Australians (50 per 1 million when age-standardised) in *Remote/Very remote* areas (Figure 7.2). However, caution should be taken when interpreting the age-standardised mortality rate for *Remote/Very remote* areas, as they are based on a small number of total deaths during this period (less than 5 deaths per year, on average).



- 1. The rates were age-standardised to the 2001 Australian Standard population, and are expressed per 1 million population.
- Geography is based on area of usual residence (statistical local area, level 2) at time of diagnosis/death. The area of usual residence was then classified according to remoteness area 2011.

Sources: AIHW ACD 2014; AIHW NMD (data for this figure are presented in Appendix Table B7.2).

Figure 7.2: Incidence of all cancers combined, 2009–2013<sup>(a)</sup>, and mortality from all cancers combined, 2011–2015<sup>(b)</sup>, by remoteness area, 15–24 years

# 7.4 Socioeconomic group

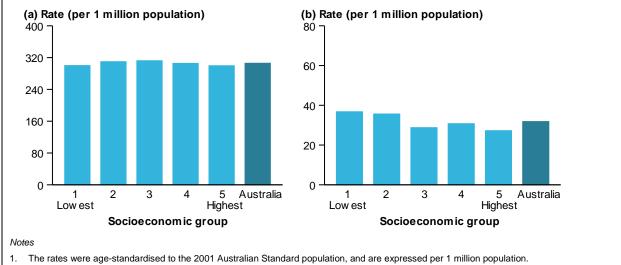
The Index of Relative Socio-economic Disadvantage is used to indicate socioeconomic groups based on where someone lives. It scores each geographic area, by summarising attributes of the population, such as low income, low educational attainment, high unemployment, and jobs in relatively unskilled occupations. This index is an area-based measure of socioeconomic group, rather than a person-based measure (ABS 2013).

#### **New cases**

In 2009–2013, incidence rates for all cancers combined for young Australians varied little across socioeconomic groups—with 303 new cases per 1 million young Australians living in the highest socioeconomic group (300 per 1 million when age-standardised), compared with 317 new cases per 1 million young Australians living in the middle socioeconomic group (312 per 1 million when age-standardised) (Figure 7.3).

#### **Deaths**

In 2011–2015, the mortality rate from all cancers combined ranged from 27 deaths per 1 million young Australians living in the highest socioeconomic group (also 27 per 1 million when age-standardised) to 38 deaths per 1 million young Australians living in the lowest socioeconomic group (37 per 1 million when age-standardised) (Figure 7.3).



- 2. Socioeconomic group was classified using the ABS Index of Relative Socio-economic Disadvantage. Sources: AIHW ACD 2014; AIHW NMD (data for this figure are presented in Appendix Table B7.3).

Figure 7.3: Incidence of all cancers combined, 2009–2013(a), and mortality from all cancers combined, 2011–2015(b), by socioeconomic group, 15–24 years

# 8 Second cancers

## **Key findings**

For the 23,021 people who were diagnosed with their first cancer as an adolescent or young adult in 1982–2009:

- 725 were subsequently diagnosed with a second cancer up to 31 December 2014
- there was a 1.9 times increased risk of being diagnosed with a second cancer compared with the risks normally experienced for people in the general population
- the largest number of second cancers followed an initial diagnosis of Hodgkin lymphoma, followed by melanoma, gonadal germ cell cancer, and non-Hodgkin lymphoma
- an initial diagnosis of glioblastoma and anaplastic astrocytoma, Ewing tumour, other non-gonadal germ cell cancer, and Hodgkin lymphoma, resulted in the highest risk of developing a second cancer
- the most common second cancers were breast carcinoma, followed by melanoma, thyroid carcinoma, and non-Hodgkin lymphoma.

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).

In this report, a second cancer refers to a new primary cancer that occurs in a person who was diagnosed with a primary cancer in the past. Second cancers can occur months or years after the first primary cancer was diagnosed and treated, and can occur at the same site (as a different histological type) or elsewhere in the body (NCI 2017). Second cancers do not include recurrences of a previous cancer (where the same primary cancer returns after a period of remission), which the ACD does not contain information on, or progressive disease.

To assess the risk of developing a second cancer, the standardised incidence ratio (SIR) was calculated for each initial cancer site. The SIR is an estimate of the occurrence of second cancers in survivors of an initial primary cancer, relative to what would be expected based on the cancer rates observed in the general population, broken down by sex, age and year.

Inherited gene mutations, the effects of cancer treatments (see Box 8.1), and exposure to certain risk factors, including tobacco smoke, might increase the risk of a second cancer (NCI 2017). While more than 2 cancers can be diagnosed in a person throughout their lifetime, the risk of a third or subsequent cancer is rare. Fewer than 1% of cancers recorded on the ACD between 1982 and 2014 were for a third or subsequent cancer. Consequently, this report only focuses on the diagnosis of a second cancer. For detailed information on the method for calculating second cancers, please see Appendix E.

The main data source used for this chapter was the ACD 2014, which consists of data provided to the AIHW by state and territory cancer registries. 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 2014 (2013 for New South Wales).

It also contains cause of death information, linked to the National Death Index data set up to 31 December 2014.

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

# Box 8.1: 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.

## 8.1 Second cancers

In 1982–2014, 725 second cancers were diagnosed in the 23,021 young cancer survivors (3.1% of all young Australians who had been diagnosed with a primary cancer between 1 January 1982 and 31 December 2009).

Fewer than 1 in 20 (26 cases) second cancers occurred between 2 months and 1 year after the first cancer was diagnosed. Two-thirds of second cancers (484 cases) occurred 10 or more years after the diagnosis of the first cancer.

Overall, young Australians who survived their first cancer had a 1.9 (95% CI: 1.8–2.1) times increased risk of developing a second cancer compared with the risks normally experienced by the general population. The largest number of second cancers followed an initial diagnosis of Hodgkin lymphoma (159 cases; SIR: 4.2; 95% CI: 3.6–4.9), followed by melanoma (151; SIR: 1.1; 95% CI: 0.9–1.2), gonadal germ cell cancer (81; SIR: 1.8; 95% CI: 1.4–2.2), and non-Hodgkin lymphoma (47; SIR: 3.1; 95% CI: 2.3–4.1).

For those initially diagnosed when they were an adolescent or a young adult, 9 cancers showed a three times or greater risk for developing a second cancer. These cancers were:

- glioblastoma and anaplastic astrocytoma (7 cases; SIR: 5.6; 95% CI: 2.3–11.6)
- Ewing tumour (14; SIR: 5.3; 95% CI: 2.9–8.8)
- other non-gonadal germ cell cancer (11; SIR: 4.2; 95% CI: 2.1–7.6)
- Hodgkin lymphoma (159; SIR: 4.2; 95% CI: 3.6–4.9)
- intracranial germ cell cancer (5; SIR: 4.1; 95% CI: 1.3–9.6)
- acute lymphoid leukaemia (22; SIR: 4.0; 95% CI: 2.5–6.0)
- acute myeloid leukaemia (17; SIR: 3.8; 95% CI: 2.2–6.0)
- osteosarcomas (12; SIR: 3.1; 95% CI: 1.6–5.4)
- non-Hodgkin lymphoma (47; SIR: 3.1; 95% CI: 2.3–4.1).

The most commonly diagnosed second cancer was breast carcinoma (146 cases), followed by melanoma (79), thyroid carcinoma (63), and non-Hodgkin lymphoma (36).

# 8.2 Second cancers by sex

Young male cancer survivors had a 2.2 (95% CI: 2.0–2.4) times increased risk of developing a second cancer compared with the risks normally experienced by the general male population, while young female cancer survivors had a 1.8 (95% CI: 1.6–1.9) times increased risk of developing a second cancer compared with the risks normally experienced by the general female population.

For males, the largest number of second cancers followed an initial diagnosis of gonadal germ cell cancer (70 cases; SIR: 2.1; 95% CI: 1.6–2.6), followed by Hodgkin lymphoma (61; SIR: 3.7; 95% CI: 2.9–4.8), melanoma (56; SIR: 1.2; 95% CI: 0.9–1.5), and non-Hodgkin lymphoma (23; SIR: 2.8; 95% CI: 1.8–4.2).

For males initially diagnosed when they were an adolescent or a young adult, 7 cancers demonstrated a three times or greater risk for developing a second cancer. These cancers were:

- other non-gonadal germ cell cancer (6 cases; SIR: 8.1; 95% CI: 3.0–17.7)
- Ewing tumour (7; SIR: 5.7; 95% CI: 2.3–11.7)
- acute myeloid leukaemia (10; SIR: 5.4; 95% CI: 2.6–10.0)
- acute lymphoid leukaemia (12; SIR: 3.9; 95% CI: 2.0–6.8)
- Hodgkin lymphoma (61; SIR: 3.7, 95% CI: 2.9–4.8)
- osteosarcomas (7; SIR: 3.3, 95% CI: 1.3–6.8)
- other specified soft tissue sarcoma (9; SIR: 3.1; 95% CI: 1.4–6.0).

The most commonly diagnosed second cancer was melanoma (45 cases), followed by gonadal germ cell cancer and thyroid carcinoma (both 29), and non-Hodgkin lymphoma (22).

For females, the largest number of second cancers followed an initial diagnosis of Hodgkin lymphoma (98 cases; SIR: 4.6; 95% CI: 3.7–5.6), followed by melanoma (95; SIR: 1.0; 95% CI: 0.8–1.2), thyroid carcinoma (35; SIR: 1.5; 95% CI: 1.1–2.1), and non-Hodgkin lymphoma (24; SIR: 3.8; 95% CI: 2.4–5.7).

For females initially diagnosed when they were an adolescent or a young adult, 6 cancers demonstrated a three times or greater risk for developing a second cancer. These cancers were:

- Ewing tumour (7 cases; SIR: 5.0; 95% CI: 2.0–10.3)
- Hodgkin lymphoma (98; SIR: 4.6; 95% CI: 3.7–5.6)
- acute lymphoid leukaemia (10; SIR: 4.5; 95% CI: 2.1–8.2)
- other glioma (6; SIR: 3.8; 95% CI: 1.4–8.4)
- non-Hodgkin lymphoma (24; SIR: 3.8; 95% CI: 2.4–5.7)
- osteosarcomas (5; SIR: 3.1; 95% CI: 1.0–7.3).

The most commonly diagnosed second cancer was breast carcinoma (144 cases), followed by melanoma and thyroid carcinoma (both 34), and colorectal carcinoma (16).

# 8.3 Second cancers by age

The number of second cancers were fewest when the first cancer was diagnosed in children (aged 0–14) (331 cases; 2.2% of all childhood cancer survivors), followed by adolescents and young adults (725; 3.1% of all young Australian cancer survivors), and adults (aged 25–39) (6,470; 5.7% of all adult cancer survivors). However, individuals diagnosed with their first cancer during childhood had the highest risk of developing a second cancer (SIR: 5.2; 95% CI: 4.6–5.7), followed by adolescents and young adults (SIR: 1.9; 95% CI: 1.8–2.1), and adults (SIR: 1.3; 95% CI: 1.3–1.3).

# **Appendix A: Cancer classification systems**

The system of grouping cancers for incidence and survival was based primarily on the SEER adolescent and young adult site recode, with additional information from the Australasian Association of Cancer Registries.

Table A1: Classification of cancers for incidence and survival

		ICD-O-3 codes
Cancer type/site	Topography	Histology
Leukaemias		
Acute lymphoid leukaemia	C000-C809	9811–9818, 9826, 9835–9837
Acute myeloid leukaemia		9840, 9861, 9865–9867, 9869, 9871–9874, 9891, 9895–9898,
	C000-C809	9910–9911, 9920
Chronic myeloid leukaemia	C000-C809	9863, 9875–9876, 9945–9946
Other and unspecified leukaemias	C000-C809	9742, 9800–9801, 9805–9809, 9820, 9823,9827, 9831–9834, 9860, 9870, 9930–9931, 9940, 9948, 9963–9964
Lymphomas		
non-Hodgkin lymphoma		9590–9591, 9596–9597, 9670–9671, 9673, 9675, 9678–9680, 9684, 9687–9691, 9695, 9698–9702, 9705, 9708–9709, 9712, 9714, 9716–9719,
	C000-C809	9725–9729, 9735, 9737–9738
Hodgkin lymphoma	C000-C809	9650–9655, 9659, 9661–9665, 9667
Central nervous system cancers		
Specified low-grade astrocytic tumours	C723	9380
	C000-C809	9410–9411, 9420–9421, 9424–9425, 9431
Glioblastoma and anaplastic astrocytoma	C000-C809	9401, 9440–9442
Astrocytoma, n.o.s.	C000-C809	9400
Other glioma	C000-C722, C724-C809	9380
	C000-C809	9381–9384, 9423, 9430, 9450–9451, 9460
Ependymoma	C000-C809	9391–9394
Medulloblastoma	C716	9470–9474
Supratentorial primitive neuro ectodermal tumours	C000-C715, C717-C809	9470–9474
Other specified intracranial and intraspinal neoplasms	C000-C809	9350–9352, 9360–9362, 9390, 9395, 9432, 9480, 9530–9535, 9537–9539
	C700-C729, C751-C753	9161, 9540–9541, 9550, 9560–9562, 9570–9571
Unspecified intracranial and intraspinal neoplasms	C700-C729, C751-C753	8000-8005

Table A1 (continued): Classification of cancers for incidence and survival

		ICD-O-3 codes
Cancer type/site	Topography	Histology
Bone cancers		
Osteosarcoma	C000-C809	9180–9187, 9192–9195
Chondrosarcoma	C000-C809	9220–9221, 9230–9231, 9240, 9242–9243
Ewing tumour	C000-C809	9260, 9364–9365
Other specified and unspecified bone tumours	C000-C809	8812, 9250, 9261, 9370–9372
	C400-C419	8000–8005, 8800–8803, 8805–8806, 9200
Soft-tissue sarcomas		
Fibromatous neoplasms	C000-C809	8810–8811, 8813–8815, 8820–8824, 8830, 8832–8833, 8835–8836, 9252
Rhabdomyosarcoma	C000-C809	8900–8904, 8910, 8912, 8920–8921, 8991
Other specified soft tissue sarcomas	C000-C809	8804, 8825, 8840–8897, 8982–8983, 8990, 9040–9044, 9120–9150, 9170, 9251, 9561, 9580–9581
	C000–C699, C730–C750, C754–C809	9540, 9560, 9571
Unspecified soft tissue sarcomas	C000-C399, C420-C809	8800-8803, 8805-8806
Germ cell cancers		
Gonadal germ cell cancer	C560–C569, C620–C629	9060–9065, 9070–9073, 9080–9085, 9090–9091, 9100–9102, 9105
Intracranial germ cell cancer	C700-C729, C751-C753	9060–9065, 9070–9073, 9080–9085, 9090–9091, 9100–9102, 9105
Other nongonadal germ cell cancer	C000–C559, C570–C619, C630–C699, C730–C750, C754–C809	9060–9065, 9070–9073, 9080–9085, 9090–9091, 9100–9102, 9105
Melanoma and skin carcinomas		
Melanoma	C000-C809	8720–8723, 8726, 8728, 8730, 8740–8746, 8761, 8770–8774, 8780
Skin carcinomas	C440-C449	8010–8589
Carcinomas		
Thyroid carcinoma	C730-C739	8010–8589
Nasopharyngeal carcinoma	C110-C119	8010–8589
Other sites in lip, oral cavity, and pharynx	C000-C109, C120-C149	8010–8589
Nasal cavity, middle ear, sinuses, larynx, other and ill-defined sites in head and neck	C300-C329, C760	8010–8589

Table A1 (continued): Classification of cancers for incidence and survival

	IC	CD-O-3 codes
Cancer type/site	Topography	Histology
Carcinomas		
Carcinoma of trachea, bronchus, and lung	C330-C349	8010–8589
Carcinoma of breast	C500-C509	8010–8589
Carcinoma of kidney	C640-C649	8010–8589
Carcinoma of bladder	C670-C679	8010–8589
Carcinoma of gonads	C560-C629	8010–8589
	C000-C809	8590–8593
Carcinoma of cervix	C530-C539	8010–8589
Carcinoma of other and ill-defined site in genitourinary tract	C510–C529, C540–C559, C570–C579, C600–C619, C630–C639, C650–C669, C680–C689	8010–8589
Carcinoma of colon and rectum	C180-C209	8010–8589
Carcinoma of stomach	C160-C169	8010–8589
Carcinoma of liver and extrahepatic bile ducts	C220-C229	8010–8589
Carcinoma of pancreas	C250-C259	8010–8589
Carcinoma of other and ill-defined sites in gastrointestinal tract	C150-C159, C170-C179, C210-C218, C230-C249, C260-C269	8010–8589
Adenocortical carcinoma	C740-C749	8010–8589
Carcinoma of other and ill-defined sites	C370–C419, C470–C499, C580–C589, C690–C729, C750–C759, C761–C769, C800–C809	8010–8589
	C800-C809	9010
Miscellaneous specified neoplasms, n.o.s.		
Wilms tumour	C000-C809	8959–8960
Neuroblastoma	C000-C809	9490, 9500
Other paediatric and embryonal tumours	C000–C809	8963–8964, 8970–8973, 8981, 9363, 9501–9523
Paraganglioma and glomus tumours	C000-C809	8680–8711
Other specified gonadal tumours	C000-C809	8600–8650, 9000
	C560-C569	8670, 9013–9015, 9054

Table A1 (continued): Classification of cancers for incidence and survival

Cancer type/site	ICD-O-3 codes	
	Topography	Histology
Miscellaneous specified neoplasms, n.o.s.		
Plasma cell, mast cell and other lymphoreticular neoplasms	C000–C809	9724, 9731–9734, 9740–9741, 9743–9764, 9766, 9769, 9960, 9965–9967, 9970–9971
		8930–8951, 8980, 9020, 9050–9053, 9110, 9160, 9270–9342, 9950, 9961–9962, 9975, 9980, 9982–9987,
Other specified neoplasms	C000-C809	9989, 9991–9992
	C000–C699, C730–C750, C754–C809	9161
Unspecified malignant neoplasms	C000-C399, C420-C699, C730-C750, C754-C809	8000–8005

The system of grouping cancers for mortality and treatment was based on the International Statistical Classification of Diseases and Related Health Problems 10th revision.

Table A2: Classification of cancers for mortality and 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
Mesothelial and soft tissue	
Mesothelioma	C45
Kaposi sarcoma	C46
Peritoneum	C48
Other soft tissue	C47, C49
Breast	C50

Table A2 (continued): Classification of cancers for mortality and treatment

Cancer site/type	ICD-10 code	
Female genital organs		
Vulva	C5	
Vagina	C5.	
Cervix	C5.	
Uterus	C54-C5	
Ovary	C50	
Other female genital organs and placenta	C57–C56	
Male genital organs		
Penis	C60	
Prostate	C6	
Testis	C6.	
Other male genital organs	C6:	
Urinary tract		
Kidney	C6-	
Bladder	C6	
Other urinary organs	C65–C66, C66	
Eye, brain and other parts of the central nervous system		
Eye	C6:	
Brain	C7	
Other central nervous system	C70, C7	
Thyroid and other endocrine glands		
Thyroid	C7:	
Other endocrine glands	C74–C75	
Blood and lymphatic system		
Hodgkin lymphoma	C8	
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.	
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.	
Other and unspecified myeloid leukaemia	C92.2, C92.7, C92.9, C93.1-C93.9, C94.6-C94.7	
Other and unspecified leukaemia	C94.1, C94.3, C95	
Myelodysplastic syndromes	D4	

## Table A2 (continued): Classification of cancers for mortality and treatment

Cancer site/type	ICD-10 codes
Blood and lymphatic system	
Other cancers of the blood and lymphatic system	C96, D45, D47.1, D47.3-D47.5
Other	
Other and ill-defined sites	C76
Unknown primary site	C80
All cancers combined	C00-C97, D45, D46, D47.1, D47.3-D47.5

#### Notes

- 1. For incidence and survival data, those C44 codes that indicate basal or squamous cell carcinoma of the skin are not included.
- 2. For mortality data before 2008, unknown primary site is coded as C77–C80. For mortality data before 2013, C97 was an applicable code.

The system of grouping cancers for the burden of disease chapter was based on the International Statistical Classification of Diseases and Related Health Problems, 10<sup>th</sup> revision.

Table A3: Burden of cancer codes

Australian Burden of Disease Study 2011 cause	ICD-10 codes
Malignant neoplasms	
Mouth and pharyngeal cancers	C00-C14
Laryngeal cancer	C32
Oesophageal cancer	C15
Stomach cancer	C16
Colorectal cancer	C18-C20
Liver cancer	C22
Gallbladder cancer	C23-C24
Pancreatic cancer	C25
Lung cancer	C33-C34
Mesothelioma	C45
Melanoma of the skin	C43
Non-melanoma skin cancers	C44
Breast cancer	C50
Cervical cancer	C53
Uterine (endometrium) 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–C72
Thyroid cancer	C73
Non-Hodgkin lymphoma	C82–C85
Hodgkin lymphoma	C81
Leukaemia	C91–C95
Myeloma	C90
Other lymphohaematopoietic (blood) cancers	C88, C96, D45, D46, D47.1 and D47.3
Unknown primary	C26, C39, C76, C77–C79, C80, C97
Other malignant neoplasms (cancers)	C17, C21, C26–31, C37–41, C46–49, C51–52, C57, C58–60, C63, C65–66, C68–69, C74–75.
Benign, in situ and uncertain neoplasms	
Brain tumours (benign and uncertain)	D32-D33, D42-D43
Breast in situ (to be confirmed)	D05
Other benign, in situ and uncertain neoplasms	D00-D04, D06-D31, D34-D48

# **Appendix B: Supplementary data tables**

Table B2.1: Trend in age-standardised incidence rates for all cancers combined, 15–24 years, 1985–1989 to 2010–2014

Years	Number	Rate	ASR
1985–1989	3,836	283.4	282.9
1990–1994	4,180	304.9	301.5
1995–1999	4,377	333.1	329.5
2000–2004	4,387	328.6	327.7
2005–2009	4,659	320.1	317.2
2010–2014	4,843	312.8	307.6

Note: Rate represents the number of new diagnoses per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Table B2.2: Percentage change in age-standardised incidence rates for specific cancers and all cancers combined, 15–24 years, 1985–1989 to 2010–2014

	1985–	1989	2010–2014		
Cancer	Number	ASR	Number	ASR	% change
Colorectal carcinoma	106	7.8	351	22.3	185.7
Thyroid carcinoma	182	13.4	445	28.1	109.5
Glioblastoma and anaplastic astrocytoma	30	2.2	71	4.5	102.2
Hodgkin lymphoma	348	25.7	661	42.5	65.3
Gonadal germ cell cancer	348	25.6	666	41.7	62.8
Acute myeloid leukaemia	92	6.8	162	10.5	54.1
non-Hodgkin lymphoma	173	12.8	293	18.7	46.6
Ewing tumour	55	4.1	86	5.7	39.2
Other glioma	44	3.3	62	3.9	19.3
Breast carcinoma	30	2.2	43	2.6	18.8
Acute lymphoid leukaemia	144	10.7	186	12.3	15.3
Chronic myeloid leukaemia	38	2.8	52	3.2	15.0
All cancers combined	3,836	282.9	4,843	307.6	8.7
Other specified soft tissue sarcoma	88	6.5	111	7.0	8.5
Gonadal carcinoma	34	2.5	42	2.6	5.4
Osteosarcomas	74	5.5	85	5.7	4.6
Fibromatous neoplasms	42	3.1	48	3.0	-2.5
Rhabdomyosarcomas	30	2.2	33	2.1	-4.2
Other sites in lip, oral cavity, and pharynx	77	5.7	76	4.8	-15.4
Cervical carcinoma	89	6.5	75	4.6	-30.1
Non-gonadal germ cell cancer	36	2.7	27	1.7	-35.9
Melanoma	1,301	95.8	707	44.1	-54.0
Astrocytoma, n.o.s.	84	6.2	32	2.0	-67.1

<sup>1.</sup> Cancers with less than 25 diagnoses during 1985–1989 or 2010–2014 were not considered suitable for the trend analysis.

<sup>2.</sup> ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

<sup>3.</sup> Cancer of the cervix rates are expressed per 1 million females.

Table B2.3: Age-specific incidence rates for all cancers combined, 2010-2014

Age group (years)	Number	Rate
0–4	1,687	225.6
5–9	848	119.1
10–14	915	131.5
15–19	1,757	240.2
20–24	3,086	377.9
25–29	5,483	646.4
30–34	7,805	977.5
35–39	11,891	1,516.2

Note: Rate represents the number of new diagnoses per 1 million population at each age group.

Source: ACD 2014.

Table B3.1: Trend in age-standardised cancer-related hospitalisations for all cancers combined, by admission type, 15–24 years, 2001–02 to 2015–16

Financial year	Same-day	Overnight	Total
2001–02	19.7	11.2	30.9
2002–03	23.0	10.7	33.7
2003–04	21.8	11.2	33.0
2004–05	20.5	11.6	32.1
2005–06	24.5	12.0	36.5
2006–07	23.5	12.1	35.7
2007–08	20.9	10.9	31.8
2008–09	18.2	10.7	28.9
2009–10	19.5	10.7	30.2
2010–11	21.1	11.0	32.1
2011–12	17.2	10.4	27.6
2012–13	17.7	10.4	28.2
2013–14	17.5	10.4	28.0
2014–15	18.8	11.7	30.5
2015–16	21.7	11.8	33.6

### Notes

Source: AIHW NHMD.

<sup>1.</sup> 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.

<sup>2.</sup> Numbers represent age-standardised rates. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 10,000 population.

Table B3.2: Age-specific cancer-related hospitalisations, 2015-16

Age group (years)	Rate
0–4	53.3
5–9	38.7
10–14	30.5
15–19	35.4
20–24	31.6
25–29	40.5
30–34	74.9
35–39	124.8

Source: AIHW NHMD.

Table B4.1: Trend in 5-year relative survival from all cancers combined, 15–24 years, 1985–1989 to 2010–2014

Year	5-year relative survival (%)
1985–1989	79.9
1990–1994	83.2
1995–1999	84.5
2000–2004	86.9
2005–2009	87.4
2010–2014	89.0

<sup>1.</sup> 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.

<sup>2.</sup> The rates are age-specific, and are expressed per 10,000 population.

Table B4.2: Trend in 5-year relative survival from the 10 most commonly diagnosed cancers and all cancers combined, 15–24 years, 1985–1989 to 2010–2014

Cancer type	1985–1989	1990–1994	1995–1999	2000–2004	2005–2009	2010–2014	% change in survival
Thyroid carcinoma	98.4	98.2	100.0	99.9	99.9	99.7	1.3
Gonadal germ cell cancer	89.8	95.5	94.5	97.3	97.0	97.0	7.3
Melanoma	94.1	95.9	97.1	95.7	95.8	96.2	2.1
Hodgkin lymphoma	84.4	92.4	95.1	97.4	96.7	95.6	11.2
non-Hodgkin lymphoma	70.7	68.3	68.7	81.1	86.2	92.8	22.1
All cancers combined	79.9	83.2	84.5	86.9	87.4	89.0	9.1
Colorectal carcinoma	80.6	85.7	87.3	82.4	80.4	87.3	6.7
Other specified soft tissue sarcoma	59.3	67.7	72.1	72.2	77.1	82.9	23.5
Acute lymphoid leukaemia	32.7	44.5	47.2	63.9	65.8	78.6	45.9
Acute myeloid leukaemia	33.2	37.1	47.7	62.1	59.9	76.9	43.7
Ewing tumour	n.p.	48.5	52.2	53.1	57.2	45.7	-2.8

Note: Numbers represent 5-year relative survival (%).

Source: ACD 2014.

Table B4.3: Trend in 5-year relative survival from all cancers combined, by sex, 15–24 years, 1985–1989 to 2010–2014

Year	Males	Females
1985–1989	75.7	84.4
1990–1994	80.9	85.5
1995–1999	81.7	87.6
2000–2004	85.0	89.0
2005–2009	86.2	88.6
2010–2014	87.8	90.3

Note: Numbers represent 5-year relative survival (%).

Table B4.4: Five-year relative survival from all cancers combined, by age at diagnosis, 2010–2014

Age group (years)	5-year relative survival (%)
0–4	84.4
5–9	84.3
10–14	83.3
15–19	86.8
20–24	90.2
25–29	90.4
30–34	89.0
35–39	87.0

Source: ACD 2014.

Table B4.5: Five-year prevalence of all cancers combined, by age at diagnosis, as at end of 2013

Age group (years)	Number
0–4	1,457
5–9	720
10–14	810
15–19	1,582
20–24	2,830
25–29	5,015
30–34	6,959
35–39	10,777

Table B5.1: Trend in age-standardised mortality rates for all cancers combined, 15–24 years, 1981–1985 to 2011–2015

Years	Deaths	Rate	ASR
1981–1985	820	62.4	62.2
1986–1990	733	53.7	53.7
1991–1995	691	50.7	50.4
1996–2000	638	48.9	48.8
2001–2005	582	42.9	42.9
2006–2010	541	36.5	36.3
2011–2015	499	32.0	31.8

- Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.
- 2. Mortality data for 1981–2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the
- 3. Rate is the number of cancer deaths expressed per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.
- 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.

Table B5.2: Percentage change in age-standardised mortality rates for specific cancers and all cancers combined, 15–24 years, 1981–1985 to 2011–2015

	1981–19	85	2011–2	015	
Cancer	Deaths	ASR	Deaths	ASR	% change
Other soft tissue cancer	41	3.1	42	2.7	-13.2
Brain cancer	100	7.6	90	5.8	-23.6
Bone cancer	101	7.7	88	5.7	-26.6
All cancers combined	820	62.2	499	31.8	-48.8
Hodgkin lymphoma	36	2.7	19	1.2	-56.6
Testicular cancer	27	4.0	13	1.6	-60.0
Acute lymphoblastic leukaemia	118	9.0	48	3.2	-64.9
Acute myeloid leukaemia	94	7.2	35	2.2	-68.7
non-Hodgkin lymphoma	62	4.7	21	1.4	-71.0
Melanoma of the skin	60	4.5	14	0.9	-81.1

### Notes

- 1. Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.
- 2. Mortality data for 1981–2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the death
- 3. Cancers with less than 25 deaths during 1981–1985 were not considered suitable for the trend analysis.
- 4. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.
- 5. Testicular cancer rates are expressed per 1 million males.
- 6. '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.

Table B5.3: Age-specific mortality rates from all cancers combined, 2011–2015

Age group (years)	Deaths	Rate
0–4	156	20.6
5–9	182	24.9
10–14	113	16.2
15–19	211	28.8
20–24	288	34.9
25–29	501	57.9
30–34	793	96.2
35–39	1,422	181.9

- 1. Deaths registered in 2013 and earlier are based on the final version of cause of death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and are subject to further revision by the ABS.
- 2. Mortality data for 1981–2014 are based on the year of occurrence of the death, and data for 2015 are based on the year of registration of the death.
- 3. Rate represents the number of deaths per 1 million population at each age group.
- 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

Table B6.1: Disability adjusted life years for the 5 leading causes of cancer burden, by fatal and non-fatal burden, 15–24 years, 2011

Cancer type	YLL	YLD	DALY
Leukaemia	1,235	34	1,268
Brain and central nervous system cancer	953	57	1,012
Colorectal cancer	335	12	347
Hodgkin lymphoma	264	35	299
non-Hodgkin lymphoma	209	18	226

#### Notes

- 1. DALY stands for disability-adjusted life years (total burden). YLL stands for years of life lost (fatal burden) and YLD stands for years of living with disability (non-fatal burden).
- 2. The 5 leading causes of cancer burden exclude other malignant neoplasms (C17, C21, C26–C31, C37–C41, C46–C49, C51–C52, C57–C60, C63, C65–C66, C68–C69, C74–C75) and other benign, in situ and uncertain neoplasms (D00–D04, D06–D31, D34–D48).
- 3. Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A3).

Source: AIHW Burden of Disease Database 2011.

Table B6.2: Cancer burden (% DALY), by age group (years) and cancer type, 0-39 years, 2011

_	Age group (years)							
Cancer type	0–4	5–9	10–14	15–19	20–24	25–29	30–34	35–39
Brain/central nervous system cancer	30.4	36.9	21.9	20.6	10.6	9.5	13.1	9.7
Breast cancer	0.0	0.0	0.0	0.0	0.1	5.4	11.2	13.9
Colorectal cancer	0.1	0.1	0.0	5.4	4.8	14.0	9.4	10.2
Hodgkin lymphoma	0.0	2.4	0.2	5.3	3.7	2.8	1.4	0.1
Leukaemia	15.6	13.5	21.3	20.2	17.3	12.8	7.1	3.8
Lung cancer	0.0	0.0	0.0	0.0	1.6	2.6	4.9	7.4
Melanoma of the skin	0.1	0.1	0.1	0.2	5.3	12.6	11.8	9.5
non-Hodgkin lymphoma	4.4	2.5	4.5	5.1	2.1	2.7	2.1	3.4
Remaining cancers	49.3	44.4	52.0	42.8	52.3	36.2	36.6	40.7
Testicular cancer	0.0	0.0	0.0	0.4	2.2	1.3	2.3	1.3

- 1. Numbers represent the percentage of total burden (DALY) accounted for by age group.
- 2. Cancer groupings are classified according to the Australian Burden of Disease Database (see Appendix A3).

Source: AIHW Burden of Disease Database 2011.

Table B7.1: Incidence of cancer, 2009–2013, and mortality from cancer, 2011–2015, in selected jurisdictions, by Indigenous status, 15–24 years

	Inci	dence		Mortality		
Indigenous status	Number	Rate	ASR	Deaths	Rate	ASR
Indigenous	114	190.2	192.8	26	41.8	43.0
Non-Indigenous	3,452	264.3	260.8	347	33.4	33.1
Total	4,278	313.2	308.3	375	34.0	33.7

#### Notes

- 1. Total might not sum to the total of each Indigenous status due to missing information.
- 2. Incidence data are for New South Wales, Victoria, Queensland, Western Australia and the Northern Territory. New South Wales have identified an issue with their Indigenous data from 2008 onwards, which they are investigating. As a result, incidence rates by Indigenous status should be considered with caution.
- 3. Mortality data are for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory.
- 4. Some states and territories use an imputation method to determine Indigenous cancers, which might lead to differences in these data, and those shown in jurisdictional cancer incidence reports.
- 5. Rate represents the number of new cases/deaths per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Sources: AIHW ACD 2014; AIHW NMD.

Table B7.2: Incidence of all cancers combined, 2009–2013, and mortality from all cancers combined, 2011–2015, by remoteness area, 15–24 years

	Inci	idence		Mortality		
Remoteness area	Number	Rate	ASR	Deaths	Rate	ASR
Major cities	3,429	306.7	299.4	330	29.0	28.8
Inner regional	847	323.1	327.8	104	39.4	39.7
Outer regional	398	320.4	323.8	48	38.7	38.9
Remote/Very remote	93	276.3	268.2	17	51.4	49.8
Australia	4,776	310.4	305.7	499	32.0	31.8

- 1. Australia might not sum to the total of each area due to missing information on remoteness.
- 2. Geography is based on area of usual residence (statistical local area, level 2) at time of diagnosis/death. The area of usual residence was then classified according to remoteness area 2011.
- 3. Rate represents the number of new cases/deaths per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Sources: AIHW ACD 2014; AIHW NMD.

Table B7.3: Incidence of all cancers combined, 2009-2013, and mortality from all cancers combined, 2011-2015, by socioeconomic group, 15–24 years

	Inci	dence		Mo	rtality	
Socioeconomic group	Number	Rate	ASR	Deaths	Rate	ASR
1 (lowest)	930	303.0	299.8	116	37.6	36.7
2	956	313.7	309.6	109	35.5	35.6
3	957	317.1	312.0	88	28.8	28.7
4	975	311.6	305.4	100	31.3	30.7
5 (highest)	946	304.1	299.4	85	27.0	27.2
Australia	4,776	310.4	305.7	499	32.0	31.8

#### Notes

- 1. Australia might not sum to the total of each group due to missing information.
- 2. Socioeconomic group was classified using the ABS Index of Relative Socio-economic Disadvantage.
- 3. Rate represents the number of new cases/deaths per 1 million population. ASR stands for age-standardised rate. The rates were age-standardised to the 2001 Australian Standard Population, and are expressed per 1 million population.

Sources: AIHW ACD 2014; AIHW NMD.

## 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 2013 for all states and territories, and for 2014 for all jurisdictions except New South Wales (for which data are estimated).

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 2014 can be found at <a href="http://meteor.aihw.gov.au/content/index.phtml/itemId/687104">http://meteor.aihw.gov.au/content/index.phtml/itemId/687104</a>>.

## **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 2015. 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 2015, 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 2013 and earlier are based on the final version of cause-of-death data. Deaths registered in 2014 are based on revised versions, and deaths registered in 2015 are based on preliminary versions, and 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)
   <www.abs.gov.au/ausstats/abs%40.nsf/mf/3302.0>.
- ABS quality declaration summary for Causes of death, Australia (ABS cat. no. 3303.0)
   <www.abs.gov.au/ausstats/abs%40.nsf/mf/3303.0>.

For more information on the AIHW NMD, see <a href="https://www.aihw.gov.au/about-our-data/our-data-collections/national-mortality-database">www.aihw.gov.au/about-our-data/our-data-collections/national-mortality-database</a>.

## **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 2014–15 can be found at <a href="http://meteor.aihw.gov.au/content/index.phtml/itemId/638202">http://meteor.aihw.gov.au/content/index.phtml/itemId/638202</a>>.

## **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 <a href="http://meteor.aihw.gov.au/content/index.phtml/itemId/480010">http://meteor.aihw.gov.au/content/index.phtml/itemId/480010</a>.

## **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 *Australian Burden of Disease Study 2011: methods and supplementary material* (AIHW 2016b).

## **National Radiotherapy Waiting Times Database**

The National Radiotherapy Waiting Times Database (METeOR ID: 598445) is a compilation of data supplied to the AIHW—based on the Radiotherapy Waiting Times National Minimum Dataset Specification (METeOR ID: 579304)—which was collected from participating radiotherapy providers for 2015–16.

Each record provides information about a course of radiotherapy that began in the reference period (that is, where the waiting period associated with the course of radiotherapy ended in the reference period).

Other data collected includes administrative details, patient demographic characteristics, and some clinical information, including principal diagnosis (9th edition of ICD-10-AM).

The data quality statement for the National Radiotherapy Waiting Times Database can be found at <a href="http://meteor.aihw.gov.au/content/index.phtml/itemId/668535">http://meteor.aihw.gov.au/content/index.phtml/itemId/668535</a>.

## **Population data**

Throughout this report, population data were used to derive rates of; for example, cancer incidence and mortality. The population data were 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

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	Z08 (Follow-up examination after treatment for malignant neoplasms)	Not a cancer code (C00–C97, D45, D46, D47.1, D47.3, D47.4, D47.5)			
additional diagnosis)	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)				

Note: Codes were sourced from the 9th edition of the Australian Classification of Health Interventions (ACCD 2014, 2015).

# Appendix E: 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.

## **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-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.

**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.

**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, adjusted to take account of population age structure, expressed per 1 million 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.

**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 2011. Cancer in adolescents and young adults in Australia. Cancer series no. 62.
   Cat. no. CAN 59. Canberra: AIHW.
- AIHW 2017. Cancer in Australia 2017. Cancer series no. 101. Cat. no. CAN 100. Canberra: AIHW.
- AIHW 2017. Burden of cancer in Australia: Australian Burden of Disease Study 2011. Burden of Disease series no. 12. Cat. no. BOD 13. Canberra: AIHW.
- AIHW 2017. Brain and other central nervous system cancers. Cat. no. CAN 106.
   Canberra: AIHW.



This report is the second national report to present key data specific to cancer in adolescents and young adults. While cancer in young Australians is rare, it has a substantial social and economic impact on individuals, families and the community. Surveillance of this population is also important as adolescent and young adult cancer survivors are at an increased risk of developing a second cancer.

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